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Participant Responses to Dilemmas
in Oregon's Health Prioritization Plan:
Rationing, Rights, Accountability, and the Role of the Community

By

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A.B. (Brown University) 1985

THESIS

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May 6, 1991

May 6, 1991

This paper is dedicated to T-7,
a bad place to sleep but a great spot for a medical school.

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I. INTRODUCTION

"It is becoming increasingly clear that major alterations in the health care system of the United States will be necessary in the coming decades if we are to avert a crisis of immense proportions,"¹ begins Robert Blank's recent book, *Rationing Medicine*. "Crisis" is the crux of the statement, as it is in so many commentaries on the U.S. health care system that it is hard for the observer even to think otherwise. Health care expenditures exceeded 12 percent of the gross national output--a greater percentage than in any other nation--in 1990 and continue to grow; the nation's annual per capita health care spending is also the world's highest, estimated at \$2,511.²

By some measures, such spending buys Americans the finest care: quick response and personal attention, utilizing sophisticated diagnostic and therapeutic technologies. Alternatively, as many as 37 million Americans under 65, most of them low- and moderate-wage workers and their dependents, lack any health insurance that might grant them access to this fine care. Another 23 million are insured under Medicaid,³ the federal/state partnership for the poor, offering access limited to those providers who accept its below-market reimbursement. People in both groups obtain their health care in a generally haphazard manner, often from providers of last resort such as overburdened county hospitals.⁴ Just as often, the costs of caring for these patients are shifted to the paying patients in the form of ever-escalating charges. According to health economist Uwe E. Rienhardt, "At its best, the American health system is

¹Blank, Robert H. *Rationing Medicine*. New York:Columbia University Press, 1988, p. 1.

²Division of National Cost Estimates, Office of the Actuary, Health Care Financing Administration, "National Health Expenditures, 1986-2000," *Health Care Financing Review*, 8:4 (Summer, 1987), p. 23; also cited in Callahan, Daniel. *What Kind of Life*. New York: Simon and Schuster, 1990, p. 268.

³U.S. Bureau of the Census, *The Statistical Abstract of the United States:1990*, (110th ed.) Washington D.C., 1990. (Figures from 1988.)

⁴Holzman, David. "Medicaid dispensed on ration plan." *Insight*, May 1, 1989, p. 54.

unmatched anywhere in the world. At its worst, no other industrialized nation would ever want to match it."⁵

An insatiable medical appetite for high technology, an aging population, an untenable insurance market, perverse incentives in the tax code, unrealistic public expectations, an upsurge in drug use and violence, the AIDS epidemic, waste, greed: all these are cited in recent years in both the professional and popular press as gremlins undermining our search for the perfect health care system.^{6,7,8} Some observers of a "new school" suggest that "society is operating on flawed philosophical assumptions: that medical care produces health, and more care produces more health; that medical progress can and should stave off indefinitely the ravages of old age and death; that health care is an individual right, not a matter of society's well-being."⁹

In fashioning a response, authors and policymakers increasingly have argued an imperative more rationally to allocate health care resources. In the theoretical realm, Daniel Callahan, Norman Daniels, Robert Blank, Henry Aaron, William Schwartz, John Golenski, Arnold Relman and others have proposed a need for an explicit look at limits. In the public arena, Richard Lamm, former governor of Colorado¹⁰ and Lee Iococca, Chairman of the Chrysler Corporation, have been vocal advocates for turning a more critical eye on health care funding priorities.¹¹ Two lesser known public figures, Oregon

⁵Reinhardt, Uwe E. "U.S. health policy: Errors of youth." *The Generational Journal* (April, 1988), p. 44; as cited in Daniel Callahan, *op. cit.*, p. 72.

⁶Aaron, Henry and William B. Schwartz. "Rationing health care: The choice before us." *Science*, 1990. 247:418-422.

⁷Cohn, Victor. "Rationing our medical care." *The Washington Post National Weekly Edition*, Aug. 13-19, 1990, p. 11-12; also Mothner, Ira. "Drawing the Line." *American Health*, July/August, 1989, p. 72.

⁸Aaron & Schwartz, *op. cit.* 1990, p.418.

⁹Kosterlitz, Julie. "Rationing health care." *National Journal*, June 30, 1990:1590-1595

¹⁰Anderson, Howard J.. "Former governor advocates health care rationing." *Hospitals*, August 20, 1990, p. 46

¹¹Mothner, *op cit.*, 1989, p. 72.

Senate President John Kitzhaber, M.D. and Alameda County, California Director of Health Services David Kears, have attempted to go beyond the stage of public debate toward a codified, systematic, explicit expression of health care funding priorities. These attempts, particularly the Oregon Basic Health Services Act authored by Kitzhaber, are the focus of this paper.

After observing with frustration the usurpation of the Oregon Medicaid budget by expensive high-technology procedures, Dr. Kitzhaber led the effort in his state to establish explicit priorities for funding health care services out of a limited resource pool. After an abortive effort to simply exchange state funding of heart, liver, lung, and bone marrow transplantation for comprehensive prenatal care that critics claim resulted in the death of a boy with leukemia, Senator Kitzhaber and his colleagues moved to develop a comprehensive prioritized list of health services (excluding long-term care and mental health/chemical dependency services). Such a list would serve as a guide for funding decisions both in the state's Medicaid program and in an employer-funded mandated coverage program slated to take effect in 1994. By sacrificing the illusion of comprehensive coverage in its Medicaid and health insurance program, Oregon would cover more people under its Medicaid program, offer employer-funded insurance to the working poor, and do both by "an explicit and accountable decision-making process,"¹² without excessively breaching Oregonians' strong distaste for taxation. Under the plan, Medicaid eligibility will rise from 58% of the federal poverty level to 100% of that level (the Department of Labor announced in February 1990 that the federal poverty level was \$12,700 for a family of four;¹³ the national average for Medicaid eligibility is

¹²Kitzhaber, John. Text of address to the American Academy of Pediatrics, Chicago, IL. Sept 8, 1990

¹³Governor's Health Policy Advisory Committee Prioritization Subcommittee, "Health Care Prioritization in New Mexico," December 21, 1990

50% of that level ¹⁴), cutting by 77,000 the ranks of the "categorically ineligible,"¹⁵ and thereby reducing the number of medically uninsured people in the state.

Oregon Senate Bill 27, the Oregon Basic Health Services Act, dictates that a new state board, the eleven-member Health Services Commission (HSC), should compose a list, rank ordering each of the eventually 800 condition-treatment pairs that comprise it. To achieve this, the HSC used extensive public and expert testimony, available research on medical efficacy, and the expertise of the commissioners. A bioethics consultant, John Golenski, EdD, SJ, was engaged as a facilitator in one effort to synthesize these contributions into a prioritized list;¹⁶ subsequently the commissioners embarked on their own process.

After ranking, the list is submitted to an actuarial firm, which assigns expenditure estimates based in part on the cost per use and uses per year in a managed care setting, under various circumstances, of a given diagnosis-treatment pair. With the list in hand, the Joint Committee on Ways and Means of Oregon's biennial legislature, runs a total down the cost column until the biennium's Medicaid allocation is reached, and there it will "draw a line." The state's Medicaid recipients are eligible to receive from a contracted managed-care provider any service "above the line," but the Medicaid program will not fund any "below the line" service.

A companion bill, Senate Bill 935, will use the ranking to establish a benefits package for an employer-funded insurance program for uninsured workers. (This bill is a reconfiguration of the "pay-or-play" model of universal

¹⁴[cite besides commonwealth address?]

¹⁵Modern Healthcare, July 28, 1989

¹⁶"Oregon pioneers 'more ethical' medicaid coverage with priority-setting project" *Journal of the American Medical Association*, 1989. 262:2, 176

health insurance popularized by Massachusetts, in which employers receive tax incentives to provide health insurance to workers, or pay a surtax which funds an insurance pool.) The implication is that Oregon "defines the population for whose health care the state is responsible as all those with a family income below the federal poverty level...[t]he private sector is responsible for the health care of those earning more."¹⁷

A third bill, SB 534, provides for the implied use of the list for an insurance pool for so-called "uninsurables": people who, for health or other reasons, have been excluded from coverage by private insurers.

All of these measures--SB 27 in particular--have spurred widespread controversy. Immediately labeled as "rationing," Oregon's attempt to prioritize health care spending received both harsh and favorable treatment in the mass media. One legal analyst demonstrated that its net effect was to shift society's resources "from the worst off to those slightly better off."¹⁸ Senator Kitzhaber, so visibly associated with every aspect of the plan, was at the same time vilified ("Dr. Death")¹⁹ and lionized. Other states, including Colorado, Kentucky, Alaska, Florida, New Mexico and California, have begun looking at the model, but hold off while the federal government evaluates its merit. Because the proposed plan breaches several Medicaid mandates, the state must receive waivers either from Congress or from the Secretary of Health and Human Services to proceed.

One who did not wait to hear the disposition of the federal government before acting was David Kears. Director of an overburdened county health

¹⁷Kitzhaber, John. Text of address to the Commonwealth Club of Northern California, Marin General Hospital, March 23, 1990, p.5.

¹⁸Mehlman, Maxwell J. "The Oregon Medicaid program: Is it just?" *Health Matrix; The Case Western Reserve Journal of Law Medicine*, 1991, 1(2), in publication.

¹⁹Pierce, Neal R. "U.S. watching state Medicaid priority listing." *The Sunday Oregonian*, Nov 26, 1989

system in the San Francisco Bay Area, Kears saw the Oregon process as a means of imposing some order upon what he judged to be an unbalanced health care funding agenda. The main county medical facility, Highland Hospital, was soaking up resources at the extremes of life, in neonatal intensive care and end-stage disease. A well-developed and historically strong community clinic network was threatened by the budget squeeze. Kears' plan was to review all county health services, establish priorities, and fund according to such priorities. He contracted with Golenski to facilitate small focus group sessions with Alameda County health professionals, including clinic administrators, county program directors, medical personnel, and others.

The focus groups concluded that prioritizing would lead to no services getting more funding, and to some getting less--an untenable outcome to health workers who saw only the desperation of an underfunded system. No priority funding list was conceived, although county supervisors heeded the discussants' recommendation that they take some sort of rational look at all county services, leading to the Value-Based Budget process now in development.

These are not the only efforts of their kind nationally. The Oregon experience is distinguished by its advanced degree of development; the Alameda County effort notable for the staunch resistance its proponents encountered. In this essay I will use the Oregon public policy development experience as a foil to explore some of the dilemmas and controversies that may arise in the process; a study of the abortive Alameda County effort is left to future commentators.

In Chapter 2, the Oregon enterprise is examined at greater depth, using public-record materials and for some matters, informant interviews. Since the project has not been fully developed in the professional or technical literature,

much of my source material is accounts in the lay press. I am certain that it is not without bias.

Chapter 3 reviews some of the more prominent dilemmas and controversies brought to the surface in attempts at explicit health care rationing. These also are culled from published accounts and commentaries on the Oregon experience, as well as from writings on current issues in health services and ethics. This section covers points related both to the content and to the process used to attain a policy of prioritized health care for the poor.

Among the controversial points regarding the content of the plans, the concept of rationing is paramount. Here advocates and detractors trade salvos contrasting *de facto* and *de jure* rationing. I will briefly review some of the theoretical rationales for explicit health care rationing, as well as some objections on the theoretical plane. On a more practical level, with respect to the proposed implementation plans for the program, I will attempt to capture the flavor of both justification and critique. Other important content issues this section touches on are the concept of a minimum acceptable level of care, viewed as what Oregon is attempting to assure, and the notion of a right to health care. This last item, the question of rights, is somewhat murky, but is a useful tool in this analysis: a right to health care implies a tension between the ideologic and the pragmatic, as well as some conflict between individual and communal needs. Thus I see the rights issue as emblematic of the dilemmas inherent in Oregon's proposed plans.

Like the contents of the plan, the process principles employed in the Oregon plan merit exploration. Chief among them for the purposes of this review is the principle of community participation in health policy development. Although there are historical examples of open testimony, these projects-- Oregon's in particular--attempted to use "community" in a new way to establish

responsive and appropriate policy. Attendant to this new use of community, however, are a host of new dilemmas. For example, even given that the Oregon plan is ultimately intended to influence health care across the socioeconomic spectrum, its first application is for the poor. The Alameda County plan also would have affected poor people disproportionately. And yet, poor people may have the smallest voice in a "community" process. Are there implications to using a "community" process to determine health care standards for poor people? Also unresolved is the degree to which the community is actually enfranchised in the process: the community influence must lie somewhere between rubber-stamp and ultimate authority. Beyond the effect on the policy outcome of the community's participation, observers also may wonder about the converse: what effect the process had upon participating communities, outside the realm of the specific health policy attained at the project's conclusion.

Another "process" issue--with traces of content implications as well--is what I will call an "accountability shift" that results from reaching beyond the normal policy development venues for contributions. Under conventional conditions, lawmakers, their staffs, chief executives and bureaucrats shoulder a personal accountability for adverse outcomes of policies they establish. By casting a wider net, drawing more directly on the opinions, beliefs and values of their constituents, lawmakers subtly shift some of that responsibility onto new actors. Additionally, in the specific case of explicit health care rationing, sufferers of adverse health care funding priorities emerge from anonymous "categorical ineligibility" to become *named* people with unfunded problems--such as the boy with leukemia. As Daniel Callahan puts it, in "a hard and open setting of priorities...[t]hose denied treatment had faces."²⁰ The combination of

²⁰Callahan, *op. cit.*, 1990, p. 18.

wider accountability and identifiable victims suggests the possibility of some future emotional fallout for participants not accustomed to such a burden.

Recalling that Chapter 3 reviews only a selection from the range of quandaries attending the Oregon plans, Chapter 4 renders these down even more. Using responses from interview subjects who participated in one of the projects, this section explores how individuals grapple with some of the issues raised in Chapter 3. Among the twenty-two subjects, responses are patterned in ways that suggest both diversity and unanimity in their experiences. The objective of this section is to illustrate the human factor of a health care revolution, from the “top” (or those who conceived and executed the plans) to the “middle” (those who attended focus group or community meetings). The “bottom,” or those who would be most affected by these proposals, are not represented among the interview subjects, in part because this is a study of the process and they were not well represented in the process.

II. HISTORY

The development of the Oregon Basic Health Services Plan is not well documented in the professional literature. Crawshaw, *et al.*, provide the most concise and inclusive record; the following history relies heavily on their accounts, on unpublished documents, and on informant interviews of, and personal communications from, participants in the process.

A. The Greatest Good for the Greatest Number

Adam Jacoby ("Coby") Howard, seven years old when he died of leukemia in December, 1987, has become an important figure in Oregon's legislative and political history. When the boy's mother, a single woman on Medicaid from a community near Portland, learned that a bone marrow transplant could save his life but was no longer covered by the plan, health care allocation choices suddenly gripped public attention. As the boy's face flickered on the state's televisions, appealing for private contributions to the \$70,000 advance fee required to save his life, a routine piece of business in the state capital also came to light: "In the final days of the 1987 session, with the legislators largely unaware of the implicit life-and-death issue and without open legislative exploration and debate, financing of heart, liver, lung, and bone marrow transplants* was eliminated, effective July 17, 1987."¹ The Joint Ways and Means Committee had recommended this action under two major influences: (1) the Division of Adult and Family Services, which administers the state Medicaid program, could within its budget either expand coverage in the

* Kidney and corneal transplants were excluded from the cuts. Kidney transplants are federally protected and paid for by the End-Stage Renal Disease program under Medicare, a program with its own colorful legislative history and which now costs \$3 billion annually. Corneal transplants are currently too rare to have been considered in the legislation.

¹Crawshaw, Ralph, Garland, Michael, Hines, Brian. "Organ Transplants--A search for health policy at the state level." *Western Journal of Medicine* 1989 Mar; 150 (3):361-363

next biennium to 1500 previously uninsured people or continue funding transplantation services to a projected 34 patients, and the Division requested the former course; and (2) Oregon operates with statutory, voter-approved limits on state revenues and expenditures.²

With the biennial legislative session over, the Howard family appealed first to state bureaucrats, and finally to the Oregon State Emergency Board, comprised of the members of the Joint Ways and Means Committee and chaired by Senator Kitzhaber, and responsible for state budget issues between sessions.³ Already more than two-thirds into their \$25 million contingency budget as a result of widespread forest fires, the Board was faced with two appellants. Services for poor pregnant women in Oregon had deteriorated to the point that the only care one could expect "was admission to hospital to deliver *after* she proved she was in labor."⁴ At the same time, despite the fact that private carriers across the state--as well as Medicaid programs across the nation-- offered vastly different degrees of coverage of many health care services, including transplants, some Oregonians passionately believed that "the state was *morally* obliged to cover transplants on the grounds of equality."⁵ Craig Irwin (whose dying mother was a liver transplant candidate, and who later founded the Oregon Transplant Project) and Coby Howard's family pressed for a return to Medicaid coverage for soft-tissue transplantation. They argued that cutting such services while funding procedures known for documented over-

²Welch, H. Gilbert and Eric B. Larson. "Dealing with limited resources: The Oregon decision to curtail funding for organ transplantation." *New England Journal of Medicine* 1988 July; 319 (3):171-173

³Crawshaw, *et al.*, *op cit.*, 1989

⁴*Ibid.*

⁵Garland, Michael J. "Setting Health Care Priorities in Oregon." *Health Matrix; Case Western Reserve Journal of Law Medicine* 1(2) Summer 1991, proceedings of Cleveland Conference on Bioethics, in publication.

utilization, such as coronary-artery bypass grafting or balloon angioplasty,⁶ was arbitrary in the extreme. Further, Irwin argued that net cost (gross cost minus savings) was the appropriate standard by which to judge transplantation services. Whereas Adult and Family Services had calculated the absolute cost of the projected 34 transplants at \$2.2 million, Irwin factored in conventional services required by those denied transplants and found a net cost of \$1.1 million.⁷ Both sets of services were offered by the federal Health Care Financing Administration (HCFA) under its optional expansion program. After intense debate, and over the strong objections of Representative Tom Mason, Senator Kitzhaber's Board chose by one vote to cover prenatal care for approximately 2,200 poor pregnant women, and held the line on transplant services.⁸

Unable to persuade the Oregon State Emergency Board to free up \$70,000, Ms. Howard began to raise money privately, through television and print supplications featuring her son. The family had raised nearly half the requisite fee when Coby died for want of treatment. (It is important to note that technically, Coby Howard was not medically eligible for a bone marrow transplant under Medicaid regulations, because his tumor did not go into remission.) Across the state, in Bend, Oregon, a 17-year-old boy with the same diagnosis as Coby successfully appealed to his tight-knit community for the fee, and lived.

⁶These advocates may have referred to Winslow, Constance Moore, *et. al.*, "The appropriateness of performing coronary artery bypass surgery." *Journal of the American Medical Association*, 1988 260 (4):505-509; or Brook, Robert H., *et. al.* "Diagnosis and treatment of coronary disease: Comparison of doctors' attitudes in the USA and the UK." *Lancet*, 1988 ; 750-753.

⁷Welch and Larson, *op cit.*

⁸Crawshaw, *et al.*, *op cit.*, 1989

State legislators recognized that the quandary highlighted by Coby Howard's death would not likely pass, and tried to establish a trust fund for private charity that would be matched by the federal government's Medicaid contribution. HCFA ruled that such a fund violated the "equal protection" mandate of the Medicaid program, and refused to match it. At the same time, fund drives to fill the minimum \$70,000 balance of the fund failed, and the charitable approach was abandoned.⁹

Bend area residents, learning that the state's epidemiologist projected another 34 cases of leukemia before the next legislative session, agitated for a public debate of health care funding priorities. A local state representative arranged with Oregon Health Decisions (OHD) to conduct such a discussion, launching what would become "Oregon Health Priorities for the 1990s," a statewide project to determine the community values regarding health care funding priorities.

OHD is "a citizen's network dedicated to raising public awareness of bioethical problems,"¹⁰ "in the belief that the health care system should reflect the values of an informed community."¹¹ The group was founded in 1981 by Ralph Crawshaw, M.D., a Portland psychiatrist, and Michael Garland, a bioethicist, to encourage informed debate and elucidate public beliefs on the question of foregoing life-sustaining treatment.¹² That project concluded with the 1984 publication *Society Must Decide*, which emphasizes the importance of community values in shaping technology-use policy. In 1987, coincident with Bend citizens' request, OHD secured a grant from the Robert Wood Johnson

⁹*Ibid.*

¹⁰Crawshaw, Ralph, Garland, Michael, Hines, Brian, *et al.* "Developing principles for prudent health care allocation--The continuing Oregon experiment." *Western Journal of Medicine* 1990 Apr; 152(4):441-446

¹¹Crawshaw, *et al.*, *op cit.*, 1989

¹²Mothner, 1989

Foundation "to determine which health services citizens considered the most important and therefore of the highest priority for government funding."¹³ The method for doing so was determined by an OHD steering committee, chaired by President of the Senate, John Kitzhaber, M.D.

John Kitzhaber is an emergency medicine specialist from Roseburg, Oregon, and has served as a senator since 1978 and as senate president since 1985. His interest in the OHD process was sparked early, and his concerns about misdirected funding decisions were consistent with the direction Crawshaw and OHD were moving. As co-chair of the "Oregon Health Priorities for the 1990s" project, he and others in the OHD leadership expanded on the community-meeting format developed by Crawshaw and his associates earlier in the decade. The plan involved community meetings statewide, culminating in a Citizens' Health Care Parliament, and its subsequent adoption of a statement of principles.

B. Community Meetings. Community Values

The first community meeting was held in Bend in February, 1988; OHD subsequently conducted another 18 meetings over six months before the Parliament. The sessions were advertised in print and broadcast media, and were held in medical, educational and religious institutions. Although total attendance statewide was said to be 1048,¹⁴ respondents to an attendance questionnaire numbered 560. (Crawshaw, *et al.* do a creditable analysis of respondent characteristics, independently and in relation to expression of beliefs and values about health care funding priorities.)¹⁵ The specific

¹³Crawshaw, *et al.*, *op cit.*, 1990

¹⁴Governor's Health Policy Advisory Committee Prioritization Subcommittee, "Health Care Prioritization in New Mexico," December 21, 1990

¹⁵Crawshaw, *et al.*, *op. cit.*, 1990

methodology prescribed that participants group themselves at tables and, following an explanatory introduction, begin discussion. The discussion groups were led by trained local facilitators, and were intended to attain consensus in three realms, described by several organizers as analogous to a chinese-box game, as exploration of each level reveals another level requiring exploration. The consensus of the groups would then be reported to the reconvened large session and opened to debate with the aim of developing a town-meeting consensus.¹⁶ The three issues for discussion were:

- O What portion of the general budget should be assigned to health care?
- O What portion of the health budget should be assigned to specific populations (infants, children, adults, and the elderly) and what portion should be assigned to specific health care approaches (acute care, long-term care, chronic care, and prevention)?
- O What is the specific preference regarding state funding of organ transplants?¹⁷

Discussion on the first question revolved around both expenditure and revenue matters; as Crawshaw, *et al.*, put it, participants had "the option of changing the way the 'pie' was sliced, changing the size of the entire pie, or both."¹⁸ Reflecting many national surveys, respondents strongly favored increased state expenditures in health care, and a majority favored hiking education spending as well. However, only a third supported higher taxes to pay for such new spending, and the only area in which they were willing to spend less was "all other," which included administrative, legislative and judicial expenses.¹⁹ OHD organizers expected such unrealistic thinking among attendants. Indeed, one of the aims of the method was "to help community

¹⁶Crawshaw, *et al.*, *op. cit.*, 1989

¹⁷*Ibid.*

¹⁸Crawshaw, *et al.*, *op. cit.*, 1990

¹⁹*Ibid.*

participants move beyond 'magical' thinking that expects resources to be available without difficult trade-offs."²⁰

The next "box" for consideration before the groups was more specific: How should our society allocate its health care dollars? To plumb community values on this question, organizers used a four-by-four grid to break down service recipients (Infants, Children, Adults, Elderly) and types of service (Critical, Long-Term, Short-Term, Preventive) (Figure 1). The task for respondents was to assign a high, medium or low priority to each cell in the matrix, using five each of "high" and "low," and six "medium" assignments.

Crawshaw, *et al.* report that this step met with some opposition, most of which they attribute to individuals playing the same "magic" game as above-- wanting to assign a high priority to all cells. Here the reaction to prioritization is related to the resistance that arose in the Alameda County focus groups, which concluded that prioritization amidst deprivation was "immoral."²¹ Crawshaw's group gives a fundamentally psychological explanation of such behavior, contending that "when the reality sets in that life-and-death decisions are being made, some degree of misgiving frequently becomes evident."²² Whatever the sources of the discord, it was eventually overcome, and all meetings attained consensus in some form (Figure 2)

²⁰*Ibid.*

²¹Alameda County Health Care Services Agency and Bioethics Consultation Group. *Rationing Health Care: A Rational Approach (Alameda County Experience)*, Oakland, California, June 1989, p. 6.

²²Crawshaw, *et al.*, *op. cit.*, 1990

FIGURE 1

		Life Cycle			
		INFANTS 0-12 months	CHILDREN 1-18 years	ADULTS 19-64 years	ELDERLY 65 years and older
Type of Health Care	CRITICAL	Organ transplants Open heart surgery Heart transplants Trauma and other emergency surgery Severe burn care			
	LONG-TERM	Hospital intensive care		Needing home care Home health care	Adult day health care
	SHORT-TERM				
	PREVENTIVE	Well-baby checkups Maternity care	Physical examinations Well-child checkups	Screening for cancer, high blood pressure, cholesterol level	
		Visit to physician and other health professionals brief hospitalizations for conditions of acute life-threatening conditions, chronic or disabling conditions, short-term care for acute life-threatening condi- tions, and preventive or early detection of ill health			

Figure 1.—The 18 squares above the types of health care services
required at the various stages of the life cycle: critical = care for acute
life-threatening conditions, long-term care for chronic or disabling
conditions, short-term = care for acute life-threatening condi-
tions, and preventive = prevention or early detection of ill health

Source: Crawshaw, et al., "Developing Principles for Prudent Health Care Allocation: The Continuing Oregon Experiment." *Western Journal of Medicine*, April, 1990, 152(4):441-446, p. 442

FIGURE 2

Health Care	Life Cycle			
	INFANTS	CHILDREN	ADULTS	ELDERLY
CRITICAL	Medium	High	Medium	Low
LONG-TERM	Low	Low	Medium	High
SHORT-TERM	Medium	Medium	Medium	Low
PREVENTIVE	High	High	High	Low

Figure 2.—The results of a survey are given in which the types of health care shown in Figure 1 were assigned ratings of high, medium, or low priority.

Source: Crawshaw, et al., "Developing Principles for Prudent Health Care Allocation: The Continuing Oregon Experiment." *Western Journal of Medicine*, April, 1990, 152(4):441-446, p. 443.

Although personal and professional background and political inclination did show up in the first level, they were notably reduced at this more focused level: "when breakdowns of the survey responses are made for age, sex, political leanings, and whether one works in health care, the extent of

agreement on at least the 16 building block priorities was surprising.”²³ Such concurrence hints at, though obviously does not confirm, shared community values, and suggests some validity in the process. The concurrence also made preventive services, which received three of the five “high” designations, impossible to ignore. Central to this shared value, as elicited by group leaders during the consensus discussion, was the idea of cost-effectiveness; the assignment of high priority rankings to “ounces” of preventive services seems a playing-out of folk medicine writ large as being worth “pounds of cure.”

The last level of discussion was the most directed: “Looking specifically at one of the types of ‘critical care,’ should Oregon state government pay for heart, liver, and bone marrow for Medicaid clients?”²⁴ Crawshaw’s group shows that 20% answered in the affirmative, 41% said no, and 39% did not know or did not answer the question.²⁵

Consensus decisions, reached after the large group reconvened from breakout, and qualitative and quantitative analyses, were referred to the Citizen’s Health Care Parliament in September, 1988. The Parliament was comprised of fifty representatives, selected by community meetings (24 delegates), county commissions (15 delegates), and various civic organizations (11 delegates). These people met first in small groups, then in general session. Following parliamentary procedure, they adopted a fifteen-point manifesto, “Principles for Health Care Resource Allocation.” (Table 1) The points are segregated into four categories: “Purposes of Health Services;” “Why Priorities

²³*ibid.*

²⁴*ibid.*

²⁵*ibid.*

Need to be Set;" "How to Set Health Priorities," and "Who Sets What Priorities."²⁶

Crawshaw, *et al.* see four themes to the principles:

O The role of government in health care is to maintain and improve the overall quality of life. Public decision makers should keep in mind the balance between length of life and quality of life when addressing the multidimensional nature of health care services.

O The need for priorities exists so long as the public's demand for health services exceeds its capacity, or willingness, to fund through third-party financing. Consequently, community consensus is necessary in deciding which services will be funded.

O The process of the equitable determination of health care priorities demands broad participation by providing open, public forums that focus on maximizing the effective use of limited funds.

O While clinical judgements remain in the domain of experts, value judgements of the general public must be integrated with expert technical judgements to produce practical, prudent, and fair health policy. Decision makers in the private sector should seek to allocate resources in a manner consistent with community values.²⁷

Each of these themes did not receive equal weight, however. Most participants and observers find that the emphasis on quality of life, which dominates at least half of the Principles' statements, is the most striking assertion of the Citizen's Health Care Parliament. But the belief in a need for priorities, in the benefit of public dialogue, and in the requirement for synthesis of professional and lay findings in establishing the value of services all also would have a strong influence in the direction of Oregon's health care reform.

²⁶*Quality of Life in Allocating Health Care Resources*, Oregon Health Decisions, Portland, Oregon, December, 1988, pp. 2-3.

²⁷Crawshaw, *et al.*, *op. cit.*, 1990

TABLE 1

**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.

C. Focus Groups Zero In

The Principles, "intended to be guideposts for the state legislature, insurance companies, and others concerned with health care resource allocation,"²⁸ were quickly circulated among Oregon legislators, and by the start of the 1989 biennium, action was imminent. Concurrently, however, a parallel process was underway that would reinforce the Assembly's will to act. In December, 1988, The Fred Meyer Charitable Trust, a Portland philanthropy, awarded Senator Kitzhaber a grant to undertake The Oregon Medicaid Priority-Setting Project.

Through the Medical Research Foundation of Oregon, which received the grant, Kitzhaber contracted with the Berkeley-based Bioethics Consultation Group's John Golenski, SJ, a Jesuit and a bioethics consultant. Golenski's prior work primarily had been with hospital ethics committees, to facilitate a focus-group process. Their hope was to demonstrate the process of establishing coherent, ethically-consistent state Medicaid funding priorities. With the Coby Howard incident fresh in lawmakers' minds, it was clear to Kitzhaber that a less arbitrary means had to be found to attain this goal. To do so they would take, according to Golenski, "a utilitarian perspective--namely, advancing the health of the population as a whole as the fundamental principle, versus doing everything for each individual patient until you run out of funds and everybody else gets nothing, which is what we're currently doing."²⁹

Just as clear was the fact that Medicaid funding priorities were not simply a matter of values. The relative efficacy of a given Medicaid-funded service could not be judged without knowing its absolute efficacy. That is, before

²⁸*Quality of Life in Allocating Health Care Resources*, p. 1

²⁹"Oregon Pioneers 'More Ethical' Medicaid Coverage With Priority-Setting Project." *Journal of the American Medical Association*, 1989. 262:2, p. 176.

evaluating whether Procedure A works better than Procedure B, one must first determine whether how well Procedure A works. For this information, planners would turn to the professional literature on medical outcomes, to judge whether a procedure is known to be effective. Unfortunately, as all those involved in the Oregon process understand, the medical outcomes literature is sparse. The studies are difficult and expensive to conduct, and the number of procedures examined to date is small.

The planners of the priority-setting project recognized this shortcoming,³⁰ and comprised their focus groups accordingly. Their aim was to use individuals knowledgeable in specific areas of medicine, and substitute a "clinical consensus" for empirically derived results. (Obviously this method would not suffice in most scientific endeavors, but the procedure is beginning to find favor for some scientific and policy applications.)³¹ The protocol stipulated four focus groups, each one representing a segment of Oregon's Medicaid population: "Women in the reproductive years (the OB/GYN group); Children from birth up to the age 18 (the Pediatric group); Adults from 18 to age 64 (the Adult group); and the elderly defined as persons over the age of 65 (the Geriatric group)."³² Focus group volunteers included "senior physicians, nurses, social workers, and health and social service program administrators."³³

Each focus group would complete two tasks: compile a detailed list of necessary care for its target age group; and rank items on that list in descending order of importance. To accomplish the second task, groups referred to the

³⁰Golenski, John D, and Blum, Stephen R. *The Oregon Medicaid Priority-Setting Project*. The Medical Research Foundation of Oregon, 1989, p.3.

³¹ The research scientists in clinical psychology have taken up expert consensus; see Waters, Everett, "Q-sort definitions of social competence and self-esteem: Discriminant validity of related constructs in theory and data." *Developmental Psychology*, 1985, 21:508-522.
[JUDY'S CITE?]

³²Golenski & Blum, *op. cit.*, 1989, p. 3-4.

³³*Ibid.* p. 4.

report published by OHD at the conclusion of the Oregon Health Priorities for the 1990s project, *Quality of Life in Allocating Health Care Resources*. In this way did they attempt to place their value-based decisions in a *community* context; Golenski and Blum contend that the values reflected in that report were “implicitly considered.”³⁴

One elected representative from each focus group advanced to the Executive Group, which in turn was charged with folding the four lists into a single, prioritized master list of “health and medical services thought to be most and least necessary for the Oregon Medicaid population.”³⁵ In Golenski’s final report, *The Oregon Medicaid Priority-Setting Project*, the four service areas were reconceptualized into: reproductive services; health promotion and disease prevention; acute illnesses and conditions and episodic therapies and treatments; and chronic disease management.³⁶ Prefiguring the legislature’s similar move, the priority-setting group isolated long-term care and mental health and chemical dependency services, in the belief that these are qualitatively different from “conventional” medical services, and should not be compared ordinally with them. Within each of the four discrete sets, categories of services (not, in most cases, specific services themselves) are assigned a numeric value from 1 (lowest priority) to 10 (highest priority) and ranked in descending order of relative value to Oregon’s Medicaid population. As a prerequisite to the ranking, the Executive Group recommended the integration of case management into the Medicaid system to promote effectiveness and efficiency.

³⁴*Ibid.* , p. 7.

³⁵*Ibid.* , p. 4.

³⁶*Ibid.* , pp. 8-17

The result, according to some participants, is a ten-plateau ranking,³⁷ with most procedures clustered at ten and nine, and a few at lower priority. Since services were not ranked within plateaus, it would be difficult to differentiate between high-priority items. A further complication was the use of general categories of services, such as "periodic focused screening" (ranked 9) or "physical therapy with predictable return to a full or acceptable level of function" (ranked 9). As one critic of the Priority-Setting Project noted, "[p]atients do not receive a bill for...diagnosis and treatment of acute illnesses, conditions, and episodes."³⁸ The same observer, a lead staff person on the OHD project, also cites the inappropriate use of health care experts in establishing the rankings, and inadequate use of available quantitative medical outcome data.

According to Golenski's report, it was the belief of the Priority-Setting Project organizers that they could not only demonstrate the process, but provide an early form of a priority list--ready for the 1989-90 biennium--for the purposes of designing legislation and regulation.³⁹ In fact, the report "has subsequently confused several commentators who mistakenly presumed that the demonstration had permanent standing and authority."⁴⁰ For example, a *San Francisco Chronicle* story on April 4, 1989, portrayed the report and the bills later passed by the legislative assembly as essentially the same material.⁴¹

While they did not achieve quite this degree of success, Golenski's group did greatly influence the direction of legislative action in the realm of health care

³⁷Draft report of the Health Services Commission, Unpublished, March, 1991

³⁸Brian Hines, *Pitfalls in Priority-Setting: A Critique of the Oregon Medicaid Prioritization Project and Senate Bill 27*, unpublished, April 2, 1989.

³⁹Golenski & Blum, *op. cit.* pp. 2-3

⁴⁰Garland, Michael., "Setting Health Care Priorities in Oregon," *Health Matrix*, ms 8, 1991, in publication.

⁴¹"Rationing Health Care--Oregon Lists Priorities." L.A. Chung, *San Francisco Chronicle*, April 4, 1989, p. A-1

reform in Oregon. Senator Kitzhaber's experiences with this project and the OHD process surely were shaping his vision for a package for such reform.

D. The Legislative Turn

The 1989-90 biennial legislative session would end with a major health care reform package in place, one that would incorporate the principle of prioritization in attempting to remedy the problem of Oregon's medically indigent population.

One of the first acts of the 65th session of the Oregon legislature, in January, 1989, was the creation by the president of the senate of a new committee, the Committee on Health Insurance and Bioethics. In laying the groundwork for passage of his incipient health care reform package, Senator Kitzhaber helped recruit to the senate Robert Shoemaker, a Portland attorney with an interest in medicine and bioethics. Shoemaker was former counsel to the county medical society, had participated in the OHD Parliament and had informally observed the Priority-Setting Project, and was fully aligned with Kitzhaber's emerging ideology. The liberal democrat overcame long odds in his West-side district, and joined the 65th session as the Chairman of the Committee on Health Insurance and Bioethics. According to one insider, Kitzhaber knew that he could not allocate the chairmanship of an established and powerful committee like Judiciary--where his anticipated reform package likely would have been referred--to a freshman senator, so he launched a new one. The new committee would be the vehicle for Kitzhaber's perhaps "intuitive concept:"⁴² that the "proposed instrument of reform [should be] the prioritized list of services which could be used by the legislature and the agencies to guide

⁴²Garland, *op. cit.*, ms 9.

the painful process of cutting back on the Medicaid budget or shifting resources from one category to another."⁴³

The committee began quickly with testimony on the Citizens' Health Care Parliament principles, the Oregon Medicaid Priority-Setting Project, as well as invited witnesses representing the corporate sector, labor, physicians, hospitals, insurers, seniors, consumers, and others.⁴⁴

On March 31, after two amended versions, the senate ordered that Senate Bill 27, known as the Oregon Basic Health Services Act, become law. The Act takes as its premise that: there are thousands of uninsured Oregonians; the number rises in periods of high unemployment; uninsured persons receive what little care they get in "costly, inefficient acute care" settings; and that the unpaid medical bills of this population are subsidized by faster-rising costs borne by paying patients. The policy statement goes on: "In order to provide access to adequate health services to those in need; to contain rising health care costs...; to promote the stability of the health services delivery system and the health and well-being of all Oregonians; it is the policy of the State of Oregon to provide adequate health services to those in need and eligible for services under...this act." ⁴⁵

SB 27 provides a coherent model for total reform of the Oregon Medicaid system. Its aim is to eliminate so-called "categorical" eligibility from state Medicaid regulations, allowing all people living in poverty--not just poor women with children, not just families earning less than 58% of the federal poverty level--equal access to a uniform set of Medicaid benefits⁴⁶. This move will add an estimated 77,000 people to the rolls. Further, it forbids manipulating

⁴³ *Ibid.*, ms 8.

⁴⁴ Shoemaker, Dick, Personal communication, 5/1/91.

⁴⁵ Oregon State Assembly, Senate. SB 27, 65th Assembly, 1990, reg. sess., section 1.2

⁴⁶ SB 27, section 2.

eligibility standards as a means of cutting expenditures⁴⁷. In an attempt to broaden access further, SB 27 eliminates another common cost-cutting route, that is, reducing reimbursement rates to providers⁴⁸. As such reduction may have the effect of reducing the number of health care providers who accept Medicaid patients, lawmakers believed that holding the line on reimbursement would help prevent attrition from the ranks and thereby improve access to medical care by poor people. (These two strategies--changing eligibility standards, reducing reimbursement--along with arbitrary cuts in the benefits package, are the most common means of accommodating new demands on states' human services budgets.)

The plan stipulates that the state Insurance Pool Governing Board, an existing (though reconstituted) body, will contract with managed care groups (usually health maintenance organizations, HMOs) to care for Medicaid recipients⁴⁹. These providers have been shown in many cases to be more prudent health care providers than those in the conventional fee-for-service market.⁵⁰ In areas with poorly developed managed-care options, fee-for-service providers can receive contracts.

These all are indeed estimable achievements, but the focus of the controversy sparked by SB 27 is the method Oregon plans to use in determining its uniform benefits package. Here emerges the label that has become Oregon's reformers' *bete noir*: health care rationing. Consistent with the Oregon Health Decisions principles, SB 27 provides for an on-going health services prioritization process, under the guidance of integrated professional

⁴⁷SB 27, section 10

⁴⁸SB 27, section 10.

⁴⁹SB 27, section 8.

⁵⁰Siu, Albert L., Leibowitz, Arleen, Brook, Robert H., Goldman, Nancy S., Lurie, Nicole, and Newhouse, Joseph P., "Use of the Hospital in a Randomized Trial of Prepaid Care." *Journal of the American Medical Association*, March 4, 1988, 259(9):1343-1346.

and lay judgements about the relative values of health services. The aim of the legislation is to make more rational choices about funding health care services, or shifting from implicit rationing, in which decisions about level of service are made by arbitrary standards such as income, geography, and insurance status,⁵¹ to explicit rationing, where such decisions incorporate expressions of social values as well as technical knowledge.

This priority-setting function sets an historic precedent in the evaluation of medical services. Its administration is entrusted to a new body, empaneled by the legislation, called the Oregon Health Services Commission (HSC), now essentially at the center of the controversy.

The act prescribes an eleven-member panel, proposed by the governor and confirmed by the senate. The HSC should comprise five physicians (four allopathic and one osteopathic physician) with expertise in obstetrics/perinatology, pediatrics, adult medicine, geriatrics and public health. The balance "shall include a public health nurse, a social service worker, and four consumers of health care."⁵² All should serve *gratis*, and once the initial turmoil subsides, their terms will last four years.

The task of the Commissioners is to "solicit testimony and information from advocates for seniors, handicapped persons, mental health services consumers and low-income Oregonians; providers of health care, including but not limited to physicians licensed to practice medicine, chiropractors, naturopaths, hospitals, clinics, pharmacists, nurses and allied health professionals."⁵³ With this testimony and information, Commissioners are

⁵¹Cohn, Victor. "Rationing Our Medical Care." *The Washington Post National Weekly Edition*, August 13-19, 1990, p. 11.; Hilton, Bruce. "How We Already Ration Health Care." *The San Francisco Examiner*. December 3, 1989, p. D-19.

⁵²SB 27, section 3.1

⁵³SB 27 section 3.3

instructed by the act to "recommend to the Governor and to the Legislative Assembly a prioritized list of health services ranging from the most important to the least important, representing the comparative benefits of each service to the entire population to be served."⁵⁴ The act makes no recommendation as to the method used to derive the ranking. This list is then to be referred to an actuarial firm, to determine the cost per year per service, based on estimated uses per year and cost per use. The "costed" list is then in turn referred to the Ways and Means Committee (or to the Emergency Board, which has the same composition as Ways and Means), which is expected to "draw a line" through the list at a point consistent with its target expenditure level for the state Medicaid contribution. Services above the line are included in the biennium's Medicaid benefits package, services below the line are not covered by enrollment in the program. In other words, explicit health care rationing.

The actuarial values are expected to vary according to the rate of new enrollment, as well as by the level of service authorized by the legislature; Commissioners understand that the number, range and type of services left unfunded will heavily influence the use and therefore the ultimate cost of those services that end up "above the line." Therefore they expect to use several different "scenarios," or projections for likely Ways and Means actions.

Because of the provisions cited above restricting manipulation of reimbursement and eligibility standards, the "line" is the only means available to the legislature to modify Medicaid expenditures. According to advocates of the program, this gambit is intended to increase direct pressure on both legislators and the public to face the difficult choices that face the state's health care system. Restricting services, they contend, is far less oblique than a "hidden"

⁵⁴SB 27, section 3,2

cut in reimbursement, which decreases access, or a cut in eligibility, which adds to the rolls of the uninsured. According to one insider: "In this way both the legislature and the general public will be forced to confront the reality that the socially acceptable minimum level of health care is ultimately the level we are willing to pay for."⁵⁵

The final list, according to the legislation, was to be submitted to the governor and the Emergency Board by March 1, 1990, allowing essentially one year, start to finish. After the first iteration, the Health Services Commission is ordered to continuously review the priorities, and submit revised lists on the September 1 preceding each biennial legislative session.⁵⁶ Only the Commission, and not the legislature or the governor, has the power to move an item on the list.

Because no prioritized list existed in the 1989-91 biennium, legislative insiders believed that the priorities the Golenski process had produced would be used as an interim solution. However, the state required waiver of several regulations by the federal Department of Health and Human Services or by Congress in order to operate the plan. Though the Oregon Medical Assistance Program (OMAP), which administers Medicaid, was explicitly authorized by SB 27 to seek waivers, Oregon has waited to finalize its application for these waivers (more on this below). Without the waivers, OMAP could not run the program, therefore no interim solution was needed and the Health Services Commission went about accomplishing its mandate--assembling its own list by its own method--independently.

Two other features of the bill are noteworthy: The Senior Services Division and the Mental Health Division are exempted from the priority listing,

⁵⁵ Oregon State Senate, "SB27 Section by Section Analysis" Internal document.

⁵⁶SB 27, section 3.4.

and providers are released from criminal, civil, and professional liability for services they withhold that are "below the line."

The isolation of long-term care services^{*} from the prioritization process has generated significant criticism.⁵⁷ Because as much as 70% of Oregon's Medicaid expenditures are directed to long term care⁵⁸, and the remainder go to AFDC recipients, pundits portrayed the decision as capitulating to seniors and balancing the Medicaid budget on society's poorest segment, women and children. SB 27's planners contend that this criticism "confuses prioritization with resource allocation."⁵⁹ Comparing medical and custodial care services is an apples-and-oranges proposition, they say, and invalidates their method. Moreover, no statutory provisions exist protecting the state's long-term care budget from the Ways and Means scalpel; if Ways and Means decides that an adequate level of health care can only be provided by moving the "line" down, requiring more money, then the Senior Services budget may be the source. Oregon, say SB 27's advocates, has the longest-running national demonstration project in community-based long-term care, a strategy widely viewed as a more efficient and humane alternative to nursing homes: continued innovation promises further economies and should obviate the tensions many

* Exempted services include: nursing facility services and home-based and community-based services funded through the Senior Services Division; medical assistance for the aged, the blind and the disabled or medical care provided to children under current Oregon law; institutional, home-based and community-based Medicaid programs special to Oregon; Community Mental Health Program care for mentally retarded or developmentally disabled, or chronically mentally ill, or emotionally disturbed, and substance abuse treatment programs; services to children who are wards of the Children Services Division by order of the juvenile court, and health and mental health services to children and families provided through the division. *From Garland, op. cit.*

⁵⁷See, for example, Albert Gore, "Oregon's Bold Mistake," *Academic Medicine*, 1990. 65:11, p. 634; Peter P. Budetti, "Medicaid rationing in Oregon: Political Wolf in Philosopher's Sheepskin." *Health Matrix*, 1991, special issue, proceedings from Cleveland Conference on Bioethics, *in publication*; Bruce C. Vladeck, "Oregon's Rationing is Misguided." *Medical World News*, October, 1990, p. 69

⁵⁸Vladeck, *op cit.*

⁵⁹Kitzhaber, John. Text of address to American Academy of Pediatrics, Chicago, IL, Sept 8, 1990, p. 10.

critics have highlighted between the two families of services. For their part, the state's mental health/chemical dependency services are under examination by a special subcommittee of the HSC, and are undergoing a prioritization process of their own.

The liability provision appears to be precedent-setting. Protection of providers from the consequences of essentially public decisions to eliminate certain services seems fair, but is untested in judicial law. Without such exculpatory protection, "providers who refused furnish their patients with medically necessary services merely because the state refused to pay for the services could be liable for the tort of abandonment and for malpractice."⁶⁰ Some critics view this provision as a direct contradiction to today's strong "anti-dumping" laws, which restrict a provider's ability to withhold treatment on the basis of ability to pay. Bruce Vladek, president of the United Hospital Fund of New York, contends that this proviso in particular makes "critically ill poor people in Oregon...worse off under the new law."⁶¹

E. Completing the Plan

Detractors and supporters agree that Senate Bill 27 would cut into Oregon's estimated uninsured population of 400,000,⁶² but Senator Kitzhaber and his associates sought to take a larger step toward eliminating altogether the problem of the state's uninsured. To achieve real progress, they knew, the law must address two additional sub-populations: poor working people and "uninsurable," or persons with medical histories or conditions rendering them undesirable risks for private insurance carriers.

⁶⁰Mehlman, Maxwell J. "The Oregon Medicaid program: Is it just?" *Health Matrix; The Case Western Reserve Journal of Law Medicine*, 1991, 1(2), in publication, ms. 24.

⁶¹Vladek, *op. cit.*

⁶²Governor's report

Shortly after passage of SB 27, the Committee on Health Insurance and Bioethics referred two companion bills, Senate Bills 935 and 534, to the Assembly for consideration, and both were made law. SB 935 is a mandated employee benefits law, or what is commonly called "pay or play" legislation. This act stipulates that all businesses employing 25 or fewer are eligible to pay into a state insurance pool for their employees (this is the "pay" of "pay or play"). The law prescribes the employer contribution and restricts the worker contribution, but stipulates a partnership. It attempts to prevent the "dumping" of undesirable-risk employees--those that might raise a company's premiums--into the pool by limiting participation in the pool to only those employees who were uninsured during the two years prior to enactment. To encourage employers to provide insurance through the private sector, SB 935 offers capitated tax credits per insured worker, to be phased out over four years (this is the "play" component.) All employers must do one or the other--pay or play--by 1994 to be in compliance with SB 935. Eventually, as many as 280,000 currently uninsured workers and their dependents in Oregon could gain coverage under this plan.

The distinguishing factor of this legislation, as compared to other pay-or-play plans, is that the minimum benefits package in the pool is determined in substance using the Health Services Commission prioritized list.⁶³ Thus some of the discomfiture expressed by some OHD participants⁶⁴ regarding the use of the values of the privileged for the benefits of the underclass, is relieved. Furthermore, other observers in Oregon believe that this "mainstreaming" of the prioritized list will encourage its diffusion into the private insurance market, setting the list up as a minimum benefits package for all the state's citizens.

⁶³SB 935, section 5.5

⁶⁴Interview with MJL, 1/31/91

However, perhaps because of its gradual phase-in, SB 935 is rarely referred to in either the professional or the popular press accounts of the Oregon plan. A bill before the 1991 session, SB 1076, proposes to strengthen the insurance mandate through three major avenues: guaranteed issue to any employer of three or more who applies for private insurance; community, rather than experience, rating for new insurance issues; and a mandated minimum benefits package based on the prioritized list.

The second sister bill was Senate Bill 534, which created a state-sponsored high-risk pool for so-called "uninsurable" Oregonians. Persons considered uninsurable are those people who represent undesirable risks to insurance carriers and may have lost their coverage in a job transition, or whose employer may have terminated group coverage. Persons with chronic illnesses or pre-existing conditions but who are categorically ineligible for Social Security's supplemental insurance, are also seen as uninsurable. The pool is funded primarily by contributions from insurers and with an initial state subsidy of \$1 million, and is expected to cover ten to fifteen thousand presently uninsured Oregonians. In the 1991 legislative session, a stronger insurance carrier contribution to the pool is expected to be mandated, in the belief that the carriers profit by insuring the healthy, and should help pay to insure the sick.⁶⁵

Although there is no statutory requirement that the pool provide a benefits package consistent with the SB 27 package, a number of observers believe that, with the "mainstreaming" effect of SB 935, this will come to pass. At the same time, people recognize that the insurance needs of the high-risk pool users may differ significantly from those of the broader-based populations covered by SB 935 and SB 27.

⁶⁵ Interview with DS, 4/17/91

F. Moving Forward

As they took shape, the three components of the Oregon Health Plan-- particularly SB 27, the most controversial--enjoyed broad endorsement among diverse interest groups. Supporters included a consumers' voice (the Oregon Health Action Campaign); providers' interest groups (the Oregon Medical Association, Oregon Hospital Association, and the Oregon Nurses Association); business groups (the Greater Portland Business Group on Health); and organized labor (Oregon AFL/CIO).⁶⁶ Although members of each of these groups report some hesitancy both about the content of the plan and about the alliance, the coalition remains essentially intact. Health Action continues to press for a universal health coverage system, modified from the Canada model. Some members of the OMA, support of which was perhaps carried by the votes of the more activist members of the Multnomah County (Portland-area) Medical Society, remain suspicious of the managed-care provision, believing it encourages a trend toward increased third-party intervention in medical decision making. Business leaders are reportedly nervous about tax implications--there is no explicit statement of revenue-neutrality in the act. And labor leaders share concern that the benefits package represent a "basic health plan," perhaps because their membership risks being "dumped" into the SB 935 pool. But, again, the center has held despite this range of reservations.

In such an atmosphere of cooperation, appointees to the Health Services Commission took office in August, 1989, and held their first meeting in September. Within a short time, the Commission established its primary ground rule: all Commission functions would be conducted entirely before the public.

⁶⁶Garland, 1991, ms. 9.

All materials are public, all testimony, all deliberations. This decision would later bring associated costs to light, but the Commissioners for the most part are pleased with the position.⁶⁷

The HSC mandate provided no guidance as to a method for determining either the public values term or the medical efficacy term of the priority equation, or how to weight the respective contributions, or indeed whether the decisions should be formulaic or more improvised. According to the HSC's preliminary report, the Commissioners viewed the task as comprising three major realms: social values; health outcomes and comparative benefits; and mental health and chemical dependency. The first two suggest an approach highly consistent with public policy decision theory, which takes all policy determinations to be a mix of facts with values.⁶⁸

For the Commission, "the challenge became how to blend those three issues into a ranked list of health services."⁶⁹ Commissioners agreed to parcel out their tasks, as they began to determine an appropriate methodology, by using subcommittee assignments. Bill Gregory, a Glendale lumber-mill owner and chairman of the Commission, named the early subcommittees. These included: Social Values, chaired by Commissioner Yayoe Kuramitsu, M.S.W.; Health Outcomes, chaired by Harvey Klevit, M.D.; and Mental Health/Chemical Dependency, chaired by Donalda Dodson, R.N., M.P.H.

1. *How We Feel*

⁶⁷Interview with TC, 2/14/91

⁶⁸Thompson, James D. and Tuden, Arthur. "Strategies, structures and processes of organizational decision" in *Comparative Studies of Administration*, ed. staff of University of Pittsburgh Administrative Science Center, James D. Thompson [and others]. Pittsburgh: University of Pittsburgh Press, 1963.

⁶⁹Oregon Health Services Commission. Preliminary Report. March 1, 1990, p.4.

The Social Values subcommittee construed its charge as identifying and measuring social health care values, as well as identifying the best way to do so. Ultimately, the citizens' input mandated in SB 27 took three forms. So as to capitalize on the momentum and experience of Oregon Health Decisions' community meeting process, the HSC would authorize OHD to conduct another round of fifty meetings under the Commission's aegis, to serve as part of the "community consensus" component of the priority list. To complement the OHD process, the Commissioners ordered a public survey of beliefs and values about relative health statuses, and held 11 sessions of open public testimony around the state.

The first of the three forms, coordinated by an unreimbursed sub-contract to Oregon Health Decisions, consisted of another series of community meetings to elucidate the values Oregonians hold with regard to health and health care. These, like the 1987 series, were conducted following a structured format, designed to provide some consistency across the fifty sites. The format, along with other strategy decisions, was designed by a thirty-member advisory panel comprised of OHD leaders, past community facilitators, activists, and several people who had been critical of the 1987 process.

Like the "Quality of Life" meetings, these OHD town meetings were attended primarily by middle- and high-income people, mostly well-educated as well.⁷⁰ Community meetings were held in all but one of Oregon's counties, and one was held in Spanish for the benefit of Mexican-American residents. In all, 1000 people participated. The meetings began with a slide show describing the current health care system in Oregon, as well as the provisions of the three pieces of the Oregon Basic Health Services Act. The final slides convey the

⁷⁰ Hasnain, Romana and Garland, Michael. *Health Care in Common.. Oregon Health Decisions*, Portland, Oregon, April, 1990, p. 30.

following charge to participants: "This is what we will do during this meeting: We will make individual judgements. We will develop community consensus on the values to be used in determining health benefits. We will make recommendations to the Health Services Commission. Our job is to determine the values for our community. A health care value makes us ask why a health service is important to us."⁷¹

In OHD's final report on the process, *Health Care in Common*, the authors list with the frequency of appearance those values--careful not to rank them numerically--that "Oregonians indicated should be considered" ⁷² as Commissioners try to assemble a fair and responsive ranking. Of the thirteen values, prevention, quality of life and cost-effectiveness were mentioned most frequently, and community compassion, impact on society, length of life and personal responsibility least frequently (Table 2).

TABLE 2

<ul style="list-style-type: none"> o Prevention (very high--all community meetings) o Quality of Life (very high--all community meetings) o Cost-Effectiveness (high--more than 3/4 of community meetings) o Ability to Function (moderately high--3/4 of community meetings) o Equity (moderately high--3/4 of community meetings) o Effectiveness of Treatment (medium high--more than 1/2 of community meetings) o Benefits Many (medium--1/2 of community meetings) o Mental Health and Chemical Dependency (medium--1/2 of community meetings) o Personal Choice (medium--1/2 of community meetings) o Community Compassion (medium low--less than 1/2 of community meetings) o Impact on Society ((medium low--less than 1/2 of community meetings) o Length of Life (medium low--less than 1/2 of community meetings) o Personal Responsibility (medium low--less than 1/2 of community meetings)⁷³

⁷¹ *Ibid.* p. Appendix B-5.

⁷² *Ibid.* p. 5.

⁷³ *Ibid.*, p. 5-6

Organizers acknowledge that more thorough and inclusive outreach is required to obtain the most appropriate results, but nonetheless stand by the elucidated values as presented to the HSC. The values enumerated by participants do not masquerade as "representative" or statistically relevant; one organizer described the report's findings as a glimpse of the views of "concerned, civically-involved people," and characteristic of "a democratic exercise."⁷⁴ Another suggested that the conclusions reflect "a sample of people who felt they would exemplify Oregonians."⁷⁵ Later, during the Commission's public meetings, these values would be taped to the walls around the room as a reminder to those engaged in the ranking of items on the list.

Two who attended the meeting in Corvallis, Oregon were not so enthusiastic about the democratic nature of the exercise. They felt that the "selected values" model did not acknowledge creative ideas, manipulated participants, and insulted their intelligence.⁷⁶

The second means of citizen participation used by the HSC was less structured: all its meetings are entirely public. Thus, they accept citizen participation more or less as it arises, and the public is invited to join in nearly every stage of the Commission's deliberations. Further, they held 12 open hearings, in Portland, Salem, Coos Bay, Pendleton, Eugene, Bend and Medford. To attract a low-income population to these sessions, the HSC urged OMAP to include announcements in Medicaid card mailings, and informally encouraged grass-roots community organizations, the Oregon Health Action Campaign and its sister organization Oregon Fair Share, to solicit testimony. Fair Share performed door-to-door canvassing, and through its 72 member

⁷⁴Interview with MJG , 1/29/91

⁷⁵Interview with PSM, 1/30/91

⁷⁶Interview s with MJL, MW, 1/31/91

organizations, OHAC helped ensure that a variety of Medicaid recipients and uninsured people would attend the open hearings. Average attendance was 150, with testimony generally by 45 people.⁷⁷ Often testimony produced unexpected results. Dental care, for example, was a relatively low-priority item for Commission members until pleas for adequate dental coverage arose repeatedly in the hearings. Commissioners were persuaded, and rearranged their lists to afford routine dental care a higher position. Thus, although it provided a less tangible result, Commission members say this window on the target community was a helpful reminder of the ways in which their decisions might change lives.⁷⁸

Lastly, the Social Values subcommittee felt they needed a device to establish the relative priority Oregonians give to certain physical limitations or medical prognoses. They began by exploring three existing instruments or study concepts that integrate health outcomes with individual and social values: the Hadorn Classifications, developed by David Hadorn, M.D. at the University of Colorado; the Sickness Impact Profile (SIP), from the University of Washington; and the Quality of Well-Being Scale (QWB), developed by Robert M. Kaplan at the University of California, San Diego.

The Commissioners determined that the Hadorn classification, which "places medical treatments in categories related to productive outcomes based on a value system,"⁷⁹ while incorporating an implicit value basis, did not sufficiently respond to expressed social values and therefore would be an inappropriate choice (although they are still undergoing refinement). The SIP, a commonly used instrument in functional health outcomes research, was found

⁷⁷OHSC draft report

⁷⁸Interview with TC, 2/14/91

⁷⁹OHSC report, p. 4.

both too lengthy and too inflexible. The Commission had decided to rank medical services in condition-treatment pairs, but the SIP was limited only to specific medical conditions.

The subcommittee did elect to use the QWB scale as one among several ultimate data components. The QWB asks survey respondents to assess different hypothetical health states, which then later could be correlated to treatment outcomes to judge how people feel about a post-treatment health state. The scale "seeks to measure the important criteria of health related quality of life--that is, the [relative] value society puts on the prevention of death, on various levels of functional impairment, or on the alleviation of a variety of symptoms such as pain, stiffness, depression, visual problems, fatigue, weakness, etc."⁸⁰ (With Kaplan's consent, Commissioners modified the standard QWB "to include the issues of mental health care and chemical dependency and psycho-social levels of functionality."⁸¹) The QWB survey was assigned to Oregon State University, which polled 1,000 Oregonians statewide, asking for this subjective evaluation of symptoms and levels of functioning. Site-specific mini-surveys also were conducted among special populations, "such as the economically and educationally disadvantaged, the bedridden, the chronically depressed."⁸² Responses were used to place health outcomes on a scale of 0-100, where 0 represents death and 100, perfect health. The QWB rating of the probable outcome of a given medical treatment determines the value component of its "net benefit" as part of a condition-treatment dyad.

Each of these three projects influenced the ultimate outcome of the service ranking in specific but different ways. The OHD process established

⁸⁰Oregon State Senate, "Summary: The Health Services Prioritization Process." December, 1990

⁸¹OHSC report, p. 5.

⁸²Senate Summary, 1990.

broad priorities and principles that characterized Oregonians' beliefs about the health care system. These helped to determine the relative rank of categories of services, such as "preventive care for children" or "comfort care." The open testimony contributed to the category ranking, but also influenced the individual commissioners as they rearranged items that had been ranked by a computer according to a "net benefit" formula.⁸³ The QWB study formed the values term of the "net benefit" formula, which gave Commissioners a skeletal structure to begin their ranking.

2. *What We Know*

Of course, for the QWB rating to have any usefulness, the probability of a given outcome must be known, which in the vast majority of cases it is not. It is to this quandary that the Health Outcomes subcommittee directed its attention. Medical practitioners in most instances do not know the empirical data on the relative efficacies of the procedures they perform. The quest for better data on outcomes has spawned a new federal agency, the Agency for Health Care Policy and Research.

Lacking the technology or funding for definitive answers, the Oregon HSC assembled 53 "provider panels"⁸⁴ of specialists--"conventional" and "non-conventional"--to gauge their expert opinions of relative efficacies, described in terms "compatible with various states of well being,"⁸⁵ so they would mesh with the QWB data in the compilation of a net benefit formula. (For services without Oregon-based experience, or for which methodologically sound research results exist, "selective literature searches"⁸⁶ would supplement the provider

⁸³Interview with TC, 2/14/91

⁸⁴Garland, *op. cit.* ms 17.

⁸⁵*Ibid*

⁸⁶OHSC report, p. 6.

panel deliberations.) The format highlighted “expected outcomes of condition-treatment pairs as well as the probability of those outcomes occurring,”⁸⁷ the expected duration of benefit, and the estimated outcome without treatment (called “proxy” treatment in the report).

Treatment and proxy costs were examined by this subcommittee as well, using historical data provided by OMAP. The commissioners decided to restrict the debate to direct costs, including “diagnosis, hospitalization, professional services, non-medical but prescribed services and ancillary services,”⁸⁸ using an average of a “reasonable range” of charges.⁸⁹ In clearly delineating these cost sources, the HSC avoided a dispute about the validity of measurement devices for indirect costs, such as the lost productivity model or the market value model. The cost element was structured so it could be factored into the net benefit formula to produce a “cost-benefit” index.

The dyads were established using codes from the *International Classification of Disease, Ninth Revision* (ICD-9) and *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised* (DSM-III-R) for the condition function, and *Physician’s Current Procedural Terminology, Fourth Edition* (CPT-4), all in common currency in the Oregon Medicaid program. Clinicians were encouraged to aggregate codes where appropriate; in the list’s most recent draft, the code pairs have been reduced to just over 800, from a possible 10,000. To account for ancillary services, those services (such as durable medical equipment or prosthetics) which do not fit the conventional definitions of diagnostic or therapeutic procedures but are nonetheless integral to a successful outcome, a temporary subcommittee determined to fold them in to

⁸⁷ *Ibid.*,

⁸⁸ *Ibid.*, p. 11

⁸⁹ Draft HSC report

the treatment function of the dyad. Some of these services fell under the Priority-Setting Project's case-management guidelines, and so included services not currently under the purview of OMAP, but viewed by the commission as consistent with its mandate to help the state "provide adequate health services to those in need."⁹⁰

3. A Special Case

The Mental Health Care and Chemical Dependency Subcommittee was alone among the original three subcommittees to be directly implied by the SB 27 legislation. This body might be more accurately described as a "task force," because only one member, its chair, is a commissioner. The remaining twelve members are from the two fields, with representation from both the provider and consumer communities. The subcommittee has further parcelled out its mandate to three task teams: one to identify research topics; one to evaluate outcomes research methodology (presumably to assess its application to mental health); and one to develop a report.⁹¹

G. Making it Whole

Fitting together the pieces took longer than either the legislature or the HSC had anticipated, but the Commissioners steadfastly refused to adopt a rating system or list before working out as many details as possible. As their March 1, 1990 statutory deadline passed, HSC members were working on a rough model for accomplishing their goal. The first attempt at a prioritized list merged the "value" elements (from community meetings, open testimony and

⁹⁰SB 27, sec 1.

⁹¹OHSC preliminary report, p. 7.

the QWB survey) with the “data” elements into a net benefit formula. The simplified formula is written:

$$\frac{\text{Net Benefits}}{\text{Net Costs}} = \text{Net benefit value}$$

where:

$$\text{Net Benefits} = \text{With Treatment benefits} - \text{Proxy Treatment benefits}$$

and:

$$\text{Net Costs} = \text{With Treatment costs} - \text{Proxy Treatment costs}$$

Benefits encompass the concepts of morbidity and mortality, duration of outcome, resultant health state as viewed by the public (QWB score), and finally the probability that such an outcome will occur. **Costs** are as cited above.⁹²

(For a more complete expression of the formula, see Appendix 1.)

The Commission contends that five of the 13 community values are incorporated into the net benefit formula: quality of life (reflected in the QWB function); cost-effectiveness; ability to function (also from QWB); effectiveness of treatment (reflected in the “outcome probabilities” function); and length of life (incorporated in the “duration of benefit” function).⁹³

The condition-treatment pairs would be arrayed from most important (most negative numeric value) to least important (least negative numeric value), “implying cost savings or cost avoidance in relation to benefit gained” in the former case, proceeding with increasing cost to the latter case.⁹⁴

⁹²OHSC preliminary report, exhibit 5.

⁹³Health Services Commission Final Report, unpublished draft

⁹⁴OHSC preliminary report, p. 11.

The net benefit formula did indeed produce a prioritized list of condition-treatment pairs, one that the commissioners hoped would "form the core"⁹⁵ of a final list. "The List," as it became known, was 1600 condition-treatment pairs strong. It ranked highest many bacterial illnesses, including bacterial meningitis, septicemia, salmonellosis, listeriosis, and general bacterial infections. Also high were several cancers and other life-threatening but treatable illnesses such as autoimmune hemolytic anemia and insulin-dependent diabetes. Low-priority items included diverse vascular defects, such several kinds of varices (vulval, pelvic, hemorrhoidal), dental diseases, hormone-related goiter, and hernia. So-called late- and end-stage treatments for HIV-related disease were ranked in the bottom 100; thumb-sucking and athlete's foot in the top 100. It was incongruities such as these, compounded by misconceptions about the influence of this "dry run," that led to much of the widespread criticism of the Oregon Plan.

The draft run of the formula concept, presented to an open session of the Health Services Commission on May 2, 1990, was picked up by the national media, sparking a maelstrom of debate and controversy throughout the country despite its intent as a "working document." The list was portrayed as the HSC's "main tool for their program" and the "centerpiece for the plan to begin limiting medical services."⁹⁶ On May 12, the lead editorial in *The New York Times* hailed "Oregon's Brave Medical Experiment." In the same newspaper two months later, two prominent thinkers in the field of health care resource allocation, William B. Schwartz of the Tufts Medical School and Henry J. Aaron of the Brookings Institution, wrote in the op-ed section that Oregon's "meat-ax

⁹⁵OHSC preliminary report, p. 11.

⁹⁶"Oregon Lists Illnesses by Priority to See Who Gets Medicaid Care." *The New York Times*, May 3, 1990, p. A-1.

approach" was "fundamentally flawed" and would "inevitably lead to gross misallocations of resources" and "set back efforts to fashion more equitable strategies for rationing."⁹⁷ Their primary reservation was the "blunt instrument" problem: medical care is too variegated for regulators to capture the range of diagnostic and treatment options in a few broad strokes.

Commissioners may have felt a little ambushed by the criticism, considering they had only commissioned the draft run to see what the formula might produce. Some were circumspect; such misappropriations were a liability of an entirely public process.⁹⁸ Despite the newspapers and magazines, however, the HSC pressed on, attempting to discover how to perfect the formula, or how they might accomplish their task without one. Commissioners were divided. "We're eventually going to come back to making it [the list] reflect our beliefs of what is adequate, functional health care," Commission member Richard Wopat, M.D., was quoted as saying at the first meeting since the draft run imbroglio began. "My gut level feeling is we can do that without the formula."⁹⁹ Commissioner Paul Kirk, M.D., expressed the belief that "abandoning the formula would ultimately skew the final product... Things are jumbled now, but you have to start somewhere," he said.¹⁰⁰

In trying to "untangle" the list, HSC members first disaggregated the condition-treatment pairs back up to 3,000, and, before re-aggregating them, ensured that groupings would only be maintained if they would be expected to have similar outcomes.¹⁰¹ After study, commissioners determined that a finer

⁹⁷Schwartz, William B. and Aaron, Henry J. "The Achilles heel of health care rationing." *The New York Times*, July 9, 1990, p. A-17

⁹⁸Interview with LR, 1/28/91

⁹⁹"Group tries to untangle health care priority list." James Thalman. *The [Eugene, Oregon] Register-Guard*, May 20, 1990 (a).

¹⁰⁰Thalman, 1990 (a).

¹⁰¹Senate Summary, 1990

distinction between "life-time" benefits was necessary, to separate self-limiting diseases (such as pediatric measles), from chronic disease with successful treatment (e.g., insulin-dependent [Type I] diabetes mellitus), from acute situations where a single intervention generally produces relief (such as appendicitis).¹⁰² In the first run, these conditions had all been given the same life-time benefit. Further, commissioners attempted to improve their cost data, and to discover the margin of error produced by wide variations in cost.

It was during this period also that the Commission determined to include with their list a recommendation for a "minimum standard of health care below which no person should fall," despite the fact that such a determination fell beyond its legislative mandate.¹⁰³

The HSC then created a new subcommittee, *Alternative Methodologies*, chaired by Rick Wopat, M.D., to determine how more faithfully to reflect the perceived community values. In addition, this subcommittee was charged with creating a compatible ranking system for services that do not fit the condition-treatment paradigm, such as health education interventions and preventive services.

Alternative Methodologies considered several possibilities: they explored the creation of a compatible coding system for "outlier" services; weighed relying on Commission judgement, assuming an accurate picture of the Social Values subcommittee findings; reviewed the Hadorn Classifications, which create categories of services based on condition and likely outcome.¹⁰⁴

The method they ultimately chose was complex, involving a "perspective weighting" of the OHD values--with respect to value to society, value to an

¹⁰²Senate Summary, 1990

¹⁰³"Minimum health care standard urged." James Thalman. *The [Eugene, Oregon] Register-Guard*, May 21, 1990 (b).

¹⁰⁴Draft of HSC report.

individual at risk of needing the service, and value to a basic health care package. These perspectives then were used to rank 17 modified Hadorn Classifications, using a variation on the Delphi rating technique. Functionally, this meant that each category was ranked three times, once each for its value to society, for its value to an individual at risk, etc., according to the relative weight each commissioner gave to these values. Next, Commissioners would examine the resultant category rankings to allow for argument and advocacy. (Category rankings were rearranged into the final months of deliberations.) Each condition-treatment pair or other service would be assigned to a category, and ranked, by its standing according to the net benefit and cost-benefit formulae, within that category. Finally, Commissioners would use subjective review to insure that the "out of position" items were appropriately placed.¹⁰⁵

In an attempt to further refine the formula, thus increasing its value as a basis for hand-ranking, the Commission's statistics consultant ran a test. He compared the hand-rankings of selected data items by three physician members of the Commission to formula rankings, varying the weighting of each formula component to most closely approximate the hand-rankings. Although an interesting strategy, he could not attain significant correlation between the lists short of virtually eliminating entire functions from the formula. Consequently, the Commission determined to stay with the manual rearrangement of the formula-ranked list as the preferred method.

When the final list was released on February 20, 1991, the category ranking had been rearranged several times. The final ranking (Table 3) reflected the Commission's competing desires to maintain a standard of care

¹⁰⁵Draft of HSC report.

while offering the preventive services repeatedly brought up during the town meetings and open hearings.

TABLE 3

1. **Acute fatal, prevents death full recovery**
Repair of deep, open wound of neck; appendectomy for appendicitis; medical therapy for myocarditis.
2. **Maternity care, including disorders of newborn**
Obstetrical care for pregnancy; medical therapy for drug reactions and intoxications specific to newborn; medical therapy for low birth weight babies.
3. **Acute fatal, prevents death, without full recovery**
Surgical treatment for head injury with prolonged loss of consciousness; medical therapy for acute bacterial meningitis; reduction of an open fracture of a joint.
4. **Prevention care for children**
Immunizations; medical therapy for streptococcal sore throat and scarlet fever (reduces disability, prevents spread); screening for specific problems such as vision or hearing problems, or anemia.
5. **Chronic fatal, Improves life span and QWB**
Medical therapy for Type I diabetes mellitus; medical and surgical treatment for treatable cancer of the uterus; medical therapy for asthma.
6. **Reproductive services (excluding maternity and infertility)**
Contraceptive management, vasectomy, tubal ligation.
7. **Comfort Care**
Palliative therapy for conditions in which death is imminent.
8. **Preventive Dental (Adults and Children)**
Cleaning and fluoride treatment.
9. **Preventive, Adults (subgroups A, B, C)**
Mammograms, blood pressure screening, medical therapy and chemoprophylaxis for primary tuberculosis.
10. **Acute, nonfatal, return to previous health**
Medical therapy for acute thyroiditis; medical therapy for vaginitis; restorative dental service for dental caries.
11. **Chronic, nonfatal, one-time treatment improves QWB**
Hip replacement; laser surgery for diabetic retinopathy; medical therapy for diabetic retinopathy; medical therapy for rheumatic fever.
12. **Acute, non-fatal, without return to previous health**
Relocation of dislocation of elbow; arthroscopic repair of internal derangement of knee; repair of corneal laceration.
13. **Chronic, nonfatal, repetitive treatment improves QWB**
Medical therapy for chronic sinusitis; medical therapy for migraine; medical therapy for psoriasis.

- 14. Acute, nonfatal, self-limited, treatment expedites recovery**
 Medical therapy for diaper rash; medical therapy for acute conjunctivitis; medical therapy for acute pharyngitis.
- 15. Infertility services**
 Medical therapy for anovulation; microsurgery for tubal disease; in-vitro fertilization.
- 16. Preventive, Adults (subgroups D, E)**
 Dipstick urinalysis for hematuria in adults less than 60 years of age; sigmoidoscopy for persons less than 40 years of age; screening of non-pregnant adults for Type I diabetes mellitus.
- 17. Fatal or non-fatal (non-self-limited), minimal or no improvement in QWB**
 Repair fingertip avulsion that does not include fingernail; medical therapy for gallstones without cholecystitis; medical therapy for viral warts.¹⁰⁶

H. Steps to Come

The prioritized list of services and the accompanying letters from Commission members contained no mention of a basic package. As released, the list bears the disclaimer that it is subject to change until submitted to the legislature, which will occur when the actuarial estimates are completed. After this task is accomplished, and the Joint Committee on Ways and Means has ruled an expenditure limit--effectively drawing a line through the list--the Office of Medical Assistance Programs will apply to the U.S. government for the appropriate waivers permitting Oregon to administer its new Medicaid plan. The waivers would allow OMAP to garner federal matching funds for services and populations not covered under current regulations, and would prevent penalty for omission of mandatory services.

According to Budetti, the Oregon Basic Health Services Act requires waiver of federal Medicaid regulations regarding "freedom of choice...statewide availability of services...comparability of services across beneficiaries... protection against exclusion based on specific diagnoses...provision of

¹⁰⁶"Prioritized Health Services List of February 20, 1991." Oregon Health Services Commission.

mandatory services, and...requirements that contracted providers be federally or state certified."¹⁰⁷

There are two mechanisms for waiver available to the state. One is the so-called "Administrative" waiver, which comes from the Department of Health and Human Services. Section 1115 of the Social Security Act authorizes the Secretary of the DHHS to grant waivers of department regulations to experimental, pilot, or demonstrations projects judged by the Secretary to be likely to promote the objectives of the Medicaid program.¹⁰⁸ Some, like Maxwell Mehlman, read this authorization as a certain rejection of the Oregon request, arguing that Oregon's utilitarian approach runs contrary to the objectives of Medicaid.¹⁰⁹ Other observers examine the record of HCFA director Gail Wilensky, whose recommendation to Secretary Louis Sullivan is judged to be crucial in the decision, and see cause for optimism. Specifically, Wilensky's public remarks granting that Oregon "ought to be able to respond to what it believes is the best way to provide health care for its poor population"¹¹⁰ are encouraging to the plan's supporters.

There is a believe, however, among those close to the waiver application process, that the 1115 waiver is not the proper avenue to pursue. They believe that the administrative waivers, which usually have a short time limit (often three years), would not offer the momentum they require to get the Oregon plan operational. Furthermore, some see HCFA as too politically vulnerable to be at the center of the decision. In early 1990, Sidney Trieger, a HCFA program

¹⁰⁷Budetti, *op. cit.*, ms. 25, citing Congressional Research Service. "Analysis of Oregon Senate Bill 27, for the Senate Committee on Finance." June 11, 1990.

¹⁰⁸Mehlman, *op cit.*, ms. 10, citing 42 U.S.C. §1325 (a).

¹⁰⁹*Ibid.*

¹¹⁰"Reps ask OTA study on Oregon." *Medicine & Health*, 1990, p. 3.

director, was quoted as saying: "Given a proposal of this sensitivity, it doesn't hurt to have Congress show its support."¹¹¹

With these considerations in mind, Oregon administrators have been communicating simultaneously with HCFA and with Congressional officials regarding an alternate waiver mechanism. Congress has the right to build into law a waiver of its own laws and regulations. Such a waiver likely would have more lasting value and would carry more political weight. Garnering support for a Congressional waiver would require persuading Representative Henry A. Waxman (D-Calif.), Chairman of the House Subcommittee on Health and the Environment, that the Oregon plan is fair and nondiscriminatory. Waxman, along with Tennessee Senator Albert Gore, have been Washington's leading critics of Oregon's efforts.

As a result of early discussions, skeptical federal lawmakers have dispatched to Oregon analysts from the Office of Technology Assessment to observe and report on the Health Services Commission's process. That report is due in early Summer, 1991, at about the same time that the Oregon legislature expects to have determined the charter benefits package and finalized its waiver application.

If the waivers are granted, OMAP is ready with a workplan for the complex implementation tasks that would lie ahead. As enumerated by Lynn Read, Director of Prioritized Health Care within OMAP these tasks include: Determine eligibility of new Medicaid enrollees; coordinate outreach to new eligibles; develop an enrollment system and computer support for the new program; let contracts for the provider network, including health maintenance organizations and primary care case managers; establish mechanisms for

¹¹¹Lund, Diane S. "Oregon plan to rank services rapped as cutting benefits." *American Medical News*, February 16, 1990, p. 3.

ensuring and monitoring access to services; training all players, including providers, bureaucrats, and client, in the use of the new system; and, finally, evaluation of the Prioritized Health Care plan. This list illustrates yet another dimension of complexity to the massive social experiment that began with the death of Coby Howard.

III. ISSUES

In this chapter I will explore from both a theoretical and practical view a selection of the prominent questions brought to the surface in the Oregon health services prioritization plan. These include: rationing; health care as a right; a standard for adequate care; decentralized accountability in health policy development; and the role of citizen participation. As questions develop in this chapter, the dilemmas that arise for participants in the Oregon process may become clearer, so that their voices, as presented in the next chapter, may sound more familiar.

Current attempts at explicit health care rationing, specifically the projects in Oregon and Alameda County, are rich objects for a critical analysis of many dimensions of health care resource allocation. The Oregon Basic Health Services Act already is the subject of a wide-ranging scholarly debate. At the Cleveland Clinic Foundation's 1990 Cleveland Conference on Bioethics, presenters and discussants looked prismatically at the program, producing a spectrum of commentaries in the ethical, sociological, philosophical, legal and public policy realms. Other commentators have published observations regarding technical and political aspects of the Oregon plan. I use specific commentary sparingly, referring instead to more general writings as they apply to current contemporary "rationing schemes."

A. Understanding Rationing

*Rationing is here...rationing goes on everyday, all the time...we ration in terms of who's served, we ration people out of the system. I've been uninsured, so I know what that's like.*¹

Given the range of the Cleveland papers, a separate but equally relevant means of approaching the Oregon effort is to examine the concept of explicit rationing. According to George Agich,

[r]ationing has several definitions, but essentially involves any method of allocating or distributing resources or goods that are scarcer than the demand for them...The ration is determined along two axes: availability or supply of the good in question and some rule of distribution based on, for example, individual need, equity, or social good. The term 'rationing' thus has connotations involving the sparing use of resources and inevitably involves a denial of some claims based on supply conditions or the rule of distribution.²

Why did Senator Kitzhaber believe that a prioritized list of services, one that would deny claims on specific benefits to several thousand people already receiving them, was the best public policy alternative for his state? Why explicitly ration health care for the poor?

As Callahan surmises, in 1987, when Senator Kitzhaber was deciding to move forward with some type of prioritization scheme,

They [critics] could point out that there was a \$200 million surplus in the Oregon state budget at the time. The transplant crisis was provoked by a voter-inspired expenditure limit that need not have happened and could be reversed in the future. They could in addition point out that millions of dollars are wasted, in Oregon and elsewhere, on cosmetics, expensive automobiles, VCRs, high-priced restaurants, and wasteful government programs...Coby [Howard] might not have had to die.³

Were conditions in Oregon truly conditions of scarcity? Agich questions whether scarcity "brought on by an unwillingness of society to pay ever-

¹Interview with Health Services Commission member, 1/29/91

²Agich, George J. "Rationing and professional autonomy." *Law, Medicine & Health Care*, Spring-Summer 1990, 18 (1-2):77-84

³Callahan, *op. cit.*, 1990, pp 18-19.

increasing costs for medical care in the face of striking disparities, if not inequities, in the distribution of care constitutes genuine scarcity."⁴

Kitzhaber, for his part, has defended his rationing plan in numerous addresses nationwide to both professional and lay audiences. Kitzhaber, who of all proponents best grasps all the details and implications of the Oregon Basic Health Care Act, answers his critics with pointed remarks. Among his common themes are the existing patterns of implicit health care rationing, the insidious effects of cross-subsidization of care for the poor, and, above all, the need to set limits on health care spending. He frequently points to "three fundamental realities: (1) the reality of fiscal limits; (2) the reality that health care is not necessarily synonymous with health; and (3) the reality that all medical services are not of equal value and efficacy."⁵ Kitzhaber's imperatives provide a useful tool for surveying current thinking about rationing.

The first "reality" point reinforces his belief in the social value of explicit rationing. Implicit rationing, of the type our society now engages in, does not allow for our need to set --through conscious action--limits. Kitzhaber recalls the 1985 Illinois legislation authorizing up to \$200,000 for any uninsured citizen requiring an organ transplant, while ignoring the fact that 60 percent of state's Black children were not immunized against polio.⁶ More subtle is the marketplace rationing, which distributes care according to the individual's by ability to pay.*

⁴Agich, *op cit.*, p. 80.

⁵Kitzhaber, John. Text of address to the Manufacturers' Alliance for Productivity and Innovation, San Diego, CA, October 5, 1990, p. 6; see also

⁶Kitzhaber, John A. "A healthier approach to health care." *Issues in Science and Technology*, Winter 1990-91, 7(2): 59-64.

* Many observers have pointed out that marketplace rationing would indeed be appropriate in the health care realm if market preconditions could be established, that is: availability of commodity at true social cost; complete information among consumers; near-equitable distribution of income.

The commonly cited standards for existing rationing, such as income, insurance status, time, and geography, do not appear to involve direct limit-setting action by society. Other, less well-described means of rationing, including rationing by age, health status, corporate countervailing power, and public relations are similarly insulated from social policy decision making or public accountability. Some of these implicit rationing standards warrant a closer look.

The health sector has always rationed care indirectly, in part through financing systems. Fee-for-service medicine, with its incentives for more treatment, does ration care by ability to pay, and does so in favor of the sick patient who will buy more care (note that, as highlighted below, this does not always result in better health). Although practiced ubiquitously as the "wallet biopsy," rationing by ability to pay has long been considered unacceptable in common law.⁷ Prospective payment schemes, such as HMOs or Medicare's diagnosis related groups (DRGs), where the incentives favor less treatment, may use health screening criteria and other means to ration care by health status in favor of the well patient.⁸ As Luft points out, rationing by health status is directly contradictory to the risk-pooling common to "socially desirable" insurance.⁹

The incentive system and its effects on "macro" health service distribution and rationing have been widely studied, but the effects can perhaps be seen

⁷Mehlman, *op cit*, ms. 24, note 59, specifically reference to Meiselman v. Crown Heights Hospital, 285 N.Y. 389, 34 N.E. 2d 367 (1941), holding the hospital liable for injuries to plaintiff after discharging him prematurely due to his inability to pay, and Wickline v. State of California, 228 Cal Rptr. 661, 183 Cal. App. 3d 1064 (1986), holding that the physician is responsible for insuring adequate patient care despite cost constraints imposed by third-party payers.

⁸Fleck, Leonard M. "Justice, HMOs, and the invisible rationing of health care resources." *Bioethics*, 1990 4(2):97-120.

⁹Luft, Harold S., 1983. "Health Maintenance Organizations and Rationing of Medical Care." In *Report of the President's Commission on Securing Access to Health Care*. Washington, D.C.: GPO, as cited in Blank, *op. cit.*, p. 93.

even more plainly at the level of the individual provider. Although physicians for many years pretended that they operated independent of a profit motive, such a pretense has grown thin. Economic incentives inducing physicians to over- or under-treat are strong and getting stronger, and they present a serious problem in the equitable distribution of health care resources. As Daniels points out:

When economic incentives to physicians lead them to deny...beneficial care there is a direct threat to what may be called the ethic of agency. In general, granting physicians considerable autonomy in clinical decision making is necessary if they are to be effective as agents pursuing their patients' interests. The ethic of agency constrains this autonomy in ways that protect the patient, requiring that the clinical decision be competent, respectful of the patient's autonomy, respectful of other rights of the patient (e.g., confidentiality), free from consideration of the physician's interest, and uninfluenced by judgements about the patient's worth. Incentives that reward physicians for denying beneficial care clearly risk violating the fourth-mentioned constraint, which, like the fifth, is intended to keep clinical decisions pure--that is, aimed at the patient's best interest.¹⁰

Agich adds an important qualification, writing that "the professional commitment to benefit patients does not establish the profession's prerogative to over-ride justly determined cost-containment measures."¹¹

And yet, even among those with insurance, there are disparities based on race, age and income in access to health services, including office-based services.¹² Agich does point out that "bedside" rationing often comes with the best of intentions; for example, maintaining a high standard of care. He tells the story of the legendary surgeon Harvey Cushing, who, during days with 50,000 combat deaths in World War I, held his daily surgical limit to two patients, in order to preserve his standard of care.¹³ Even in contemporary medicine, small-area variations in standard of care, as has recently been shown, can be quite extreme, with few patterns to help explain them. Such unpredictability in

¹⁰Daniels, Norman. "Why saying no to patients in the United States is so hard." *New England Journal of Medicine*, 1986, 314:1382-1385

¹¹Agich, *op cit.* p. 82.

¹²Hayward, Rodney A., *et. al.*. "Inequities in health services among insured Americans: Do working-age adults have less access to medical care than the elderly?" *New England Journal of Medicine*, 1988 318(23):1507-1512.

¹³Agich, *op cit.*, p. 81

practice patterns suggests an even more arbitrary means of bedside rationing, that is, physician preference.

Payers outside the health field also practice indirect rationing. Government and corporate institutions are beginning to assert a "countervailing power" on health care practice standards. U.S. corporations are, after the government, the major payers for health services. Kitzhaber paints a grim picture of the impact of rising health care costs on corporate America:

Americans pay more for health care in each new car they buy than for chrome or upholstered bucket seats. For each day a patient spends in the hospital, some \$30 of the bill goes to pay health benefits for hospital employees. A new automobile tire costing \$57 includes \$2 for health care; a \$200 airline ticket, \$4. Health benefits for active and retired employees account for \$60 of the cost of every metric ton of aluminum ALCOA produces.¹⁴

Joseph Califano, after resigning as Secretary of Health, Education and Welfare, joined the board of directors of the Chrysler Corporation when chairman Lee Iacocca told him: "You won't believe our health care costs. Alone, they can sink this ship."¹⁵ Blank cites Califano's claim that in 1983, \$600 of every Chrysler car went to health care, and the \$375 million that the corporation paid in premiums to Michigan Blue Cross/Blue Shield in that year made the Blues Chrysler's largest supplier.¹⁶ Califano describes the Chrysler predicament in his book, *America's Health Care Revolution: Who Lives? Who Dies? Who Pays?* Chrysler sought cursory data on utilization rates and appropriateness, and began taking steps to curb--or ration--what it perceived to be excessive use of specific health benefits., from podiatry and chiropractic through extended hospital stays.¹⁷ Other corporations are taking an active role in determining which health services employees and their dependents can and

¹⁴Kitzhaber, MAPI, 1990, p. 1.

¹⁵Califano, Joseph A., Jr. *America's Health Care Revolution: Who Lives? Who Dies? Who Pays?* Random House: New York, pp. 12-13.

¹⁶Blank, *op. cit.*, p. 18.

¹⁷Califano, *op cit.*, p. 12-13

cannot use. Hewlett-Packard, for example, no longer authorizes payment for organ transplantation; Honeywell will fund transplants only in otherwise healthy patients, and even then only when death is imminent.¹⁸ Blank argues that this private-sector rationing is "haphazard and patently inequitable," and question "whether corporations ought to be in effect setting medical decision-making criteria that have broad social ramifications."¹⁹

Public relations also is a common means of rationing health care. Coby Howard's story, a story which helped to launch Oregon's health care reform project, was by no means unique. Blank reminds us that:

In a well-publicized case, the parents of 11-month-old Jamie Fiske led a campaign in 1982 to obtain funding for her liver transplant. With the leverage of the local press and politicians, the Fiskes forced Blue Cross/Blue Shield to agree to pay for the surgery. Once successful at that stage, the Fiskes appeared at the national convention of the American Academy of Pediatrics to ask for a live donor. Although initially their request was refused, the story made it into the national news, and Jamie had a new liver in eight days.²⁰

It is also instructive to note that two Oregon adults died in need of medically indicated transplants during the summer of 1987, both reported in the local media with no attendant public outcry.²¹ Obviously, then, rationing by public relations value is inequitable. Blank contends that the "popularity" criterion also obscures medical facts, pitting a single dramatic case against thousands of less dramatic but medically indistinguishable cases, and lead as well to sensationalization and exploitation of the ill.²²

How do other society's manage health care resource allocation? Many in the health field believe that the United Kingdom has forced itself to confront "the reality of fiscal limits." Is the British rationing scheme more explicit than the arbitrary and unpredictable American one? A British cardiologist writing in a

¹⁸Blank, *op. cit.*, p. 94.

¹⁹*ibid*, pp. 94-95

²⁰*ibid*, p. 48.

²¹Welch, *op cit.*, p. 171

²²Blank, *op cit.*, pp 97-99

British journal suggests that this postulate has no basis. He describes a system that "is neither directly responsive to market forces nor subject to strict central control. Priorities are determined at a local level by a process that is ... often without a full appreciation of the weight of competing needs."²³ The predicament he poses for the British physician has a familiar ring: "Should doctors face the costs of their decisions? If they do not, the result can be inefficiency and favoured provision of patient care for the few to the detriment of the many. If they do, then the result could theoretically be a downward pressure on the quality of service."²⁴

Given the consistency of certain dilemmas across the two systems, how has the British National Health System (NHS) managed to provide universal coverage, spending roughly half what the U.S. spends proportionate to its gross national output, and still remain solvent? One method is what Grumet calls rationing through inconvenience,²⁵ or what the British call the queue. Another, cited by Miller and Miller, is a greater skepticism on the part of British health professionals of "the technological imperative--the notion that more sophisticated medical procedures are synonymous with better health care."²⁶ Finally, the NHS reportedly rations by systematically refusing referral to specialist care to those over 65.²⁷ none of these, of course, is written into law., which point brings one back to Senator Kitzhaber's first imperative, regarding society's need to *set* limits. Proponents of the Oregon Basic Health Services

²³Chamberlain, Douglas and Alderslade. Richard . "Can rationing of cardiological services be rational?" *British Heart Journal*, 1990, 64:219-22.

²⁴*Ibid.*, p. 221.

²⁵Grumet, G. W. "Health care rationing through inconvenience: The third party's secret weapon." *New England Journal of Medicine*, 1989, 321:607-611.

²⁶Miller, Francis H. and Graham A.H. Miller. "the painful prescription: A procrustean perspective." *New England Journal of Medicine*, 1986, 314 (21):1383-1385; as cited in Blank, *op. cit.* p. 5.

²⁷Aaron, Henry and William Schwartz,. *The Painful Prescription*. Washington, D.C.:Brookings Institution, 1984.

Act contend that a rational and systematic set of *de jure* prioritization criteria has a high probability of being more just than does any existing schemes of indirect rationing.

Kitzhaber's second "reality" point--that health care and health are not synonymous--explains for him the disparity between national health care expenditures and health indices, and helps to justify his own skepticism of the technological imperative. Here he reaffirms that a decrease in health care benefits is not *ipso facto* a destructive act, and that an increase is not necessarily better. Blank highlights this idea by citing a recent study finding "no statistically significant difference in the survival rates of patients treated for lung cancer over the last 30 years, despite the introduction of sophisticated diagnostic tools such as CAT scans, nuclear scans, and ultrasound during that period."²⁸ The appearance that survival rates have improved is an artifact of earlier diagnosis, which allows for longer follow-up and thus the illusion of longer survival. The researchers conclude that the new technologies have actually harmed roughly as many persons as they have helped. These findings complement the growing body of research on unnecessary and inappropriate care (see above), all of which carry decided risks of iatrogenic disease.

At least one commentator, Ivan Illich, has written widely on this tendency among health professionals, criticizing medicine for introducing iatrogenic illness. His book, *Medical Nemesis*, dwells at length on overtreatment. In exploring the dilemma posed by the introduction of explicit limits into the physician's fiduciary relationship with the patient, Daniels develops Donabedian's concept of "absolute" benefits, that is, benefits minus burdens, in

²⁸Feinstein, Alvan R., Daniel M. Sosin, and Carolyn Wells, 1985. "Stage Migration and New Diagnostic Techniques as a Source of Misleading Statistics for Survival on Cancer." *New England Journal of Medicine* 213 (25): 1604-1608, as cited in Blank, *op. cit.*, p. 112.

the context of justice. The concept implies that absolute quality is a function both of the state of medical science, and of the craft exercised in its use, and that "adding services does not always increase the sum benefits and burdens--we run into unnecessary, iatrogenic services." A price on life--or maximal absolute benefit-- Daniels suggests, would relieve the physician from violating justice considerations when placing categorical constraints on care. In questioning whether such rationing violates a physician's traditional ethical obligations to patients, however, Daniels relieves the physician but comes down just as forcefully against marketplace indirect rationing as Illich--or Kitzhaber--might:

...a rationing system based on ability to pay violates fundamental requirements of justice bearing on the fair distribution of health-care resources. It thus constitutes a greater moral evil than either the need to place a price on life or the need to restrict the autonomy of the physician in his pursuit of absolute quality.²⁹

Kitzhaber's last point--"that all medical services are not of equal value and efficacy"--gives him his rationale for the prioritization process. The above point by Daniels placing ability to pay at the bottom of a justice-determined allocation pecking order is quickly followed by this qualification: "...within the constraints justice imposes on our allocations, we want to be cost-effective."³⁰ Given that some means inevitably will be used to determine who gets what care, Kitzhaber reasons, we might as well do our best to create a means that is systematic, rational and as just as possible. Without such a solution, Schramm condemns our society to a "tyranny of our own making" through which we will "impoverish ourselves and successive generations by indulging in too much medicine."³¹

²⁹Daniels, Norman. *Just Health Care*. Cambridge University Press: Cambridge, England, 1985, p. 138.

³⁰*Ibid.*, p. 138.

³¹Schramm, Carl J. "Can we solve the hospital-cost problem in our democracy?" *New England Journal of Medicine*, 1984 311(11): 729-732, p. 732.

Given Kitzhaber's three assumptions--the need for fiscal limits, the failure of the technological imperative, and inconsistency of medical services--his conclusion that the time has come to shift "the debate from *who* is covered to *what* is covered,"³² is a natural one.

Senator Kitzhaber's tripartite call to reality is indeed a common theme in his speeches and publications, and successfully captures the philosophical underpinnings of the plan he authored. But because he is so often publicly assailed, the senator's most common theme is a fatigue with his critics, and he bemoans what he perceives as their insistence on comparing the Oregon plan with a theoretical ideal rather than with prevailing conditions. In an *Oregonian* op-ed piece, he responds to Aaron and Schwartz's pointed criticism of his "meat-ax" approach by writing:

It is far easier to say what should be done than to devise a plan for doing it...they [Aaron and Schwartz] cannot, or will not, see that every day the current system results in gross misallocation of resources...[t]o characterize the Oregon effort as...'a plan to deny certain health services to Medicaid patients,' makes as much sense as saying that Medicaid is a plan to deny health services to the working poor.³³

The senator's contention is that the Oregon plan lacks any pretense of being the best possible system, but rather it "represents a better one...and that it adheres to a clearly defined policy *which we are prepared to defend*,"³⁴ which, he says, sets it in contrast to the status quo, "which no one even tries to defend."³⁵

B. The Question of Rights

³²Kitzhaber, John A. "Fulfilling obligations." *Health Management Quarterly*, 1989, 11 (4):14-15.

³³Kitzhaber, John. "Critics of health care proposal offer no alternatives." *The Oregonian*, Friday, Aug 24, 1990.

³⁴Kitzhaber, John A. "The Oregon Basic Health Services Act." *Health Management Quarterly*, 1991, 13(1)

³⁵*Ibid.*

I shouldn't get the same care as a billionaire. I don't think we can use the health care crisis as a rationale for a redistribution of wealth in our country. I do believe, though, that everyone should have a right to a basic level of health care, just not to everything science has to offer.³⁶

Whether or not you see it as a right, though, it is a matter of community compassion and social justice. You can have no workforce or healthy society without health care.³⁷

One supposes that dilemmas posed by direct and indirect rationing would be not nearly so vexing if health care were any old commodity. To a certain extent, health services can be seen as subject to market economics; the RAND health insurance experiment did demonstrate that "the 'general law of demand' applies to medical care as well as to wheat and widgets."³⁸ However, medical care clearly is not just a widget. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research Report on *Securing Access to Health Care* points out health care is special because Americans believe it to be so.³⁹ There may also be intangible distinctions between health care and most other commodities that warrant its treatment as a special case. Daniels cites Dickman in arguing that two such factors, a principle requiring us to show "equal respect for persons" and the vulnerability and tenuous self-respect of those seeking medical care, suggest that we "pay special attention to the (roughly) equal distribution" of this commodity.⁴⁰ But the critical distinguishing factor, with perhaps more common

³⁶Interview with state health services staff official, 1/28/91

³⁷Interview with physician/Health Services Commission member, 2/14/91

³⁸Fuchs, Victor R. "The 'competition revolution' in health care." *Health Affairs*, Summer, 1988, 7(3):5-24, p. 11; citing Willard G. Manning, *et al.*, "Health insurance and the demand for medical care: Evidence from a randomized experiment." *American Economic Review* (June 1987): 251-277.

³⁹President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research Report. *Securing Access to Health Care*, vol. I. Washington, D.C.:US Government Printing Office, 1983, p. 11.

⁴⁰Dickman, R. "Operationalizing respect for persons: A qualitative aspect of the right to health care." In R. Bayer, A. Caplan, and N. Daniels (eds), *In Search of Equity: Health Needs and the Health Care System*, pp. 161-182. New York:Plenum, 1983; as cited in Daniels, 1985, *op cit.*, p. 71.

currency but less clarity, is the tendency of some, articulated by the World Health Organization,⁴¹ to believe that health care is a commodity to which humans have a right.

The philosophical debate on the topic of rights in health care is at the same time wide-ranging and profound. For the purposes of this paper, the debate is important in attempting to understand the "whys" of Oregon's imperative: the background, necessarily cursory, may help elucidate some of the motivations behind the the Oregon Basic Health Services Act.

In the Western societies, certain rights are viewed as "natural rights," a concept inherited from John Locke and imbedded in the document that launched our nation, the Declaration of Independence. These are rights are held by our society "to be self-evident;" so basic to human existence that no law can abridge them. Unfortunately, natural rights are invariably vague:⁴² what are life, liberty and property, and who is entitled to them? To help clarify the imprecision of natural rights, many authors pursue a taxonomy whereby a right can be construed as being either positive or negative. Given that a right of one person imposes an obligation on another, each type of right implies different claims on other people. A positive right implies a claim on another person's positive action; to protect that right, someone must act, or society must urge someone to do so. Conversely, a negative right implies an obligation on another *not* to act; to protect a negative right, someone must avoid acting, or society must prevent someone from acting. This is the Lockian notion obligating

⁴¹"Preamble to the Constitution of the World Health Organization," *World Health Organization, Basic Documents*, 26th ed., Geneva: World Health Organization, 1976, p. 1, as cited in Matti Hayry and Heta Hayry. "Health care as a right, fairness and medical resources." *Bioethics*, 1990 4(1), pp.1-21, p. 1.

⁴²Blank, *op. cit.*, p. 190.

individuals to refrain from interference with their neighbor's life, liberty and property.

Blank uses the work of Beauchamp and Childress to suggest that a failure to distinguish between positive and negative rights has led to "much confusion in the moral discourse about public policies governing biomedicine."⁴³ He explains that negative rights require the state to "referee among competing interests" in the protection of rights, whereas positive rights require state action to "provide for the welfare of its citizens."⁴⁴ The conflict arises when the assertion of positive rights infringe on others' negative (or positive) rights.

In exploring this claim, it is first important to differentiate a right to *health* from a right to health *care*. The former, although sometimes seen in print, is quite difficult to assert, particularly as it implies a strong social claim on individual behavior. For example, if I claim a right to good health, and then proceed to compromise my own health by smoking cigarettes, drinking alcohol, or driving a car, society incurs an obligation, derived from my right to good health, to protect my health from my own behavior. This *obligation* of society to restrict personal liberty in response to a right to good health contrasts with the result of an assertion of a right to health care, which is merely an *incentive* for society to restrict individual liberty as it attempts to provide health care. This incentive complements the individual's responsibility to select behaviors in such a way that society has a "reasonable chance" of fulfilling its obligation. Such complementarity, or division of responsibility, is the basis for distributive

⁴³Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics*. New York, Oxford University Press, 1979, p. 51; as cited in Blank, *op cit.*, p. 192.

⁴⁴*Ibid*, pp. 51/192

justice.⁴⁵ And, as Daniels writes, it is by a theory of distributive justice that we may properly and justifiably derive a right.⁴⁶

Of course, this method of constructing a right is largely theoretical. But there is an intuitive appeal, if only in its rhetorical power, to the statement that we have a right to health care. Even absent a credible theoretical derivation, as Daniels points out, "The assertion of a right may simply be the natural or only way that comes to mind to argue for just reform and to insist that the health-care system eliminate the particular inequalities found objectionable."⁴⁷

Another way pragmatically to derive a right to health care is by a model based on society's willingness to pay. That is, rights are granted by society, and demonstrated by society's willingness to allocate funds appropriately. For example, a U.S. citizen is said to have a right to counsel when she is in legal jeopardy, irrespective of ability to pay. A substantial network of local public defenders support this right at public expense. By reversing this view, the right is derived on "equal protection" grounds,⁴⁸ that is, because public funds support the public defender's office, all citizens are entitled to legal counsel, irrespective of ability to pay.

Whether derived theoretically or pragmatically, the assertion of a right to health care begs the difficult question: *how much health care?* Callahan writes that "The principle of a right to health care, lacking intrinsic limits, fails a most important legislative goal, that of developing principles of entitlement that contain...some self-limiting boundaries. A principle that provides no way...of setting priorities, no way of setting limits...cannot effectively be used for

⁴⁵Daniels, 1985, *op. cit.*, p. 38

⁴⁶*Ibid.*, p. 5.

⁴⁷*Ibid.*, p. 5.

⁴⁸*Ibid.*, p. 8.

purposes of public policy."⁴⁹ But policy implications are not always paramount in the elucidation of rights. The President's Commission Report on *Securing Access to Health Care* essentially finesses the tension between rights and applications. Begging the question, the report simply states that "Society has a moral obligation to ensure that everyone has access to adequate care without being subject to excessive burdens."⁵⁰ The phrase "adequate health care"--now opposed to "optimal" care--is echoed in the Oregon Health Decisions report, *Quality of Life in Allocating Health Care Resources*. The answer, according to the Citizen's Health Care Parliament, is to ensure that "the most important services always receive top priority in funding."⁵¹

C. The 'Decent Standard' Standard

*Basic, grandma-type medical care, or care that's provided in rural communities where you don't have access to all this high-tech equipment is often just as effective as care provided in a multimillion dollar hospital with all the latest in medical technology.*⁵²

In sidestepping the rights question, the President's Commission Report admits that an assertion of a right to health care would make "impossible demands on society's resources."⁵³ But society's obligation, whether derived from social beneficence or distributional justice, is clear in the eyes of the Commission. So the task is left to social planners to determine how to fulfill that obligation without making impossible demands on society's resources. The result would be what citizens' groups call "basic health care," or what Daniels

⁴⁹Callahan, 1990, *op cit.*, p. 61.

⁵⁰President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research Report, *op. cit.*, p. 22.

⁵¹Oregon Health Decisions, 1988, *op cit.*, p.11.

⁵²Interview with community organizer and lobbyist, 1/31/91

⁵³President's Commissions, *op. cit.* , p. 10.

calls, somewhat more poetically, a "decent basic minimum," and what Kitzhaber and associates hope will comprise Oregon's "list."

Given a failure of social consensus on what should define such a standard, it may be instructive to examine what dimensions might be used in developing one. For example, Daniels contrasts "lists versus criteria."⁵⁴ He offers three dimensions:

(1) the provision of a general *criterion* by reference to which we can tell if services are within the minimum or above it; (2) the description of a fair *procedure* for determining the minimum; or (3) the simple *listing* of the types of services included.⁵⁵

By contrast Callahan proposes two alternative dimensions of criteria: "categorical" versus "individual."⁵⁶ By Callahan's accounting, all Daniels' means of evaluation would fall under the categorical rubric; individual evaluation is "bedside" rationing.

Hayry and Hayry suggest that the morally relevant (not to say justifiable) factors in individual rationing include the following: medical need; race; the prospect of medical success; merit, or desert, of past social contribution; future life expectancy, or welfare maximization; whether or not the ill-health is 'self-inflicted; social worth, or expected social contribution; and family relationships. The authors discount most of these as ethically spurious.⁵⁷ After inspection, Callahan too dismisses the individual option, for many of the same reasons we have already explored: it is unpredictable, it is difficult to balance individual with social demands, and often implicit, meaning difficult to criticize. Conversely, the value of categorical decision making is in its appeal to equal opportunity. Daniels suggests that "rationing by age [for example] could be justified if it were

⁵⁴Daniels, *op. cit.*, 1985, pp. 74-75.

⁵⁵*Ibid.*, p. 74.

⁵⁶Callahan, 1990, *op. cit.* pp. 202-206.

⁵⁷Hayry and Hayry., *op cit.* , pp.7-8.

part of a unified, prudent social saving scheme," but not if applied "piecemeal' to constrain costs in our system."⁵⁸ (Callahan, of course, has made the most comprehensive argument for categorical denial based on age in his popular *Setting Limits*.)

In elucidating their model for managed-care-based universal health insurance, Enthoven and Kronick propose as a minimum the standard already set in the HMO Act of 1973 (as amended, presumably). This standard, intended to constrain HMOs, is both broad and non-specific. Such qualities are obstacles to explicit, categorical rationing, so the authors allow for "tighter definitions and restrictions to reduce costs,"⁵⁹ which commits them to neither narrower nor more specific explications of a minimum standard of benefits, and ends up saying little about what benefits they expect recipients of their universal coverage to receive.

The Oregon Health Decisions Parliament, to answer the "adequacy" conundrum within the context of universal coverage, proposed to refer back not to a notion of rights, but to some of the theoretical foundations for such a notion. Principle #10 of their "Principles for Health Care Resource Allocation" suggests that "Both efficiency and equity should be considered in allocating health care resources."⁶⁰ The authors view this principle as analogous to a hearts/minds dichotomy, reminding readers that the rescue impulse is strong in our society, regardless of the social costs

Rescue impulses aside, The Oregon Health Services Commission is compelled by the legislature to provide a framework allowing government to set

⁵⁸Daniels, *op cit.* 1985, p. 228

⁵⁹Enthoven, Alain and Richard Kronick. "A consumer-choice health plan for the 1990s: Universal health insurance in a system designed to promote quality and economy (first of two parts)." *New England Journal of Medicine*, 1989; 320(1): 29-37, p. 33.

⁶⁰Oregon Health Decisions, 1988, *op cit.*, p.13.

limits on medical services funded by the state. The path they have taken, also determined by the legislature (read, Senator Kitzhaber), implies categorical denials based on a conjugation of Daniels' three alternatives: a general reference criterion; a procedure for determining the package; and a simple list of services. But there is precious little guidance in the legislation as to what services shall comprise the list.

Heart transplantation, one of the therapies that initiated the debate in Oregon, is a good example. There is no doubt that transplants save lives. Mehlman cites data demonstrating that heart transplantation results in a five-year survival rate between 73.9 and 81.9 percent, with 73.33 percent of recipients alive after ten years; with a high percentage reporting a satisfactory quality of life.⁶¹ But with an estimated ceiling of 10,000 beneficiaries per year--imposed by a scarcity of potential heart donors--a heart transplantation program structured like the End-Stage Renal Disease Program could cost \$1 to \$2 billion per year.⁶² Should .5 to one percent of the federal government's annual outlay for health benefit .003 percent of the population? Years ago, when it was believed that an artificial heart powered by a tiny nuclear engine might succeed, some physicians were concerned that this beneficial technology might cause harm as a radioactive device. But now we must wonder if heterologous transplant is any less harmful, due to the disproportionate health care resources it requires.

⁶¹Mehlman, *op cit.*, mss 21-22; citing: Heck, Shumway and Kaye, "The Registry of the International Society for Heart Transplantation: Sixth Official Report, 1989" *Journal of Heart Transplantation*, 1989, 8:271-275 and Meister, McAleer, Meister, Riley and Copeland, "Returning to work after heart transplantation," *Journal of Heart Transplantation*, 1986, 5:154.

⁶²Daniels, 1985, *op. cit.*/p. 222.

The problem for the Commission, of course, was that nothing in the legislative mandate, or in the Oregon Health Decisions process, or elsewhere, could determine how to rank services so that the line would be drawn below the point where "adequate" fades into "optimal." Determining adequacy based on a concept of "average" level of care, as Daniels points out, would not ease the difficulty; the tendency of *average* to actually reflect "*average daily use by people in the upper-middle income levels...risks incorporating into the decent basic minimum all that is already askew in our health care system.*" [emphases original]⁶³ (This, despite the fact that "customary practice" has long been the standard both for fee-for-service reimbursement rates and for malpractice liability.) Some observers of the HSC process have suggested that commission members are, to a certain extent, "gaming" the system, intentionally ranking "wants" above "needs," to force the legislature to draw a more inclusive package than a straight ranking might produce. Others believe that Commissioners understand the risk of such a tactic and shun it.

The process as Kitzhaber designed it accomplished his major goals: whatever did make it into the package would do so through a systematic and public review. However, with little guidance from theorists and no precedent in public policy, the Oregon Health Services Commission was left in a moral quandary: if they ranked a life-saving procedure too low to be funded--without knowing in advance where the line would be drawn--were they as commissioners directly responsible for a death resulting from consequent non-treatment?

⁶³Daniels, 1985 *op. cit.* p. 77.

D. A Shift in Public Accountability

"I'm distanced from the individual that will be impacted. I have not directly had to face a Coby Howard or someone who has died as a result of these decisions."⁶⁴

I think of the phrase in the New Testament, "By their fruits shall you know them." And I think: Do I see myself, my community, in the Oregon Health Decisions report?⁶⁵

Perhaps the moral responsibility of the Commission members is not so interesting. After all, they are public figures by virtue of their appointment to the Commission and must accept responsibility for policies they recommend. But they are caught in a troubling spot: they do not create the package--that is left to the Joint Committee on Ways and Means--but they are responsible, by their ranking actions, for denying services that fall below it. And, to stay with the transplant example, this is a potentially potent responsibility. Thousands who lose Medicaid coverage when eligibility rules change may, like those studied by Lurie, *et al.*, get sick or die,⁶⁶ but they will likely do so anonymously. But a patient with organ failure who is denied a transplant, like Coby Howard or Jamie Fiske, has a name.

Daniels calls this the "buried coal miner" effect:

Transplants present us with life-and-death dramas--we have an identifiable victim, often an appealing but jaundiced child, or a young mother or father with dependent children. It is well known that we are prepared to devote vast resources to save identified victims. At the same time we are much less willing to use the money more effectively to save *statistical* victims, for example by investing in coal mine safety (or preventive prenatal care).⁶⁷

⁶⁴Interview with state health services staff official, 1/28/91

⁶⁵Interview with former Oregon Health Decisions executive, 1/29/91

⁶⁶Lurie, Nicole, Nancy B. Ward, Martin F. Shapiro, Claudio Gallego, Rati Vaghaiwalla, Robert Brook. "Termination of Medi-Cal benefits: A follow-up study one year later." Special Report, *New England Journal of Medicine*, 1986, 314 (19): 1266-1268.

⁶⁷Daniels, 1985, *op. cit.*, p. 223.

In her "Statement on Behalf of the Oregon Health Services Commission upon Release of the Prioritized List of Services," Commission member Tina Castenares, M.D. puts this in even more poignant terms: "...[already] almost every day in my practice...it's the *patient* [as opposed to a treatment] who is low on somebody's list of priorities for receiving help and the services she can't afford are BASIC." [emphases original]⁶⁸ We can judge, then, that Commissioners are (or should be) prepared for potential emotional fallout from the priority choices.

However, the Oregon plan, from its earliest inception to its legislative iteration to its implementation, had as a cornerstone the incorporation of public values into the policy deliberation. Laypersons were asked to elaborate on values, which often by their very nature are arbitrary. Rational or not, these values--expressed by individuals in a democratic exercise--have strong policy implications in Oregon . The Oregon Health Decisions community consensus values, published in *Health Care in Common*, were after all taped to the walls at HSC meetings, and paid heed.

In his caustic critique of the Oregon Basic Health Services Plan as public policy, Peter Budetti highlights this feature of the methodology. He writes that the process "would merely insulate politicians from visible responsibility for imposing rationing on AFDC children..."⁶⁹ without offering any return benefit to the town meeting participants. Presumably, Budetti envisions that such insulation involves a swap of accountability--from lawmakers to the community meeting participants. If this is so, are these participants as confident as Dr. Castenares about the consequences of their value statements? On the other

⁶⁸"Prioritized Health Services List of February 20, 1991." Oregon Health Services Commission.

⁶⁹Budetti, Peter P. "Medicaid rationing in Oregon: Political wolf in a philosopher's sheepskin." *Health Matrix: The Case Western Reserve Journal of Law Medicine*, 1991 1(2), in publication, ms.15.

hand, if the community participation is as ineffectual and marginal as Budetti claims, then concern for the emotional fallout among town meeters is misplaced.

E. Effects of and on Communities

*One thing I'm convinced of, after going through this sometimes extremely uncomfortable adventure is that the public is far more willing to make these choices than are physicians and legislators. They understand limits.*⁷⁰

Lappe and Martin build a careful argument for a role for the public in scientific endeavor. Common law asserts, they write, that the public--not just the individual--is entitled on first amendment grounds "not only to entertain the vigorous discussion of ideas and issues but also to formulate informed public decisions."⁷¹ They cite the Supreme Court decision in *Virginia State Board of Pharmacy v. Virginia Citizens Consumer Council, Inc*⁷² that well-informed public opinion is "indispensable to the formation of intelligent opinions as to how that system [free enterprise] ought to be regulated or altered," and held the specific interest of society in ensuring the free flow of information so as to "enlighten public decisionmaking."⁷³

Given the obvious technical limitations on a citizen role in science and health policy, it seems useful, as many writers do, to point out the significance of their contribution to the *value* component of Landau's fact-value public policy formula. As Blank puts it, "although the role of health experts and planners is crucial, allocation/rationing decisions ultimately reduce to value questions."⁷⁴

⁷⁰Interview with state legislator, 1/31/91.

⁷¹Lappe, Marc and Patricia Archbold Martin. "The place of the public in the conduct of science." *Southern California Law Review*, 1978 51:1535-1554, p. 1541.

⁷²425 U.S. 748 (1976) as cited in Lappe and Martin, *op cit.* p. 1542.

⁷³*Ibid.*

⁷⁴Blank, *op. cit.* p. 176.

Value-based decisions require public support, he contends, and that support is stronger and more meaningful when it springs from true involvement in the process.

In his discussion of public participation in the area of environmental risk policy, Fiorino enumerates three arguments for meaningful enfranchisement of a citizen voice in science policy.⁷⁵ The first, a *substantive* argument, is that the lay community is as capable as are experts in judging risk; laypeople may see problems that remain obscure to experts, and may be more sensitive to the intangibles, such as social and political forces.⁷⁶ His second point is a *normative* one: policy determined by a technocracy is incompatible with fundamental democratic ideals. This idea "accepts, as an ethical presupposition, that individuals are the best to judge their own interests."⁷⁷ Last is an *instrumental* rationale, stating that "effective lay participation in risk decisions makes them more legitimate and leads to better results."⁷⁸

Fiorino lays out the various mechanisms for public participation, including public hearings, initiatives, public surveys, negotiated rule-making, and citizen review panels, and offers four criteria to judge the relative merits of each of these as they relate to the democratic process: (1) amateur participation must have a direct influence; (2) participation must be decision-related, as opposed to merely cathartic or plaintive; (3) the best examples of citizen participation offer a face-to-face opportunity at persuasion; and (4) the mechanism should put the citizen and the decision-maker on equal footing.⁷⁹ He concludes that no one mechanism adequately satisfies all criteria for

⁷⁵Fiorino, Daniel J. "Citizen participation and environmental risk: A survey of institutional mechanisms." *Science, Technology, & Human Values*, 1990 15(2):226-243, p. 227

⁷⁶*Ibid.*

⁷⁷*Ibid.*

⁷⁸*Ibid.* p. 228.

⁷⁹*Ibid.*, pp 228-230.

reflecting democratic ideals, but rather a mix, for example the Oregon Health Services Commission's open hearings, citizens review, and public (QWB) survey.

It is important to note, however, that the community input component of the Oregon Basic Health Services Act is not *sui generis*. In the realm of health care policy specifically, there is a growing tradition of public involvement in decisionmaking. Before the End -Stage Renal Disease program was folded into Medicare--creating a whole new set of allocation problems--community panels, comprised of lay and medical people, were charged with determining allocation of scarce kidney dialysis apparatus. They were to judge access claims "based on unspecified personal, familial, and social criteria."⁸⁰ In his retelling of the story, Callahan cites Fox to say that "They reported themselves unable to make meaningful comparisons and choices. They could not devise appropriate moral criteria either. They considered their effort a failure."⁸¹

At roughly the same moment in history the nascent Office of Economic Opportunity (OEO) was using its position within the federal executive branch to promote the idea of community participation and control in health services delivery for poor people. Guided by the catchphrase "maximum feasible participation" (later ridiculed by Daniel Patrick Moynihan as "maximum feasible misunderstanding"), the OEO was one of the more radical components of the President Johnson's War on Poverty. Two early OEO health-related demonstration projects were at Columbia Point in Boston and in Mound Bayou,

⁸⁰Callahan, 1990, *op cit.* p. 46

⁸¹*Ibid*, citing Renée C. Fox, *The Courage to Fail: A Social View of Organ Transplants and Dialysis*, Chicago: University of Chicago Press, 2nd. ed., 1978, pp.226-265.

Mississippi. According to Hatch and Eng, these seminal programs intended to explore the relevance of the social-action model in health care.⁸²

Like the dialysis committees, community action health projects ultimately failed. Maximum feasible participation often was interpreted in ways that did not gibe with existing power dynamics within poor communities. But documentation of progress in OEO communities, though thin, suggests that some lasting benefit survived after the collapse of the projects and departure of the federal funding. Such benefit might be seen in increased education attainment, greater demands by community members in many aspects of civic life, and an experience with a structure accepting of collective anger among poor people. Benefit may also be construed in the health sector itself, which partially as a result of the OEO experience has seen a "redefinition of health care to encompass nutrition, housing, water, and sanitation. It happened because of the voice and insights of the people living daily with these problems."⁸³ For the communities that participated in the Oregon Health Decisions town meetings or in the HSC hearings, the question of lasting benefit--both the effect of the community on the policy and the effect of the participation on the community--is a relevant one.

Subsequent to the OEO misadventure, Congress did not abandon the idea of community involvement in health planning, but did temper it. Strengthening the 1966 Comprehensive Health Planning legislation, congress in 1974 passed the National Health Planning and Resources Development Act. This act created over 200 regional Health Systems Agencies (HSAs) and 50 state Health Coordination Councils.⁸⁴ HSAs, now essentially defunct, required

⁸²Hatch, John W. and Eugenia Eng. "Community Participation and Control." in Victor W. Sidel and Ruth Sidel, *Reforming Medicine* New York: Pantheon Books, 1984, pp. 223-244,

⁸³*Ibid.*, p. 236.

⁸⁴Hatch & Eng, *op cit.*, p. 240.

between 51 and 60 percent local consumers on their planning boards, with specific language dictating the roles of health experts and laypeople.

The thorniest problem with the HSAs, as with the OEO projects before them, is the question of constituency: whom are the consumer representatives intended to represent?⁸⁵ This dilemma affects the selection of board members, as well as determining to a large degree their credibility and the legitimacy of their voices. According to Hatch and Eng, the least successful HSAs were those that, again like failed OEO projects, neglected to recognize legitimate institutions, decision-making patterns, leadership structure, and social-support mechanisms within the community.⁸⁶

The approaches taken by the SB 27 authors to the question of constituency is both disconcerting and reassuring. On one hand, there is no obvious or explicit mechanism for Fiorino's "negotiation" between the HSC and people living in poverty, one constituency for the policy developments under SB 27. Poor people did have a voice in the testimony, and to a lesser extent in the telephone survey (biased toward telephone subscribers) and the OHD town meetings. On the other hand, the expenditure of public funds should conform to public values, as expressed through a democratic exercise. In this regard, the disproportionately well-educated, well-off participants at the OHD town meetings are also a constituency of the HSC, and the mechanisms suit this constituency well. Blank reinforces this view, suggesting that for certain applications, a "specialized, attentive" public is the most appropriate participant pool.⁸⁷ It is doubtful if this need, however, supercedes the requirement for participation by a directly affected public.

⁸⁵ *Ibid.*

⁸⁶ *Ibid.*, p. 241.

⁸⁷ Blank, *op cit.* p. 176.

* * *

This analysis may barely scratch the surface. The Oregon plan confronts so many health policy conventions that each individual element is potentially subject to additional multiplex analyses. The concept of explicit priority decisions, the centerpiece of SB 27 and 935, can be viewed (as we have begun to do) from such philosophical standpoints as distributional equity or individual and societal rights and claims. A critique from a technical standpoint could be equally variegated: the use of a cost-benefit formula to rank services; the use of vastly imperfect data in satisfying the terms of the formula; or the use of flawed indices--condition-treatment pairs, charges for costs, QWB indices for individual values--in determining those data all are topics ripe for analysis. From a public policy perspective, the ranking of health services only, as opposed to all state services, is appropriate for a detailed critique, as are the attempt to include of "community" contributions in the absence of a clear definition of that term and the exclusion of the state employees' insurance plan from the prioritization process.⁸⁸ Of course these are only a few of the angles that a thoughtful analysis of the Oregon plan could take, but these and others are beyond the scope of this paper.

Those issues that are developed above are those that received substantial (elicited) comment in interviews with process participants in Oregon. Their responses to these issues add a critical human dimension to our attempt to understand the process of making the "tough choices" in health care resource allocation.

⁸⁸This issue has been touched on by several commentators, including: Albert Gore, "Oregon's Bold Mistake," *Academic Medicine*, 1990. 65:11, p. 634; and Eoin W. Trevelyan, "Comments on 'Policy and Administrative Implications of the Oregon Medicaid Priority-Setting Project.'" Behrman, R. E. and C.S. Larson, both in *Heath Matrix ; Case Western Reserve University Journal of Law Medicine*, 1991 special issue, proceedings of Cleveland Conference on Bioethics, *in publication*.

IV. RESPONSES

This paper has three primary goals. First, it aims to document the content and process of the landmark Oregon Basic Health Services Act and of related developments in that state. Next it highlights and discusses a selection of important issues made obvious by the Act's challenges to conventional policies for health services allocation. The last goal, addressed in this chapter, is to offer a sample of perceptions, impressions, opinions and experiences--pertinent to the issues raised in Chapter 3--expressed by people who participated in the Oregon process. The idea here is to examine some of the dilemmas, touched upon previously, from the perspective of *experience*. The statements that comprise the body of this chapter are drawn from the texts of interviews with these participants.

Investigations in health services are generally restricted to collection and interpretation of quantitative data, and justifiably so. Questions of allocation, appropriateness, access, functional and biomedical outcome, and satisfaction are studied using quantitative techniques because such methods can produce photographic clarity. Quantitative research also introduces a common language that allows comparison and integration of related but disparate matters. Furthermore, quantitative method is widely understood to have to its advantage that it is systematic, reproducible, and affords ready analysis of discrete variables.

The relevance of qualitative exploration of personal beliefs in this field of research is less well established. Qualitative research in general may afford a richer if more impressionistic picture, as a result of data acquisition that a structured instrument might miss. While it does not allow discriminant analysis, qualitative investigation into experts' perceptions of a new entity, such as health

services prioritization, may also expose new variables and variable interaction to be exploited in further study.

But there is another dimension to the interview data that gives it value. Charles Taylor expresses this dimension in his essay "Interpretation and the Sciences of Man,"¹ in which he argues that the convergence of opinions and beliefs-- "common meanings"--define community and communal actions. Although the interviews presented in this section do not fully capture the "intersubjective meanings" that Taylor demands for the greatest richness in social science, they do provide a glimpse at the community thinking in Oregon that allowed the prioritization process to move forward.

Method

In the week of January 28, 1991, I spent six days interviewing twenty people in Portland, Salem, and Corvallis, Oregon. I also attended two meetings of the Oregon Health Services Commission. Two additional interviews were subsequently conducted by telephone. All of these people were involved in one way or another in the prioritization process. A profile of the interview subjects is presented in Table 4.

¹ Taylor, Charles. "Interpretation and the Sciences of Man," in Rabinow, Paul and William M. Sullivan, eds. *Interpretive Social Science*, Berkeley, California: University of California Press, 1979, pp.25-71.

TABLE 4

- (A)..2 citizen "lay" participants in OHD town meetings
- (B) 1 State executive (C)
- (C) 5 current or former members of the State Assembly (B,J)
- (D) 3 current or former State Assembly staff aides (H)
- (E) 2 Health Services Commission members (H, J)
- (F) 3 Staff members from health-related agencies
- (G) 3 current or former executives of Oregon Health Decisions (J)
- (H) 4 representatives from interest groups ("lobbyists") (D,E)
- (I) 2 executives from private philanthropy
- (J) 3 physicians (C,E,G)

(Total greater than 22 due to overlapping roles; overlap cross-identified by category letter following name)

(I also interviewed six participants in the Alameda County process, all but one from the county health services agency. Their responses should be a part of a separate analysis of the Alameda County prioritization experience.)

Interviews ranged from 20 to 90 minutes. Interviews were conducted in the home or office of the informant, and in two cases in a public place (a coffee shop). All informants were audiotaped with consent, and notetaking complemented tapes for index purposes. The interview format was "semistructured:" questions ranged from closed-ended ("Do you believe in a right to health care? If so, how do you derive this right? If not, what are society's obligations to provide health care?) to open-ended ("Does anything else about the plan come to mind that hasn't yet come up in our discussion?").

In the interview responses, four broad topics emerge. Three are from direct questions: a right to health care; personal accountability and emotional consequences; and the reciprocal effects of community thought on the process

and the process on community thought. One arose in various contexts: views on explicit rationing. Within each of these topics, I impose gross typologies based on perceived patterns. I invite the reader to array the responses within or across these borders, as multiple interpretations are evident.

A. RATIONING

The concept of rationing was rarely raised directly in the interviews. Most of the beliefs and opinions about the concept came up while participants were discussing something else, such as their historical involvement, or a right to health care, or as a final word in the discussion. Despite the lack of imposed structure, the things the informants had to say about rationing were consistent in many different ways. One pattern that arises is that most participants chose to discuss rationing either from a subjective angle ("Interpretive" here), focusing on personal experiences, human values, or beliefs about social justice; or they tried to take it on more objectively ("Analytic" here), as policy analysis, political interpretation, or economic or class-based analysis.

1. INTERPRETIVE

a. Personal Experiences

A "consumer" member of the Oregon Health Services Commission held her own experiences close to the surface during much of the Commission's deliberations. She took public and expert testimony and integrated it with her own sense of justice:

The term rationing to me is not the scary word that people have thought of it as. In Oregon we made a decision to prioritize health care...we want to provide health services to everyone who is under the poverty line, not just 58% or 65%, everybody, singles included--right now it's only for families. Our current system just doesn't make a lot of

sense...you'll see a transplant victim that didn't receive funding and they'll get all sorts of headlines, but there's tens of thousands of other people that don't ever get their faces in the paper, and they need health care just as much.

Rationing is here...rationing goes on everyday, all the time...we ration in terms of who's served, we ration people out of the system. I've been uninsured, so I know what that's like. I advocate for people who are uninsured as well as people who are insured...If you make \$500 a month for a family of four, you're pretty poor, but if they make \$560...they're not poor enough. That's called rationing. You're rationing them out of the system. They're entitled to nothing. If they make just a little bit too much money, they're absolutely entitled to *no* health care in this state. I think that's worse rationing than entitling everybody to a basic standard.

A legislator, ambivalent about the Oregon Plan, had a concern for constituents as individuals that rang clear throughout the interview. He also related SB 27 to his own experience:

I'm not sure that a system of priorities can look at human beings, rather than at a diagnosis. We're all affected by personal experiences...I remember years ago I was hit by a truck, had a shoulder dislocation. I went to the doctor, and he said, "Well, in these kinds of cases, we can put in a temporary pin and you should have full use of your arm. Or we can just pop it back and let it mend, and you'd have some restricted motion, but for a person of your age that doesn't matter." And I said, "What do you mean it doesn't matter? I've got another twenty years I want to sail on my boat!" That was in a system which was reasonably flexible, and so they put the pins in, and I've had full use of my arm for the last ten years. In other words, to apply a life expectancy, and use that as a guide to an individual makes no distinction between somebody who's going to die at 55 and someone who's going to live until 75, as I have.

Another member of the Health Services Commission, this one a physician, keeps patients in mind as the deliberations continue:

If my own patients are ineligible for certain services--"zebras" [a common term, among health workers, for rare conditions] or procedures with a low likelihood of success, that sort of thing--but *everybody* is eligible for most services, I think it will be a fair trade. I have

a patient right now who needs an echocardiogram. She needs the money up front, which she doesn't have. *She can't get the echo.* I order mammograms--for a lump, for a baseline--\$75 flat. People don't go, never get it.

b. Human Values

A staff member of the Health Services Commission draws her own conclusions about the limitations of the quantitative data:

You only have one body. It's not replaceable. The cost-benefit ratio might say, "a chronic disease such as diabetes mellitus has a very low return," because you pay \$800 per year for 40 or 50 years to keep someone running, to improve their QWB and improve their life. And it is at that time that the values become very important, because you can't do a strict "I'm sorry, diabetes isn't covered," because you really will be improving their quality of life, increasing their length of life, improving their productivity so that they're not dependent on society... The community meetings and the values expressed there allow the incorporation of irreplaceable resources--an individual body--to be brought into a cost-benefit framework...

Another legislator, a self-described liberal, is firmly opposed to the Oregon Basic Health Services Act. He frames the debate on moral grounds.

The interesting thing that has emerged throughout this whole dialogue is the substitution of the concept of quality of life for the concept of sanctity of life.

The questions that are not articulated are very traditional, longstanding, Western enlightenment, and--to be very frank--Judeo-Christian values that until this epoch were unquestioned. Until we reached this pseudo-millennium of medical ethics, no one ever really questioned the value that life was sacred...I'm saying that the charlatans of health care rationing, of health care prioritization, the ethicists, have sold the public on this quality of life concept in exchange for sanctity of life.

Golenski and his ilk, the professional ethicists, are the modern sellers of indulgences. I have this nightmare vision, this *Brave New World* vision, of some patient in a critical situation, and some doctor calling the Ethics Hotline and saying, "I'm a little unsure, is it okay for me to pull the plug?" and the ethicist on the other end of the hotline asks him a

few questions, and says, "Yes, I think it is okay for you to pull the plug. [improvises Latin prayer]. My bill will be in the mail." This is absurd.

Are we going to let babies die? The public will never accept that. So what will happen is the doc will put his thumb on the scale, and say "Yep, I guess this baby's over 1500 grams." Or the father will come in, hold a shotgun to the doctor's head, and say, "Are you sure my baby doesn't weigh 2000 grams?"

A former Oregon Health Decisions official views the use of the subjective human experience in health services allocation as a critical element:

What we learned the first time out is that because facts and values are blended there, you have to very careful looking at a priority list, because you don't know whether its the values or the facts that have put certain things at a certain place on the continuum of services.

We needed to learn how to get the *value* message loud and clear, and put the factual determinations in the hands of people who know the facts the best. So there results an important blending of expert knowledge of facts and general assertion of values. These are really different domains inside us, and we have to blend them all the time in order to act, but it is possible to analytically separate them

Scientific data seldom enter the human experience. We ask, "How do I raise my children, find a lover..." We need to recognize the value of intuition. Intuition allows us to take prudent risks.

An official of Oregon Health Decisions has a more applied view of rationing as a blend of facts and values:

The Nancy Cruzan case is an extreme example, where a medical system was in place which valued keeping her body alive, with no quality of life, in a persistent vegetative state. I wouldn't think that sort of medical intervention would get very high marks in a prioritization system based on outcomes and benefits, because you aren't improving any quality of life.

Finally, another OHD official, a physician, expresses unbridled optimism about the *process* of Oregon's prioritization plan:

Only from the OHD process do we hear that we do indeed have the resources to come up with a new, strong solution that will be humane and prudent. It offers the youth of the nation a mix of technology, civics and morality that will afford them a means to retain their patriotism. We ought to take the process to the schools, let the children decide Health Care 2020.

c. Social Justice

A community activist who lobbied the legislature and the Commission to be vigilant about ensuring that "basic services" be covered said:

There's an acknowledgement that we are way too far--I'm going to make up a word--"overtechnologified." We don't need all this stuff. Basic, grandma-type medical care, or care that's provided in rural communities where you don't have access to all this high-tech equipment is often just as effective as care provided in a multi-million dollar hospital with all the latest in medical technology.

A state health agency staff member who participated both in the policy development and in the town meeting planning and process, shared some of these views:

I think the process is very worthwhile--I think it's essential that we go through it as a nation--but I still have some misgivings about how it's being targeted to the poor. Bringing it in to those people who have no insurance through their employment is getting another group involved, but we're still far from saying that Blue Cross needs to provide that same level of basic health services. It's OK for people to dispense with their income as they wish, as long as people who can't afford to do that have the same access, regardless of ability to pay. I mean, do we really need all that high-tech stuff? Even if we can afford to pay for it, do we really need it? And can we take some of that money and apply it to basic services.

Another activist, a critic of the plan, kept his hand in the planning process despite his objections:

The process explicitly rations health for the poorest segment of the population, the population that is least able to deal with the ramifications of that rationing. Let's take a procedure that costs \$5000. A person who is at 53 percent of the poverty level, if they don't have coverage for that service, certainly doesn't have the personal resources to pay for that, whereas somebody making \$50, \$60 thousand a year, and does have a certain amount of wealth accumulated--they can pay for it. So we are really taking out our health care problems on the segment of the population where it's going to do some major damage.

The community worker and lobbyist recalls that some of her organization's members felt the same way:

The calls we got came from the gut: "This isn't *right*. We as a country should be able to provide health benefits. I don't buy--as someone who knows very little about the system, as a low-income, working uninsured person or as a Medicaid client--I don't buy that we have to make these kinds of decisions. I think the question you are asking us is *wrong*. It is morally, ethically *wrong*." Low-income people don't understand the complexities of the health system, and honestly believe that a country with our wealth and resources ought to be able to provide health care for its citizens.

2. ANALYTIC

a. Policy Analysis

A member of the medical assistance program staff, who believes that society must move forward argued that:

outcomes research will probably never get to the point where you could prioritize services just based upon the scientific literature

This legislative staff member, close to the process sees policy implications reaching beyond the realm of health care:

'Politics as usual' isn't necessarily the only way that difficult policy questions can be approached. I think this [SB 27] is enormously important for the immediate impact that it has, but also for the strategic importance. If you can figure out processes to solve health care issues--with all the attendant emotional overlay--in an age of limited resources, those processes hold promise for helping us unlock some of the real dilemmas that remain in public policy in our day.

The ambivalent senior legislator, again thinking of the individual, observes complications in making population-based decisions:

I have a real concern about the prioritization: it seeks to determine health care by categories of illness, or categories of procedures, and I'm not sure that it takes into account the necessity of always considering the special needs of the individual. It's like mandatory sentencing in our penal system...you don't leave the judge any discretion to look at the individual and say, what kind of penalty really should be applied, what kind of penalty will bring about the desired social end?

I believe that the Canadian system is a better way of rationing than the system under 27. And that's really a triage system, that people who have immediate true needs are taken care, and those who don't have to wait. In my opinion that waiting period sorts out the people who really needed medical care and those who didn't.

Yet another legislator, influential in all stages of the process, explains his view of the rationale behind the policy:

I said to myself, "What is the policy that convinces us that we should fund eight transplants as opposed to nine? What do you tell the ninth person or the tenth person? And why do we spend money here instead of prenatal care or some other place? And the fact is, there was no policy. And I visualized in my mind: If we'd had this big list, of all the services that you could possibly provide--and transplants were not on it at this point because we'd already discontinued funding them--and decided to take transplants and put them at the top of the list, *and not put any more money in*, we would see very graphically what would fall out, what services would no longer be provided. And I said 'Aha.' If we had this kind of information, the legislative debate would be a lot different.

Someone was going to get squeezed out somewhere...and legislators couldn't just take the easy way out.

The former OHD official makes the assumption that this explicitness, based on human values, makes better policy:

The concept [of SB 27] is: "Since we *must* make budget decisions about benefits for people on Medicaid or state insurance programs, we could make *better* budget decisions if we put our benefits in some kind of qualitative order. If we knew where the margins were that we ought to be debating about, we would have confidence that we had protected the most important parts of the benefits package." That is the whole central concept of a list of prioritized health services. Put services in some priority, *independent of the funding choice*--the funding decision has to be made by the legislature, looking at all the things they can do with state dollars--and give them a decision-making instrument.

The same influential legislator goes on to explore the larger context:

There are three questions you have to ask about a health care system: Who's covered, who pays for what's covered, and what is covered. Every Western nation in the world has answered the first two questions: universal access and most of them have a government-funded basic package. The United States hasn't answered any of the questions. But the one question nobody's answered is *what's* covered. Including Canada, including Australia, including Great Britain. Our difficulty in Oregon is that we've tried to answer all three of them together.

The critical legislator, who reminded us above of Judeo-Christian values, might well agree that people get "squeezed out;" his disagreement here is with the criteria used to perform the "squeeze"

Every time you hear the term quality of life discussed, be very dubious, because the effect is usually to preserve the incomes of the health care establishment *per se*. This is something that very few people have touched on. Quality of life arguments and the quality of life rationing process is also basically an economic process...They tried to assign certain values to certain aspects of health. The original formula had death as a value of 1, and having to wear glasses as a value of 0.1, so in other words, the economic value--the

quality of life value, the formula value--of saving someone's life was 1, the formula value of giving someone glasses is 0.1...First blush, that seems acceptable. It's not the least bit acceptable, because 11 pairs of glasses have more value, more quality of life value, than one life. And you get to the point where you are making your health care decisions not based on lives you can save, or on the sanctity of life.

Finally, a physician member of the Health Services Commission, circumspect about the gradual process of crafting acceptable policy:

This is a first-generation list. It has lots of problems, such as co-morbidity, that we talk about a lot. It will be humbling; this primitive list will get more elegant as time passes. This first pass will look like accounts of surgery a hundred years ago look now when we read them. But our efforts are consistent with the oath to "do no harm."

b. The Politics of Rationing

A former legislative staff member, now a lobbyist, is attuned to the political ramifications of the Oregon Plan:

The most often expressed explanation [for the Oregon Medical Association's support of SB 27] is that the life-and-death decisions, decisions about who gets health care, are too much to place on a physician, and really ought to be borne by the whole society.

The idea that the State of Oregon is committed to universal access is now accepted by majorities of just about every constituency group, and that goal occupies one of the center rings in this multi-ringed circus...I'd say that is fairly significant progress. It is interesting to note that if the program fails, it will probably be due more to disagreements among people who share that common vision, but have different ideas of how to attain it, than it will be those who don't feel health care is a right, the people who'd vote no on anybody's plan.

The critical activist, whose theme above was the plan's disproportionate effect on poor people, sees politics as a culprit:

If the legislature tries to inject the funding into Senate Bill 27 that is needed to provide an acceptable minimum level of health care, then you are looking at something that is going to blow the top off the state budget, way more money than the state is willing to

appropriate. Especially after the effects of Measure 5 [a revenue limit referendum], it is going to be difficult for legislators to fund it to any acceptable level. So then you look at insufficiently funding it, and the implications of that are *disastrous* to that section of the population. You'll see so much public outcry that it will kill the measure. *There is nothing in this bill that says that a minimum level of benefits has to be provided.* The system is based not on a minimum level of acceptable benefits, but a system based on "What can we afford? What are we willing to pay for as a state legislature."

I see a tendency on the part of the Health Services Commission to consider things that will or will not be palatable. The whole point of the process was to make an objective list, to look at things in realistic terms. If all of a sudden we begin to make opinions and political influence a part of the process, then I don't think we're any better off than we are now. So much of what's going on now is influenced by who has the strong political voice and who doesn't. Take the case of the AIDS-infected community. From a pure economic standpoint, you are looking at health care that's very expensive, and not very cost-effective. At the same time, you have a lobbying group that has done an excellent job of getting its point across, and therefore has been very effective at getting the type of health care and the resources that these people need. Supposedly, SB 27 was an attempt to get away from that, to make decisions more objective. Despite its best intentions, I see us getting back in to what is politically palatable.

B. RIGHTS

As people respond to the question of a right to health care, much of the uncertainty and ambivalence raised in the prior discussion of rights comes through in their words. The responses also demonstrate the proximity in people's thoughts of the rights concept and the idea of a decent minimum. (This explains why, although these ideas are treated separately in Chapter 3, they are collapsed together here.) The interpretation of a right to health care appears to be so individualized that the responses may be grouped only loosely. The general schism is between those informants who believe it to be a human right and those who find health care to be an obligation carried by society.

Among the former group, some saw the right clearly and absolutely. Others viewed health care as a "limited" right, which suggests that Senator Kitzhaber's call for limit-setting is widely shared among those who played some role in the process. Because the philosophical rationale for the idea of a "limited" right is so difficult, the expression may illustrate participants' discomfiture with explicitly denying services. They hold on to the language of rights, incorporating it into their growing belief in the need to set limits. The apparent contradiction often finds its way out in their words. Still within the realm of rights, some others see an individual entitlement to society's resources, to ensure survival. A few construe the right in somewhat idiosyncratic ways.

Those who portray the matter as a social obligation largely see the entitlement as a reflection of a society's wealth. The section then concludes with an eloquent statement tying the two strands together.

1. HEALTH CARE IS A RIGHT

a. A Right is a Right

A former legislator, supportive of the Oregon Basic Health Services Act during his term, sees the efforts of the Oregon Assembly as moving in the right social direction:

Health care is too important to merely be a social obligation; it should be a right in the constitutional realm...not just a market-directed good

The lawmaker who strongly resisted the Act sees an unqualified right, framed like his view of rationing, in moral terms:

I do believe there is a right to health care. You're looking at a fugitive from the 70s...the value is a basic Christian-Judeo value. I think that life is sacred. Don't try to nail me down as some type of right-to-life nut-- I'm not, I'm pro-choice. But it comes down to this: we have a duty to preserve life. I think the current ability to get people to check out early--the Death Cult, with euthanasia, and the right to die, and the good life, and...those nuts down

in Eugene [The Hemlock Society], is all synonymous with a degradation of some very, very basic values. Human life is a basic value.

The lobbyist and former legislative staff member, whose attention is primarily on the political realm, moves into the moral life of society for a few thoughts, but his preoccupation is clear:

It's my view that the right to life and the right to a high quality of life is one of the freedoms that we should participate in as part of this common culture we maintain in the United States. Whether I could trace that back to the constitution or not, I don't know. But, I do believe it's a *human* right, and there needs to be equal opportunity to access, because of its relationship to quality of life. I do support the court opinion that the Medicaid program is an entitlement, is a property right, in that once having been given belongs to the people for whom it was meant--that is, to people who are poor and unable to purchase care on their own without public assistance--as opposed to charity, which we give every Christmas. Or almost every Christmas.

The activist and lobbyist, whose vocal opposition to SB 27 did not keep him from participating in the process, doesn't view as essential any philosophical rationale, although he can conceive of a few, including the equal protection argument:

I think everybody has the right to health care...I heard somebody try to make the argument that in the Constitution when we talk about life, liberty and the pursuit of happiness, that technically dictates that everyone has access to health care. I don't know whether explicitly the Constitution says that, but *philosophically*, why should people have to suffer purely because they're poor, when medical technology can provide so many benefits.

You also have to look at the NIH, and the public health care grants that have been administered throughout the years, and an awful lot of public money has gone into developing a lot of these technologies. If we're going to use public funds to develop these new technologies, then the public over all should be able to benefit.

The physician-Commissioner puts forward the same intuitive--almost visceral--response to the question of rights:

The way I see it is that an individual has a right, in the society in which they participate, to have their health needs attended to. If I were a philosopher, it might be different, more precise, but I *feel* like it is a right.

b.. A Right with Limits

A lead staff member of a state human services agency exemplifies the dilemma between rights and limits:

I do believe that everyone should have a right to a basic level of health care--not everything science has to offer. I shouldn't get the same care as a billionaire. I don't think we can use the health care crisis as a rationale for a redistribution of wealth in our country--that's really what you'd have to do to have everyone be equal.

This official of Oregon Health Decisions, who argued above for an applied view of facts and values in rationing, here demonstrates again a synthetic outlook:

Health care should be a right of being human. Whether you get health services shouldn't depend on who you work for, where you live, what kind of health insurance you have, or how much money you have. The public generally says, "health care is a right, but don't raise my taxes" but so far the public hasn't demanded in such a way that it's come out of the political system. It is a right more analogous to food or housing. It is not an absolute right to everything--resources are limited, and you have to prioritize, set limits, set priorities. But I believe that people should have a basic, or some minimum, access to a basic set of services. You might also approach it as whether it's an injustice if people can't get health care, and are unnecessarily handicapped because they can't get access to health care.

One legislative aide, who later related his observations from travel in abroad, frames his conception of limited rights in a social context

I do believe that we have a right to health care, in a very pragmatic sense. Underlying the success of a nation, of a society, and lending to the success of a great many other pursuits, is a certain level of health among the citizens. It's a tremendous strain on resources if people are not of good health. The right is to a minimal level of health care,

as well as such things not normally thought of as health care but important to health, like nutrition, vaccination, safe water, sanitation...More advanced health care is not a right, but basic services definitely are. "Basic" is defined by resources and population--this is what I mean by pragmatic. The right is more related to prevailing circumstances than it is a birthright. For example, the Sudan *can't* provide what the U.S. *should*.

c. A Citizen's Entitlement

The entitlement phraseology is helpful to many who wish to avoid the rights term, while setting health care within framework of social benefits. The legislator who played a key role in the process takes such an approach:

If you assume everyone had a right to health, then individuals who want to smoke and drink and pursue self-destructive behaviors have no individual responsibility--society owes them health. If you take care of yourself, I think you should have an opportunity under this society, if you have personal needs, to have access to some fundamental, basic level of health care, as well as good nutrition, housing, education.

Health care is not an end, it is a means to an end. It has intrinsic value only to the extent that it improves or maintains or restores health. So I think people should have an equal opportunity to *health*. That means that they should have access to a certain amount of health care--that amount of health care that we know produces health--but they should also have access to housing, shelter, nutrition, transportation, and other things that are critical factors affecting health.

For example, a mother is denied prenatal care not just because she doesn't have insurance for it, but also because of transportation barriers, communication barriers, lack of day care. Clearly, infant mortality reflects a lot more than a lack of prenatal care: you have to factor in housing problems, environmental problems, teenage pregnancy, substance abuse. So the issue to me isn't really health care, it's health.

Entitlement language also seems appropriate to the legislator who holds a different, more ambivalent view of the Oregon plan:

I guess I have a basic ethical point of view, that everybody should have access to adequate health care. I believe that it is just as fundamental as not wanting to let people starve on the streets, or drift about homeless.

d. A Potential Right

Another legislator, who supported all phases of the process, finds a right to health care conditional upon society's stage of development; he calls this a "latent right:," and he share's his former colleague's view, expressed above, that once present, it should be codified:

I think we have a right to health care. It's not one of those fundamental rights. I think it's a right that comes when a society reaches a certain point of affluence and development. It would be foolish to say that in a poverty-stricken third-world country everyone has a right to health care to the extent that the government has to make that its first priority. It's a latent right that at some point in a society's development, emerges. And it certainly has emerged here. It's just wrong to have an affluent society which denies health care to some of its people. I don't see how you can justify it. It's not a legal right, but it might be one that someday we'll embody in a statute or maybe even in a constitutional amendment, and make it a legal right.

2. Society's Obligation

The community organizer and lobbyist understands the political value of "enlightened self-interest." She frames the rights question as a win-win situation:

We as a society owe it to our economy, owe it to our businesses, owe it to future generations, owe it to the development of our children, the educational capacity of our children, to provide basic health care to all of our citizens.

A citizen participant in an Oregon Health Decisions town meeting also takes a utilitarian approach, but appears to derive it as much from skepticism as from hope:

I don't know if we have *any* human rights. That implies that there's someone around who will give us rights, or that someone can bequeath upon us certain things...If I went to another country where the government hasn't [granted a right to free speech], I wouldn't expect that I should have it...I don't know if we have any rights to life, liberty or the pursuit of happiness, or health care. Aside from that universal idea of rights, I think it makes good sense for governments to provide health care to their citizens, in terms of economics, in terms of productivity for their citizens, a contented citizenry.

The legislative aide who was close to the process stays within the boundaries of society's role, but makes more a moral and political argument than a utilitarian one. But like those who spoke of a "limited right," he too weds the obligation to a sense of limits:

If a society has the wherewithal to provide a certain level of health care, then it is an immoral society that does not do so...In a pure form, I would say that health care is not a right, that there is a limit to what people should be given. The process here forces that question. It makes the state of Oregon sit down, through its ninety elected representatives, its chosen form of self-government, and debate the question: what is the level below which no one in the state should be allowed to fall?

A citizen who participated in an Oregon Health Decisions meeting in 1989 did so as part of a sense of social responsibility. He sees that role as a one instance of a pattern of interdependence in society:

What I really feel is that human beings have the *responsibility* of setting up systems that care for one another. I generally think of it more in terms of the responsibility of the system or the society than of the rights of the individual. I consider the Reagan administration, for instance, to be the most irresponsible administration I've ever known and maybe in the history of the country, because of the way they hacked at any kind of people-caring system.

3. A Thoughtful Synthesis

The former Oregon Health Decisions official who so eloquently stated the case for a search for values in an explicit rationing process also has carefully formulated a position on the question of a right to health care, one that reflects people's ambivalence and uncertainty, but leaves the listener with a sense of meaning:

I'm persuaded that we have at best a "manifesto" -level right to health care. This means that there is no legally-established right, and there is no clear moral philosophy argument that nails it down on which everyone could agree, but that it makes a lot of sense in a context of community--a community ought to provide this. So I have simply stopped trying to make the case--the philosophical case--with all the baggage of rights. I was persuaded in this way in part by the President's Commission report in 1983, *Securing Access to Health Care*, where they simply said whenever this comes up, people get into a big dispute over "Well, Okay, there is a right, now who really has the duty? To whom does the duty fall?" And the effort to actually make practical movement will crash on the rocks of the

philosopher's debate over whether there's a real right, a natural right, a legal right, whatever.

I'm also persuaded by the kind of reasoning that was used by a philosopher named Michael Walzer in *Spheres of Justice*. He writes that the sense of a right, or the sense of obligation or *owingness* of access is really on the community. The social affirmation of certain desires give them standing as needs, and needs ignite the notion of rights. But they are all *community-derived*. Of course, once something can be seen as a need, if any form of collective financing is used then anyone left out has a double insult.

C. COMMUNITY

Discussion of the role of communities in the unfolding of the Oregon Plan dominated the interviews. In part this is a result of the interview structure and focus, but the informants' excitement--or agitation--about the subject also may have influenced the attention it received. I did not seek to define the term "community," because it seems to have taken on a specific contextual meaning within the debate in Oregon; the term appeared to be used with currency between informants. The use seems to relate to a motivated or mobilized citizenry, although the degree of such mobilization is in dispute among participants.

The responses cluster along four primary lines: (1) The process of community participation; (2) the effect of community participation upon the substance of the Oregon Basic Health Services Act; (3) the effect of such participation upon the communities involved; (4) and, in light of any marked effect on the substance, an exploration of distinctively Oregonian characteristics within the resulting policy.

The first topic complements the material in Chapter 2, presenting some interpretive variation on the process and the validity of the process. Here the accounts are broken down by critics and proponents, and each of these is segmented further according to the nature of the remark. Discussion of the

second topic is limited primarily to *policy* effects, although some speakers allude to other effects. Comments on third topic relate both to political impact upon the communities and to psychosocial impact. The last question, "What is Oregonian about the Oregon plan," elicited many different interpretations, and is presented without imposed typology.

1. PROCESS

a. Skepticism and Problems

i. Selection Bias

The senior legislator, who has expressed mixed feelings about the plan, is unambiguous in his skepticism about the validity of the results of either the town meetings or the open Health Services Commission hearings:

I've been involved in lots of things where we've had hearings about them. We'd have hearings in a number of different areas, but the same people would show up, so we'd hear the same people. Or, we'd have a hearing, and three people would come, and the question was, did that represent a community of 5,000 or 10,000?

The town meetings were well-attended, but some who were involved are sensitive to the criticism of a socioeconomic and ethnic/racial slant at the sessions. The state agency staff member who participated both in the design and in the administration of meetings shares these reservations, but expresses frustration:

Some of the problems are really unavoidable, in terms of getting... poor people to come to a community meeting and feel that their voice is going to be heard; it's a different thing to address. Most people who feel powerless don't usually come to things like this....We worked very hard at having some meetings held in Spanish with Spanish-speaking people--I think we had some success with that. Trying to get the Afro-American population involved--sending people banging on doors to let them know of meetings, and them not coming anyway, I mean, how do you address those issues? Those are things that I think we all recognized when we looked at the demographics of the people who did attend those meetings.

The community organizer also was frustrated with the selectivity of the participants at the town meetings. Her criticism, however, relates less to a skewed outcome than to skewed assumptions at the outset, assumptions that then shaped the entire debate:

Oregon Health Decisions is a provider-based organization. The majority of folks who came out were not the people who are going to be first and foremost affected by this process, which are Medicaid clients and low-income, uninsured working Oregonians, but you had to be in that provider, academic network in order to know about the community meetings, although they really did try to do outreach. People were more interested in a philosophical debate...When the folks in the [consumers'] coalition found out what was going on, they said, "This is wrong. These are the wrong questions." Because the first series of community meetings tried to get people to look at one health care dollar and make a decision where to put that health care dollar on this chart. The chart had four columns across and four down. The seniors said "This is nuts." Of course this is going to lead people to say that preventive care for children is more important than acute care for seniors or care for chronic conditions for seniors. But that's not the real issue. The real issue is that our dollar goes for a lot more than benefits. Maybe 60 percent of that dollar goes for benefits. The rest of it goes for profit, insurance company administration and marketing, to a variety of things that have nothing to do with the benefits that consumers get and in fact detract from their ability to get benefits.

That's the frustration...when you go in and your questions are framed like that, you respond to the question; but the question is much bigger than that...That was the philosophical opposition to this process. It was a gut-level reaction from consumers who know that there's more to the health care system than just benefits, who rebelled against the idea that the only way to solve the crisis of increasing costs and decreasing access is to reduce benefits.

ii. Stifling Creativity

Two informants--the only citizen-participants in the sample--attended the same Oregon Health Decisions town meeting in 1989. They shared the observation that facilitators were divided between an apparent need to satisfy an organizational agenda and a desire to entertain a wider discussion. Both

participants believed that the facilitator erred to far in favor of the OHD organization. The first speaker is active in community affairs, particularly regarding health:

A lot of people had very strong feelings that the process was not designed correctly. It was designed to elicit certain viewpoints, which it did. The categories--things like quality of life, prevention, general value types--just irritated people to no end. They were saying something that was terribly important, but they didn't feel that it fit into the category that it was put into. So people kept saying, "Just *list* them! Don't put them into these pre-determined categories." When people come to a meeting like that, they just want to get something off their chest. That was the weakness of the process.

The following speaker is a local health professional, only moderately active in civic affairs. He was animated in describing the gathering, but expressed enormous frustration with the process and consequent skepticism about the outcome::

I had very mixed reaction to the experience. I liked the idea of it very much, and had participated in similar types of things with other groups. I think that brainstorming with groups of people is a very productive activity, and we came up with some very interesting thoughts. The people there were all excellent and all had very good ideas, and we had a very good discussion...What was frustrating to me then, and to a lot of the people there, was that there were pre-determined categories that the leader was putting our responses into that didn't necessarily fit the ideas that we had come up with. Our group and other groups became angry. She [the facilitator] would put a check-mark in a pre-determined category and not write what we had actually *said*...our actual creative ideas were not going to get recorded anywhere; the feedback is not going into the system at all.

She only changed her system when people became vocally very insistent. I think it's insulting to an intelligent group of people for them to go through a creative process, and then the kind of feedback they see is a check-mark in a box. And people were insulted by that.

I had a lot of thoughts at the time, and meant to write a letter saying it was not a valid process...It began to feel like a manipulative process...I think that may work with a lot of people, but these folks had brought together some of the most highly skilled people in the community, and they knew better. They need to be a little careful with the process: do they really want to bring in creative people and take their real thoughts, or do they want

validation for what their own thoughts are? In this case, what they seemed to be after was validation of their own thoughts, and setting the group up to do that. And the group didn't like that.

iii. Out of Their Depth

The last critic of the process, the activist and lobbyist who stayed involved despite rejecting the plan, is skeptical of the *principle* of citizen involvement, both at the town-meeting level and the survey level:

I have some mixed feelings about the community involvement. I guess it's good to get a general perspective as to what the general public thinks. But at the same time, we're dealing with some issues that are very complex; scientific issues which the lay public certainly is not going to be very learned about. From that standpoint, you have to take what the public says with a grain of salt...Public input is vulnerable to a high level of subjectivity. You can certainly get good input as to attitudes, to make some *general* decisions about health care choices, but I think it's very difficult to put that into numbers that will be plugged into a formula.

The other problem is that when you talk about the quality of well-being, we're essentially talking with well people, people who, for the most part, did not have any health problem, and asking them about what it would be like to be sick. I think if you'd have asked sick people, "What is like to be sick," you'd get a totally different array of answers. You're going to see things like preventative health care come out very high. Not because it's more cost-effective, but more from the standpoint that nobody wants to be sick. So of course that's going to be their primary focus. "I feel well, and I don't want to be sick, therefore preventive health care is a high priority for me."

b. Advantages

i. Selectivity

One OHD official, the physician, sees some benefit in the selectivity of the town meeting process. Although he understands that the process is not inclusive, he sees a "silver lining:"

The report represents people who have a concern--unknowingly, of course--about giving meaning to sacrifice. It represents people who will ask publicly, "Isn't there a better way?" Yes, 85 percent are from the professional class, so you may wonder if the debate has any relevance to them. These are people to whom society grants implicit authority by respect. It also demonstrates that the community meetings weren't about the lunatic fringe--people out for coverage for rubbing with carrot juice or concerned that flouridation is poisoning our kids or believing that the system can only be seen as a problem.

The former OHD executive is more equivocal, and more descriptive, in discussing participants. He sees the act of *participation* as the redemptive characteristic of the "community" component of the plan:

How do we elect presidents, how do we run a representative government, how do we move policy forward? We really don't do it by scientific, random-sample surveys; to some extent, the politicians play to them, and try to manipulate them. I'd portray [the OHD process] quite simply as an exercise in democratic process. Democratic process means taking responsibility for the community in which you live. A problem of American democracy right now--on any front, whether it is education or health care or transportation--is that most of us are generally fairly well served, so we're just along for the ride. Not complaining, just riding. We complain about taxes, but we don't take responsibility for either the good we do with taxes or the evil we leave. We have a problem of alienation from democratic mechanisms broadly in our society, and most alienated are people who are least well served by the democratic process.

So I am not surprised that we have great difficulty getting alienated and underserved people to participate in our meetings; they have no strong reason to believe that democratic process serves them well.

ii. Creativity Within Limits

The Oregon Health Decisions executive is, quite naturally, enthusiastic about the contributions of a process he helped to design. His language may confirm some of the community organizer's criticisms, and he openly acknowledges the conflict between structure and creativity, but his conclusions differ from those in the "laypersons'" accounts:

It turns out the format of a community meeting is pretty important if you're going to have 50 of them around the state and you're going to try and draw some conclusions from those. So you need to have a format that is much more structured than just everybody complains or comes in and says what's on their mind. But it can't be so structured that people feel they're being manipulated by the structure of the meeting.

It's a little hard to get the general public to talk about their values--it's a bit of an academic, conceptual term. So the facilitators who we trained from around the state to conduct these meetings had some guidelines for how to talk about values--to explain to

the public what we mean by values--and some examples of medical conditions to think about which one is more important to be treated and which is less important. These were only given as examples to spark thinking to get behind initial impressions, to thinking about *why?* Why is something more important than something else? What's the value?

Each table would report and the facilitator would write up the values that they had, and discussed, and should be used, verbatim, on a board. So each community meeting had all these, and each facilitator had forms to fill in different values. Often, the tables would come up with some of the same values, and if it was stated differently, they would either modify the statement so it captured both of them if they were pretty similar, or just keep them separate--whatever the group wanted. These were turned in from each community meeting--however the public reported their values. In reviewing all those, we looked at the values and put them in clubs.

There was no template; we wanted to provide a forum for people to clarify and discuss their values. It didn't make any difference to us what those values people had. We were more interested that people can express them, and that they can be conveyed to the policymakers.

iii. In Their Element

The state agency worker who participated in the planning and execution of OHD meetings sees citizen participation as a validating measure:

I think the perceptions of communities are important because they view problems not from CPT codes or diagnoses, but from what's important to them. I think you have incorporate that into any planning process, to see that what you're seeing as the problem is really the issue.

The physician-legislator believes that the priority process comes more naturally to lay citizens than to health workers or elected officials, further confirmation for him of the central role of citizen participation:

One thing I'm convinced of, after going through this sometimes extremely uncomfortable adventure is that the public is far more willing to make these choices than are physicians and legislators. They understand limits. They have to balance their budgets. If you say to them, "If you had four children and you could give one of them a liver transplant but would deny health care to the other three--immunizations and right on down--what would you do?" They can make that judgement call...they can make those choices.

The OHD physician sees a rebirth of his colleagues' faith in their profession reflected in their participation in the process:

I hear only dissension and despair within the medical community. The golden years of the 1950s have become sooty. But they seem to be somewhat brightened by the idea that doctor and patient can once again join in these decisions--as they once did, as they do in the Oregon Health Decisions process--and get the *best* out of the process...Critics, on the other hand, have little tolerance for the ambiguity inherent in the human condition. They would rather project evil around them than recognize it within themselves...

2. IMPACT OF COMMUNITIES UPON THE OREGON PLAN

a. Impact on the Process

The lobbyist and former legislative staff member, who has observed the influence of the town meetings over time, sees them as the key to the plan's success:

The Health Decisions process, which is after all a community and public participation process, is the greatest benefit and single defining characteristic of Senator Kitzhaber's plan. Ideally. Not necessarily in practice.

The plan has certain characteristics that would not have been arrived at by a group of health care professionals working in isolation, particularly the emphasis on preventive programs and on mental health programs. Those are largely due to what people said they wanted, and what people expect out of their health care system, at community forums. It certainly heightened the sensitivity of the Commissioners to those concerns.

The Health Services Commission staff member sees political advantage conferred by the community element:

Because of the community involvement prior to Senate Bill 27, and the fact that Senate Bill 27 reflects the Parliament process held by Oregon Health Decisions over the early eighties, we haven't been subject to recall or to people being scared, if you will, by the sensationalization in the press.

And a state legislator has watched the plan's main proponent develop under guidance from the participants in the town meetings:

The OHD process, going clear back to 1983, has left more than a mark. The policy itself arose out of that process. John Kitzhaber's ideas were formulated within that process, because he was part of that process. There was a recognition of a need to allocate resources in a rational way, and to recognize that we can't do everything for everybody, or at least at this stage in our society we're not willing to.

b.. Impact on the Outcome

The health services agency official watched the process closely, as if for intelligence about the coming changes in her own work. She noted some specific changes:

It was very clear through those town meetings that people really value preventive care when it comes to ranking services...that was a really important piece of information to get from those meetings, and it has allowed the Commissioners to give it a higher importance than maybe the scientific process would allow.

The HSC staff member observes that the influence can be broad as well:

Depending on where you were, different issues came in. For example, in Portland you have flouridated water. If you are in Medford, you drink well water, and all of a sudden the topic of flouride put on kids teeth is real important. The topic of flouride in Portland is not important. So you have environmental or demographic variables made visible by going out in the community.

The physician-Commissioner found the community meeting input to be less helpful overall than the testimony from public hearings, which, although perhaps more anecdotal, had a direct appeal:

Its hard to say what effect the community meetings had on the outcome. I admire the intent of the process, but the meetings didn't draw a good cross-section; the process solicits input only from selective segments of society. But the public hearings drew more poor and potentially affected people in, and these were qualitatively very influential.

The consumer Commissioner will use both community voices in her own deliberations:

When it comes gets right down to it, we are going take what we see is right and move things around, and what will guide us is the values that were gleaned from the Oregon Health Decisions meetings and from what we heard in testimony.

Despite the optimism for a positive effect on policy by community participation, the state agency worker who also served with PHD reminds the listener that how the community preferences will *operationalized* is an unanswered question:

We still don't know how that's going to translate. The number-one thing was prevention. Well, what does that translate into in terms of services that are paid for, and how does that turn into a change in policy for the state? Our health division doesn't even have a coordinated health education section. We don't have health educators working with the private sector to do prevention activities, and I don't see that happening.

3. IMPACT UPON THE COMMUNITIES BY PARTICIPATION

i. Political Impact

The political impact of participation in the SB 27 process upon participating communities may be seen in the health field and outside of it; and may take the form of town meetings or be less structured.

The key legislative aide looks at the health field and the OHD mechanism and sees a lasting change:

The Oregon Health Decisions process further develops the sense of social responsibility that surrounds these issues. Suddenly you have a situation where communities across the state have a wider and wider segment of the population involved in thinking about bioethical issues and about the way our health system doesn't work. It expands and raises this issue in the political realm, legitimizes the issue in the political realm by having that kind of environment.

Some informants, though, consider potential developments outside the realm of health care as even more promising. The physician-Commissioner, who derived so much guidance from the open testimony, hopes that the process will set a precedent:

The public hearings will ultimately have an effect on the communities. The civic process opportunity will have a snowball effect--people will bring new people into the process. A telephone survey can't do this. Also, the "no constraint" format--except time-- as opposed to having a facilitator with fixed ideas, contributed a lot; people could say whatever, be contentious. It was your opportunity to make a statement with an influential audience. For most people, it was the only state-sponsored invitation to tell their problems with health care, their view of health care, hear kindred spirits, network, whatever, that they ever will get.

The physician legislator also looks beyond the medical field for durable effects, and finds them in the OHD process:

There's a framework out there. If now we began talking about health, health care being just a part of that, I think that format lends itself very readily to those kinds of discussions. The debate over the homeless, for example, is a very amorphous, nebulous kind of debate in terms of constituency. But the homeless, if you could focus that problem, and begin to recognize that homelessness is not just being without a house, that homelessness means that you don't have the same kinds of opportunities other people have to have good health, or to have educational opportunities, or a job--then you could see that kind of activism developing. But you have to link it in with something more than just hopelessness. And that's what we've done with the debate in Oregon.

Community involvement leads to broader and broader interest in participating in these kinds of decisions--that is the single most important thing.

The HSC staff member's optimism is not constrained by any process or any sector of society:

As the more explicit decision-making begins, and the whole arena of health comes up, meaning housing, education, economic development and security, as well as environmental quality, then you'll see more activity in that area, trying to make sure that it's

not special interest groups, but rather an overall policy that blends everything together toward a higher goal.. There is already some increased activism, particularly in education.

In the view of the former OHD official, the community involvement confers a participatory quality on the process that distinguishes from political processes that came before it:

The difference is not so much in content so much as in the overall quality of the product. A good idea is a good idea, and it doesn't matter who comes up with it. We normally exercise our democracy largely by relegating it to elites--intellectual elites, political elites--and that tends to reduce the rest of us to the role of ignorant bystanders, probably well-served, neither guilty nor worth of praise. I think the difference is that we have deliberately unleashed something that intends to make the general public not be ignorant bystanders, but people who take ownership of the processes that come along.

ii. Psychosocial Impact

Participation in the community component of SB 27 may have psychosocial benefits either to the community involved collectively, or to the individual participating as a citizen. One of the lay participants at the OHD meeting observed a community effect:

There is value in the sense that everybody there was so tickled to see such a crowd of people who are concerned. It bolsters you, if you have an axe to grind, to see that there's a whole lot of other people with the same interests and concerns. I don't know if people felt "My participation had meaning," in terms of getting something done. At my age though, I think I'm getting pretty cynical about citizen participation.

The individual effect may be an enhancement of self-efficacy in the health realm, an understanding that the citizen's contribution to decision-making, i.e., values, are significant and worthy of attention. The key legislative aide expresses this belief:

For most people, it is tough for them to go into their physician to ask questions, or to pin the physician down or to impose their value structure on their physician. We are

socialized to give a certain amount of deference to that person. [This process] encourages an equal footing...they feel much more enfranchised in saying, 'you know, these are my values: it's *not* that important for me to live at all costs...my quality of life is what's important to me.' Medical practitioners are trained to think that it's in the patient's best interest to do everything possible this allows people to say that there are trade-offs, helps them develop some clear thinking

4. OREGONIAN CHARACTERISTICS

Informants were divided about whether the substance or process of the Oregon Basic Health Services Act contained elements that are distinctively Oregonian. The logic of the inquiry was related to the assertion that the community component had impact--did it matter that the communities were in Oregon?

Of informants who believed not, only those affiliated with OHD explained the belief; generally they believe that the community findings are more universal than local. The physician-legislator finds an essentially human element:

Oregonian? I don't think so. That's a gut feeling. Once you get the theologians and the philosophers off here and actually talk to real people, I see this commonality...the same kinds of concerns people have, the same questions that they raise, the same frustrations that they experience.

Whereas the OHD executive and the former OHD executive both detect something essentially communal:

What is distinctively Oregonian about the process was that it was done in Oregon. Attendance was higher in smaller communities. People know each other; there is a tendency for people to know who each other are, and sit down and talk about things, rather than politically posturing about things.

The values reflected in the report are American values; part of the reason we are able to hold ourselves together as a widely distributed community is, in fact, shared values.

Those informants finding an essence of Oregon in the plan for the most part focused on boldness, its departure from convention. The voices that follow echo this theme:

The HSC staffer:

Not being an Oregonian, I can say that they're willing to stand behind what they say. This is a somewhat homogeneous population, somewhat conservative, and yet they're willing to take stands on hard issues, and I think that's Oregonian. They did it on the environment, and they're willing to do it now on health.

The supportive legislator:

Oregonian?: Something about this society [Oregon] makes it more able to make societal decisions before others are ready to do so. That's true in land use and environmental protection. I don't know that this makes the societal values different, I just think we seem to be able to formulate them or express them. I doubt they're much different.

The legislative aide:

Independent thinking. It sounds cliché, but I think it goes back to being the Pioneer State that it was. I think there is a real pride in independence, independent thought here that might enable us to pursue new paths that haven't been pursued.

The resistant lobbyist:

My feeling is that this is uniquely Oregonian. My sense of Oregonians is...a certain level of independence. We are able to make decisions about our own lives, take care of ourselves, and, where necessary, we are going to fight federal guidelines. And along with that the state, over the years, has been successful in getting certain waivers, because it has had some powerful people, especially in the U.S. Senate. Senators Packwood and Hatfield sit on important committees, and from a legislative standpoint, from a regulatory standpoint, we've been able to get what we wanted throughout the years. This has kind of fostered that attitude that "We know what's best for us so leave us alone." In all the places I've lived and travelled, I think that is uniquely Oregonian.

And the supportive lobbyist and former legislative staffer:

Oregonian? There is in Oregon politics and in the Oregon political way of life an expectation that they will be involved in political decisions. They are fairly used to community meetings, and certainly in the areas of land use and the environment it's become expected that these issues will be discussed in public forums.

The Oregon health Decisions physician agrees that there is a kernel of Oregon in the Plan, but believes this is the best argument for dissemination of the model:

The message to other states that have shown an interest in the project is *Do not do it the Oregon way*. Do it the Georgia way, the Nebraska way. The policy must rise from below.

D. ACCOUNTABILITY AND EMOTIONAL CONSEQUENCES

As I learned more about the Oregon plan and the process that sparked it, I became increasingly interested in potential emotional consequences. There are two main hypotheses in this corner of the inquiry: (1) that the decentralization of the value component of public policy making would spread the accountability for adverse policy outcomes to emotionally unprepared people; and (2) that those denied services under explicit rationing criteria have greater public appeal potential, therefore a more public identity, which finally could personalize and enlarge the emotional impact of health service denial.

Although the informant responses in no way resolve either hypothesis, they do serve as a discovery tool, to expose a slice of the range of responses. The most salient observation is that among the group I interviewed, very few expect to be visited by emotional fallout as a result of their allocation decisions. Although they recognize that the consequences of their decisions are more visible under the prioritization plan, most informants clearly see the status quo as more harmful. Among the informants who have already accepted the role of

policy-maker--the legislators, aides, and Commission members--most did not feel any more vulnerable to emotional fallout with the new system. Those who participated in a more peripheral way were skeptical that the process accounted for their opinions to a degree sufficient to confer responsibility upon them. Official policymakers agreed, speculatively, that this would be true for the citizen participants.

Some informants did fear emotional consequences of benefits denied to Medicaid recipients currently receiving them.

The legislative staff member appears energized by the public-policy potential of the prioritization process. Further, he notes the importance of accepting the responsibility that attends his public service role.

It is a sorrowful specter to see people suffer because of a lack of resources. Admitting that you have limited resources doesn't alter the fact that you have limited resources, it empowers you to maximize the good you can get out of those resources. It is not easy to look and there and say that there are certain people who will suffer as a result of this. The only thing that makes it do-able is that I am personally convinced that there are many more who would suffer even more grievously if we didn't.

I faced this stuff all the time in the fire service. I was a company officer on an engine. There were any number of times when I would come up to a situation and say, 'If I send my people into that, there's a real element of danger. I could be knocking on the door and talking to somebody's wife.' But we had a superordinate goal. We had a role in that community, and this is part of what we do to make our community a better place.

As a legislator who stayed close to the process throughout its development, this physician sees the trade-offs with great clarity. He believes that the accountability implied by the new plan actually strengthens the moral position of the policy-maker:

The question is how honest do you want to be with yourself. We have over thirty neonates that die directly due to low-birth weight--consequences of poor prenatal care in

this state. Thirty. Plus. There's forty thousand kids that die before their first birthday nationally every year. Those kids are being *killed* by legislative decisions to cut back a program, just as surely as a child that doesn't get a liver transplant...I personally don't believe that there's a difference in the scope, the magnitude of the human tragedy of the child who dies an anonymous death in a neonatal ICU, because of an explicit social decision, and a child who dies a public death due to lack of an organ. I think they're both tragic, and we should try to avoid both of them...But as long as we can pretend those [anonymous] people don't exist, I don't think there's any motivation to take care of them. Yes, I'm sure there will be another Coby Howard. But--maybe it's because I've been in medicine...I've stood by the side of an incubator where a neonate dies of ARDS [acute respiratory distress syndrome, a common killer of premature infants], and I know that things I've done down here [at the state capital] have resulted in that, even though I don't know them individually. But you know, as Huxley said, 'Facts don't cease to exist just because we choose to ignore them.'

This former legislator, now a state executive, demonstrates a firm faith in the political process:

I expect no personal emotional repercussions. When I was campaigning [for the legislature], I talked to 7000 individuals, only one brought up the Medicaid prioritization plan. Listen. People die all the time without insurance. By being explicit, we build a powerful argument to expand the safety net and increase funding for Medicaid.

This optimism is shared by another legislator, who also believes that the political process corrects inhumane policy:

The fact that such [Coby Howard-type] decisions will be made, I don't think that will trouble me. As society begins to realize the result of denial of some health care, that they will expand that list, and we will work toward universal coverage.

The physician-Commissioner finds that the plan accounts itself accounts for such course-corrections. The checks and balances system spreads thin any emotional accountability. Similarly, the Commissioner believes speculates that citizen participants are spared by the load the public sector has assumed:

The way the legislation was crafted absolved the legislators of any responsibility and gave the ultimate responsibility to us. SB 27 removes the politicians *absolutely* from the list. I think it's appropriate; they would have been subject to lots of lobbying. Of course, we are lobbied too, but we have nothing to lose--we're appointed. But it also would have been inappropriate to make us draw the line, or work within a fixed budget. They gave us a clean job, and kept the political job for themselves. I won't feel guilty if the line is drawn, for example, above preventive care for children, because *they drew the line*.

There will be no public accountability because the public was not adequately consulted. For that we would have needed more public outreach. I can't say the public really had its chance, or a chance equal to the Commission, for input.

The consumers' Commissioner accepts the role's responsibility only conditionally. Although she recognizes the stakes, her view of the checks and balances places the ultimate accountability at a distance:

This kind of thing is not to be taken lightly. I'm not God, I'm just a consumer that's participating in the process. My job is to advocate for consumers. If the list comes out and its not funded well, I'll be the first one down there, telling them that I think they should scrap the program. If the legislature does not fund it to a decent level, then we'll walk away from it.

The Health Services Commission staff member, whose direct, statutory accountability is less than the Commissioners', still feels that her role has had impact. However, she does not worry that this influence will bring emotional costs; she, too sees benefit to the compromise:

I expect that there will be emotional cases that will be presented to the press, but I think I will be able to remember that I have 400,000 people that couldn't even get in to see a doctor, who now have access, and I will keep it in that perspective. I know that there will be people denied services.

As a full participant in the OHD town meetings process as well as a state bureaucrat, this informant surely played an important part in the playing-out of

the Oregon plan. Her view is the same as the others', the benefits outweigh the risks, both in her public life and in her emotional life:

I don't think you can set policy based upon Coby Howard. While we have done that in the past, I don't think it works on any global level. We really need to separate faces from the process. Some people get hurt no matter what you do. Now it's just more explicit. I've seen so many people that had no access to health care, who suffered the consequences of delayed health care, in terms of disability and disease that certainly could have been ameliorated long before if they had some access, and that's what we have now. I don't think this process is going to make it any worse; it will be better.

This state health agency official also sees the benefits in the trade-off of breadth for depth. Although she feels remote from direct accountability, the new system adds an impetus to perform better, so that she may contribute to the most fair policy possible:

I Support wholeheartedly the idea of increased responsibility in explicit decisionmaking--I've been able to transfer that a little away from from me, looking at our legislators, selected by our society, who will make those line-drawing decisions--and so I can move that part of the accountability away from me. But in my own role in the process...there is a sense of accountability. I have to do the best possible job.

I'm distanced from the individual that will be impacted. I have not directly had to face a Coby Howard or someone who has died as a result of these decisions. Although I have seen people who don't have coverage and some of the results of that, and that's what I'm willing to trade off. Some people will die, some people will be harmed, in order for more people not to be harmed, more people not to die.

The former Health Decisions executive is clear about the emotional shield he uses to maintain his equilibrium:

I think of the 15 percent who are uninsured and unserved, who can't rely on the rest of us to share their burden. They don't get treatment, and their life gets worse, crushed, and then they get acute enough that they can get access to an emergency room. Life and death is not hanging in the balance when most people seek health care. Most people are seeking a loss of pain, comfort, correction of a crippling injury. I resist the unity that health care rationing equals life and death.

This Health Decisions executive carries little official responsibility. He feels he shares a moral responsibility as a result of his role in the prioritization process, but that, again, because the policy is sound and fair, the emotional consequences will be minimal::

A weakness of our system is in human nature. We focus on one individual identified case as a means for making policy, because it's easy to empathize or identify one case, whereas there maybe hundreds of other cases that are just as serious or heart-wrenching but are unseen. Public policy can be manipulated by the publicity of an individual's case, or by one eloquent spokesman or representative. So to the extent that the public and the representatives are informed of the *whole spectrum* of how things happen, I believe that you get better policy.

If I were confronted with somebody who needed a transplant that wasn't on the list, I would feel that the policy process had represented me, to an extent, as an individual, and that the policy represented community values, to some extent. That means there are limits, and some are going to fall within, and some are going to fall without. With an individual case I would do what I could.

This informant tried to include her voice during the search for community values. She is ambivalent about the policy, and fears some emotional consequences. To protect herself, she maintains a strong skepticism that her voice ever will find its way into the ultimate decisions:

I don't feel any personal accountability. We were such a very small number, and I don't know what weight in the formula this process is going get, in terms of the prioritizing.

When they get this finished, and if they have plugged in these values that the citizens have articulated, and it will mean cutting off supports, and it will mean denying transplants, I think I'll feel very bad. I've gone on to another way of thinking about health care. Now I'm saying, let's go forward and do it even better: Let's go for a single-payer system in the state. Let's not have to deny people services. It's at least more equitable than Senate Bill 27, though Senate Bill 27 is better than nothing. And I will personally feel badly if it's going to be cutting people off from...but if I put on my society cap I will think it's better for society. So I'll have a personal feeling about it but I'll know that yes, if that's all we can do, we have to do it.

Finally, this lobbyist and former legislative staff member sees both sides of the coin for his own circumstance, but agrees that community participants are well insulated from the emotional risk:

On any given day I can go from feeling very good about what I've done, and that my part--which was a fairly significant part in its development--was for the greater good, to the opinion in the same day that what a horrible sham we are perpetuating on people and it's criminal to take away benefits under these so-called excuses of rationalism, and in fact we're deserting people who need our help. I go from those poles constantly. So I'm ambivalent about it, uncomfortable about it, and often feel guilty about it. But at the same time feel resolved to do something too. I feel I've come to terms with it.

I think attendees are more isolated from the consequences. For them it's more of an exercise in an ideal endeavor. They may have an area that is important to them, so they go to a meeting, and if they prevail with their sub-group, then it becomes part of whatever that community meeting adopts, then will have felt that they've done their job and can go away happy. They don't have to see the consequences in very much detail.

V. CONCLUSION

Retrospective reflection aside, the attention of most participants in the Oregon process is firmly fixed on the future. Where will the legislature draw the line? Will the necessary waivers be granted? And from the standpoint of the Oregon lawmaker, bureaucrat, Medicaid recipient, small-business employee, these are important questions.

But the outside observer, maybe in another state, who reads what she can of the Oregon proposal, may ask different questions. Ambivalent about the plan, perhaps unpersuaded by Senator Kitzhaber's rhetoric or sensitive to the idea that people now receiving benefits should lose them, this observer may suppose, *It doesn't really matter what happens next*. From this perspective, the outcome is immaterial, but the assertion that certain public-policy benefits have grown out of the project is, I believe, indisputable. Central among these contributions, discussed more broadly in the body of the paper, are: (1) the introduction of *explicit* and *accountable* limit-setting into government health services allocation; and (2) the activation of discussion among citizens, however limited, about how to set such limits.

In the words of an Oregon Health Decisions informant, the central premise of Senate Bill 27 is that "Since we *must* make budget decisions about benefits for people on Medicaid or state insurance programs, we could make *better* budget decisions if we put our benefits in some kind of qualitative order." This statement acknowledges the existing rationing patterns--such as eligibility criteria and provider reimbursement--as well as a desire to move beyond them into a "better" mechanism; the speaker also reminds us that a qualitative ordering--a rank based at least in part on values--is critical to meeting the challenge.

Accepting the above premise implies the need for a source of the value determinations. For Oregonians, the community-meetings process, the public hearings, and the quality of life survey served this role. All three mechanisms have a unifying theme: that the public are expert on the subject of public values. Of these mechanisms, however, only the first was actually a forum for *discussion* of values. The importance of this interactive quality, which appears on its face to be significant, is unknown; the validity of the Oregon iterations provide an equivocal standard for judging such importance. But despite disagreement about the degree of their influence on the process, community values *were* enfranchised in the debate over health services allocation

In this paper, I sought to follow the example. In attempting to understand better the Oregon plan and how it was accomplished, I lay out both facts-- Chapter 2, a chronology of events in Oregon--and values. To explore the latter, Chapter 3 describes a large-scale chart of relevant thought; and Chapter 4 follows the paths, the values and interpretations, of twenty-two individual participants in the process. In this way, an understanding is built that mimics the Oregon process.

In doing so, I offer implicit support to the trend toward communal discussion of community values initiated by community-oriented organizations, such as Oregon Health Decisions and the seven of state Health Decisions groups nationally, as well as other groups in low-income and minority communities. If sufficiently incorporated in health policy development, this movement will strengthen health care, conferring legitimacy, ownership, and moral relevance upon future programs. Further, because health care is special, because it evokes images of vulnerability and human suffering, because everybody has experienced it, community participation in health policy

development can be a lever for broader, more active participation by communities in determining their collective future.

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APPENDIX 1

Complete Cost-Benefit Formula

Summary of Prioritization Process 12/90

Appendix I

Benefit/Cost Formula

The information collected at the HSC's public hearings and at Oregon Health Decision's community meetings will be used to weight the following benefit/cost formula.

$$B_n = \frac{C}{Y^* \left(\sum_{i=1}^5 [(p_{i1} * (1 + \sum_{j=1}^{30} d_{ij1} w_j)) - (p_{i2} * (1 + \sum_{j=1}^{30} d_{ij2} w_j))] \right)}$$

[with treatment]
[without treatment]

Where:

B_n = the net benefit value ratio for the nth condition/treatment pair to be ranked. This value will be used in determining the actual rankings of health services from highest (0) to lowest (∞).

Y = the years for which the treatment can be expected to benefit the patient with this condition. This may be the remainder of the patient's lifetime or some shorter amount of time.

p_{i1} = the probability that the ith outcome will occur after five years with treatment.

Appendix I (continued...)

d_{ij} = an indicator variable denoting the presence (=1) or absence (=0) of the j th health limitation (MOB, PAC, or SAC) or chief complaint for the i th outcome with treatment.

W_j = the weight given by Oregonians to the j th health limitation or chief complaint ranging from (0=no significant effect) to (1=death).

p_{i2} = the probability that the i th outcome will occur after five years without treatment.

d_{ij2} = an indicator variable denoting the presence or absence of the j th health limitation or chief complaint for the i th outcome without treatment.

C = cost with treatment, including all medications and ancillary services as well as the cost of the primary procedure.

