Light on the Black Box of Basic Health Care:
Oregon’s Contribution to the National Movement Toward Universal Health Insurance

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The American community soon will complete its slow march toward universal health insurance, which began before World War I with debates about “compulsory insurance” for workers. Back in 1935, when the United States annually spent under $30 per person on health care, the overall U.S. health-care budget accounted for only 4.1% of the Gross National Product (GNP). As of 1940, hospital insurance still covered less than 10% of the U.S. population. Today, the health-care backdrop looks markedly different. Approximately 85% of our nation’s citizens now have some form of third-party assistance (public or private) to help pay for medical goods and services. National per capita spending on health care approaches $3100 per year; the 1992 health-care budget likely will exceed $800 billion, approximating 13% of the GNP.

We cannot sustain this spiralling trend much longer. Other domestic priorities increasingly compete with health care for our nation’s scarce economic resources. Families increasingly worry that an unexpected illness will send them straight to the poorhouse. Voters—and politicians—increasingly talk about the need for “change”. Nevertheless, the road to universal health insurance leads across difficult terrain. Here, on the last stretch, we not only must expand access for those now left out, but we also must find a way to lower the overall growth rate of our health-care system.

Whether ten years from now we will have a single-payer system or a fully coordinated system of multiple payers is not clear; but new calls to “get back on the road” sound with increasing frequency. A range of typical proposals—

† Editor’s Note: In early August 1992, the Department of Health and Human Services rejected Oregon’s request for waiver from federal Medicaid requirements. See Robert Pear, Plan to Ration Health Care Is Rejected by Government, N.Y. TIMES, Aug. 4, 1992, at A8. See also POSTSCRIPT infra p. 429, for a discussion of these developments. Despite the adverse effect of this rejection on the Oregon Plan, this article adds to the national health-care debate by describing one state’s attempt to reform its health-care system. Oregon’s experience should prove particularly helpful to state and national policy makers as they attempt to develop viable health-care reform.

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3. Id. at 108.
each including the goal of universal access to some form of third-party assistance—will be discussed below. The proposals differ on the particulars: how many payers will run the system’s financial administration; who must contribute financially to the system (e.g., employers, workers, or taxpayers); and which equity system shall be used to ensure coverage for the poor and near-poor. Yet these details tend to overshadow another salient issue: what should be the content of the “basic-benefits” package to which everyone will have guaranteed access? A “black box” thus lies at the center of every current proposal.

Which benefits and services should the universal guarantee cover and what role can the general public’s values play in determining the guarantee’s content? What role should technical experts play in identifying the services that best serve the community’s conception of health care as one component of its overall common good?

I begin this Article by summarizing the current system employed in Oregon to build benefit packages around prioritized health services. I then explore this system’s lessons for national reformers, who soon must define the “basic-benefits” that will form the core of any universal guarantee. I conclude by relating this impending challenge to the recommendations of the 1983 President’s Commission report, which advocated using equitable access to “adequate” health care as a moral standard. Even if Oregon’s experience cannot shed direct light on the national “black box” of basic health care, it can better illuminate the last leg of the journey toward national health-care reform.

I. OREGON’S PLAN FOR ESTABLISHING HEALTH SERVICE PRIORITIES

Oregon currently is testing a democratic decision-making model as part of the state’s effort to develop sensible health-care coverage for uninsured Oregonians. Many Americans have come to know the Oregon plan by the popular and professional debates portrayed in the media. Elsewhere I have described the plan’s methodology in relation to principal attacks on its justice or fair-

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6. See infra notes 39-40 and accompanying text.
8. The primary documentation of the Oregon Plan is found in Oregon Health Services Comm’n, Prioritization of Health Services: A Report to the Governor and Legislature (1991) [hereinafter Prioritization]. A copy of Prioritization may be obtained from the Office of Medical Assistance Programs, Department of Human Resources, 203 Public Service Building, Salem, Oregon 97310, (503) 378-2263.
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Opponents of the plan primarily argue against its exclusive focus on programs for the poor. For example, Norman Daniels contends that justice cannot be served unless limitations on health services apply to everyone, not only to the poor. Others have asserted that the Oregon Plan actually will improve the lives of the poor (and thus serves justice) even though perfect parity would require that prioritization be used to define a basic minimum standard for everyone. I will argue that by opening the "black box" of basic health care and defining its contents—through a process sensitive to both public values and expert opinion—we will move one step closer toward the march's finish line, where all Americans will have genuine access to fundamental medical care.

A. Overview of the Oregon Plan

The Oregon Plan emerged from open political discussions about options for allocating collective health-care dollars. The plan employs two principles highly relevant to the development of a national health-care guarantee: (1) we should prefer explicit political choice to the hidden rationing that now occurs; and (2) we should base decisions about what belongs in the universal guarantee on both expert data and community values.

The plan comprises a trio of laws passed in 1989, which seek to bring every Oregonian into the security of third-party coverage. One statute addresses Medicaid reform, the second creates new employer incentives for health insurance purchase, and the third provides funding for a high-risk insurance pool coordinated by state government. The plan principally aims to bring relief to more than 450,000 Oregon citizens who now lack health insurance, the majority of whom are employed but do not receive health insurance.

9. See Michael J. Garland & Romana Hasnain, Community Responsibility and the Development of Oregon’s Health Care Priorities, 9 BUS. & PROF. ETHICS 181 (1990) (discussing issues of practical and theoretical ethics, in particular, the issue of community responsibility); see also Michael J. Garland, Rationing in Public: Oregon’s Priority Setting Methodology, in RATIONING AMERICA’S MEDICAL CARE: THE OREGON PLAN AND BEYOND 37, 50-57 (Martin A. Strosberg et al. eds., 1992) (discussing justice and common good issues when viewing the Oregon Plan as a form of rationing); Michael J. Garland, Justice, Politics and Community: Expanding Access and Rationing Health Services in Oregon, 19 L. MED. & HEALTH CARE 67 (1992) (discussing, among other things, fairness-in-allocation issues). Part of the present article is a revision of material published in these previous articles also describing the Oregon Plan.

10. See Norman Daniels, Is the Oregon Rationing Plan Fair?, 265 JAMA 2232 (1991). Daniels provides the most carefully articulated version of the justice arguments against the Oregon Plan. His criticism goes beyond that of requiring that all bear the burden of rationing; he also discusses several criticisms of the rationing process.

11. Id. at 2234.


as part of their employment benefit package. The plan’s cornerstone is a prioritized list of health services that serves as the basis for determining the basic benefits to which Medicaid clients and those insured through new small-business plans will be entitled.

The political methodology of the Oregon Plan creates a four-step division of labor: (1) a public commission, the Health Services Commission (HSC) generates a priority list of health services; (2) legislators use the list to determine budget allocations for publicly financed health-care programs; (3) agencies plan for and administer services within budget constraints; (4) agencies and community providers effect the delivery of services in the community and cooperate in evaluating the impact of the new service arrangements on public health.

Priority-setting rests on principles derived from a decision-analysis technique widely used in business-sector and public-sector decision-making. This technique calls for separating fact-based technical information from value judgments in preparation for a rational evaluation of the relative worth of different options. The decision-analysis technique breaks complex problems into smaller, more manageable ones, focuses attention on the justifications for “bottom-line” decisions, and assigns parties with varying expertise appropriate roles in the decision process. The HSC recognized that its mission required blending community values with the best available technical data about the effectiveness of medical services. Consequently, the Commission accomplished its task through six steps: (1) it inquired into community values relevant to setting priorities for allocating health-care resources through survey, public hearings, and structured community meetings; (2) it consulted multiple panels of health-care providers about probable outcomes of particular health services under specific conditions; (3) it established a system for categorizing health services; (4) it prioritized the categories using qualitative data from community meetings, public hearings, and commissioners’ informed judgments; (5) it employed a net benefit formula to rank order services within each category; (6) it adjusted items within and between categories based on consensus among commissioners about public health impact, cost of medical treatment, incidence of the condition, effectiveness of treatment, social cost, cost of non-treatment, and an agreed upon rule that, when possible, prevention should take priority over treatment.

Initially, the Health Services Commission developed a list of health-service priorities based on both community values about health care and technical

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16. See generally HOWARD RAIFFA, DECISION ANALYSIS (1968) (providing an introductory course in decision-analysis).
information about the effectiveness of various medical services relative to the needs of the population to be served. The list is not a once-for-all product. Rather, it will be revised continuously by the commission and reported biennially to the legislature. The first prioritized list reached the Governor and legislature in May 1991.

Upon delivery of the list, the full legislature, using the list and actuarial data as a decision guide, took up setting the budget. The budget established the specific benefit package to be offered in full by the new Oregon Medicaid Program and to be substantially contained in any private health-insurance plan offered under the aegis of the small business and high-risk insurance programs. The legislature completed step two at the end of June 1991.

Next, the relevant agencies (Office of Medical Assistance Programs, Oregon Medical Insurance Pool Board, and High Risk Insurance Pool Governing Board) received the budget decision creating the benefit package for Medicaid and associated private insurance packages. As its first essential administrative task, the Office of Medical Assistance Programs (OMAP) requested necessary waivers of several federal Medicaid regulations, such as categorical eligibility and the distinction between mandatory and optional services. Without approval from the Health Care Financing Administration (HCFA), however, the Medicaid portion of the plan cannot be implemented. The waiver request went to HCFA in August 1991 with a response expected by mid-June 1992.

At this third step, the agencies also must put in place all the administrative and evaluative elements necessary to run a complex social program. As part of this process the agencies use the priority list to guide administrative decisions so that the new programs will consistently represent the values on which the priorities are based.

At the fourth step, actual implementation of new service programs in the community occurs. These services will reach all persons at or below 100% of the Federal Poverty Level (e.g., an income of $964 per month for a family of three) who, under the new service programs, would be declared eligible for Medicaid. Currently, eligibility for most Medicaid categories hinges on being well-below 100% of the Federal Poverty Level. Those with incomes above the cut-off point (unless already included in a Medicaid categorical

17. If Oregon's Medicaid reform program is halted, some other means will need to be discovered to bring assistance to the 120,000 persons whose incomes fall below the federal poverty guideline, who are currently uninsured, and who do not meet current state or federal requirements for Medicaid eligibility. The state would need to find funds to provide coverage at allowed income levels for those categories of persons identified in federal regulations as potentially eligible. Federal regulations exclude childless men and women from eligibility as well as adults whose children have reached age eighteen and who are not attending secondary school on a full-time basis. See Oregon Health Plan 8 (1992).
program) will be served through either the Oregon Medical Insurance Pool or the High Risk Insurance Pool. At this step, the ultimate goal—improved access to basic health care—depends on the ability of agencies to maintain cooperative relations with direct care providers. If HCFA grants the necessary waivers in summer 1992, then Oregon will begin phasing in the new Medicaid program in the fall of 1992.

The division of tasks and responsibilities among the general public, the commission, the legislature, and specific agencies is an essential and often overlooked characteristic of the Oregon Plan. This division of labor makes possible the critically important separation of value considerations from technical facts at the outset of the priority-setting process. The pursuit of value articulation from the community uses democratic processes that promote a sense of community responsibility for the fairness and common-good dimensions of collectively-financed health care. The division of tasks further allows the priority list to be developed as a decision tool relatively free from political pressures in the legislature (and protects the legislature from the temptation to fiddle with the list at the request of special interest lobbyists). The lobbyists—representing organizations such as provider groups or specific disease-oriented associations like those for cancer, transplantation or Alzheimer’s—often testify in absolute terms that their group’s constituents must receive funding without giving regard to the needs of any other groups.

II. PRIORITIZATION

A. Structure of the Priority List

The Health Services Commission began its work in September 1989. Although the law required the Commission to produce a priority list it did not prescribe a method for accomplishing the task. Some early critics asserted that the task of setting health-services priorities is so complex that only nonsense could be produced in the short time frame and with the methods the HSC first tried. Conscious of their role as social innovators, the Health Services Commission listened to its critics and kept refining its methods and revising its deadlines until it was sufficiently satisfied that the list, despite its imperfections, reasonably and suitably fulfilled its intended purpose. The final list, along with an actuarial estimate of the per capita costs of implementing it, reached the legislature in May 1991. The content and ordering of the list

21. PRIORITIZATION, supra note 8, app. I at exec. summ. 3. Appendix I contains the full actuarial report from Coopers & Lybrand.
remains the responsibility of the HSC; legislators may not alter the ordering.

The entire list contains 709 items, each item comprised of a health condition or diagnosis paired with a commonly used treatment for the stated condition or diagnosis. These condition-treatment pairs emerged from standard lists of diagnoses and medical procedures used for statistical and billing purposes.22

Preferring to keep the list intuitively accessible (rather than having it appear as a long laundry list), the commissioners created a system of seventeen prioritized categories, distributed the condition-treatment pairs among these categories and, finally (using a net-benefit formula), rank-ordered the items within each category. Fashioned around values that the commission elicited from the public through forty-seven community meetings and twelve public hearings, the categories also reflect the basic priority zones (with category I representing the highest-priority group of services). Some overlap among categories exists, because certain items conceptually belong in a given category but have special characteristics that led the commissioners to place them above or below their otherwise logical position.

In transmitting the list to the legislature, the commissioners recommended labelling categories 1 to 9 as essential components of basic health care, categories 10 to 13 as very important elements of health care, and categories 14 to 17 as valuable to individuals (but significantly less likely to be cost-effective or to produce substantial benefits).23

B. Content of the List24

The following list presents the categories in priority order and provides examples of the kind of health services grouped within each category.

Essential Components of Basic Health Care

1. Acute fatal conditions for which treatment prevents death and provides full recovery: e.g., repair of deep open wound of the neck, appendectomy, and medical therapy for myocarditis.

2. Maternity care, including disorders of the newborn: e.g., obstetrical care, medical therapy for drug reactions and intoxications specific to newborns, and medical therapy for low birth weight babies.

3. Acute fatal conditions for which treatment prevents death but for which recovery is limited: e.g., surgical treatment for head injury with prolonged loss

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22. See infra text accompanying notes 35-39.
23. PRIORITIZATION, supra note 8, at 69-71.
24. This section is adapted from id. at app. G, G11-G12.
of consciousness, medical therapy for acute bacterial meningitis, and reduction of an open fracture of a joint.

4. Preventive care for children: e.g., immunizations, medical therapy for streptococcal sore throat and scarlet fever, and screening for specific problems such as vision problems, hearing problems, or anemia.

5. Chronic conditions that are fatal and for which treatment improves life span and quality of life: e.g., medical therapy for type-I diabetes mellitus, medical and surgical treatment for treatable cancer of the uterus, and medical therapy for asthma.

6. Reproductive services: e.g., contraceptive management, vasectomy, and tubal ligation.

7. Comfort care: e.g., palliative therapy for conditions in which death is imminent.

8. Preventive dental care for adults and children: e.g., cleaning and fluoride treatments.

9. Preventive care of proven efficacy for adults: e.g., mammograms, blood pressure screening, medical therapy, and chemoprophylaxis for primary tuberculosis.

Very Important Elements of Health Care

10. Acute nonfatal conditions for which treatment is likely to bring a return to previous health: e.g., medical therapy for acute thyroiditis, medical therapy for vaginitis, and restorative dental service for caries.

11. Chronic nonfatal conditions for which a one-time treatment improves the quality of life: e.g., hip replacement, laser surgery for diabetic retinopathy, and medical therapy for rheumatic fever.

12. Acute nonfatal conditions for which treatment is unable to fully restore previous health: e.g., arthroscopic repair of internal derangement of the knee and repair of corneal laceration.

13. Chronic nonfatal conditions for which repetitive treatment improves the quality of life: e.g., medical therapy for chronic sinusitis, migraine headaches, and psoriasis.

Elements Valuable to Individuals but of Minimal Gain or High Cost

14. Acute conditions that are nonfatal and self-limited for which treatment expedites recovery: e.g., medical therapy for diaper rash, acute conjunctivitis, and pharyngitis.

15. Infertility services: e.g., medical therapy for anovulation, microsurgery for tubal disease, and in-vitro fertilization.
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16. Preventive services of unproven benefit for adults: e.g., dipstick urinalysis for hematuria in adults less than 60 years of age, sigmoidoscopy for persons less than 40 years of age, and screening of non-pregnant adults for type-I diabetes mellitus.

17. Fatal or non-fatal conditions for which treatment provides minimal or no improvement in quality of life: e.g., fingertip avulsion repair that does not include fingernail, medical therapy for gallstones without cholecystitis, and medical therapy for viral warts.

The 1991 Oregon Legislature passed a budget for the new Medicaid Program that funds health services through line 587, thus providing for virtually all (98%) of the services in the “essential to basic care” group, most (82%) of the services in the “very important” group, and a few (7%) of the services in the “valuable to individuals but of minimal gain and/or high cost” group. This funds Medicaid at a higher level than under the old, non-waivered program. The auxiliary dollars will pay for services rendered to the additional persons who gain coverage under the new system.

C. Prioritization Method: Exploring Values

The Oregon Plan’s method assumes that defining a basic standard for health-care benefits requires two inputs: an articulation of relevant values from the community, and relevant technical data from experts. Using public hearings, structured community meetings, and a telephone survey, the HSC accordingly gathered two kinds of values data: individual values and community values.

Individual values data primarily issued from a random sample telephone survey of the Oregon population, which relied on an instrument adapted from Kaplan’s Quality of Well-Being (QWB) scale. These individual value statements provided a scale for weighing the outcomes of health care described in quality-of-life terms. Six categories of functional impairment (two levels each of restricted mobility, physical activity, and social activity) and a list of twenty-three symptoms form the scale. The sample represented the Oregon population fairly accurately, although women were slightly over-sampled and house-

25. Personal communication with Darren Coffman, Oregon Health Services Commission Staff Statistician (July 22, 1991). The 2% unfunded “essential” services were probably errors of categorization that were ultimately demoted by the commissioners. Similarly the few “very important” items that appear above the funding line were either categorization errors or have a significant public health value that were ultimately promoted by the commissioners.


27. PRIORITIZATION, supra note 8, at app. C, C7-C8.
holds below poverty slightly under-sampled. The results of the survey provided the HSC with a set of weighted functional categories and symptoms, which health-care providers then used to characterize the probable outcomes of treatments for specific conditions.

Twelve public hearings the Commission held at seven different sites around the state generated another variety of values information. Those giving testimony represented either individual interests or special group interests. Participants made vigorous pleas for preventive services, mental health and chemical dependency services, universal health insurance, the use of alternative providers, dental services, prenatal care, health education, and transplant services. Some spoke to the need for hearing, vision, and nutrition services. Many used the opportunity to urge the government to alter its general budgetary priorities. The HSC considered the public hearings helpful for “understanding the general tone of public needs and concerns” and brought the information to bear on the process of ranking categories described below.

A third variety of values came from a series of community meetings. Through this participatory process, Oregon Health Decisions (OHD) developed a unique set of public statements indicating what makes health care a common good. Participants had been asked to think and express themselves in the first-person plural (namely as members of a statewide community for whom health care has a shared value). OHD intended these meetings not only to generate data, but also to stimulate the sense of community responsibility for the ethical dimension of health-policy decisions.

Forty-seven community meetings took place throughout the state with a total of 1048 citizens participating. Each meeting aimed at discovering the local consensus on community health-care values. The meetings began with interactive, small-group discussions taking stock of individual priorities relating to nine categories of medical services. Next, each small discussion group identified principal values for the group as a whole. Finally, a large group discussion produced value themes representing an “authentic message” from the particular geographic community. OHD staff summarized the reports produced by these community meetings and delivered them to the HSC.

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28. Id. at app. C, C3-C4. The survey was conducted under contract by the Survey Research Center of Oregon State University. Id. at C1. The over-sampling of women is considered the result of employment patterns making women more likely to be at home during the calling hours (3 P.M. to 7 P.M.). The under-sampling of the poor is thought to result from fewer persons below the poverty line having telephones. Id. at C3. These sampling factors were considered by the Commission and its consultants not to vitiate the data nor give it a significant bias.

29. Id. at E at E1.

30. Oregon Health Decisions is a non-profit organization existing since 1983 to facilitate public participation in the development of public policy involving ethical issues in health care. Garland & Hasnain, supra note 9, at 198.

31. Romana Hasnain & Michael J. Garland, Health Care in Common: Report of the Oregon Health Decisions Community Meetings Process, in PRIORITIZATION, supra note 8, at app. F; see also the discussion of this process in Michael J. Garland & Romana Hasnain, Health Care in Common: Setting Priorities in
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The community meetings feature prominently in the Oregon Plan and they have played an instrumental role in introducing several important values into the HSC's deliberation. The values expressed in the community meetings and the testimony provided at the twelve public hearings specifically have resulted in: prioritized categories; the structure of the list in the final report; and, most notably, the high ranking assigned to prevention and community compassion (comfort care).

D. Ranking the Categories

The ranked set of categories has become the HSC's primary mechanism for establishing priorities among health services. Initially, the Commission planned to base priorities primarily on a cost-benefit ratio in which it would take the benefits of a given treatment, subtract the benefits of not treating, and then divide that figure by the costs of treatment minus the costs of not treating. Several months into the process, however, the ranked set of categories emerged as the preferred instrument for prioritization. After the categories were created and rank-ordered, a marginal-benefit ratio index (the previous cost-benefit ratio without the cost denominator) prioritized individual condition-treatment pairs within each category.

The ranking process consisted of five steps. First, HCS developed a list of categories capable of containing all condition-treatment pairs. The list drew on ideas derived from the community meetings and public hearings, from commissioners' intuitive habits of thought, and from the literature on health care. Second, the Commission arranged the community-value themes into three broad value attributes: value to society (defined as comprising the values of prevention, benefit to many, impact on society, quality of life impact, personal responsibility, cost effectiveness, community compassion, and response to mental health and chemical dependency problems); value to an individual at risk of needing the service (defined as comprising the values of prevention, quality of life, ability to function, length of life, personal responsibility, equity, effectiveness of treatment, personal choice, community compassion, and Oregon, 20 Hastings Center Rep. 16 (1990) (discussing the community meetings process). The key values that, according to those participating citizens, should guide the priority setting process are: (1) concern for preventing death, pain, suffering, and disability; (2) enhancing or recovering meaningful quality of life and functional capacity in patients including those with mental health or chemical-dependency problems; (3) cost-effective use of resources for health care, including the probable effectiveness of specific treatments, the number of persons benefitted, and the impact on society of certain services; (4) equity in access to services; (5) maintaining personal choice and responsibility for health; (6) assuring compassionate response when cure is not possible; (7) giving special attention to life-extending interventions.


33. Prioritization, supra note 8, at D1; see also infra note 37.
response to mental health and chemical dependency problems); and essential to a \textit{basic health-care package} (defined as comprising the values of prevention, benefit to many, quality-of-life impact, cost-effectiveness, and impact on society).

At the third step, each commissioner gave a unique "perspective weight" to the attributes by distributing 100 points among them. Thus, Commissioner A might have given \textit{value to society} 40 points, \textit{value to the individual} 20 points and \textit{essential to basic health care} 40 points. Keeping the "perspective weight" constant, the commissioners individually scored each service category on a 1 to 10 scale in terms of the three attributes. For example, Commissioner A might have scored \textit{Maternity Care} 9 for \textit{value to society}, 8 for \textit{value to the individual} and 10 for \textit{essential to basic health care}. Consequently, Commissioner A's rating of \textit{Maternity Care} would be 920, the sum of the weighted scores \[ (40 \times 9) + (20 \times 8) + (40 \times 10) \].

At the fourth step, after individually scoring each category, the commissioners engaged in a discussion session to examine the reasons for differences among them in rating the categories. It became apparent in this discussion that the commissioners felt obliged to act as "instructed representatives" of the community; they repeatedly alluded to the community meetings and public hearings to interpret their scores for one another.\textsuperscript{34} Finally, after the commissioners exercised the option to alter their scores in response to arguments brought out in discussion, they rank-ordered the categories by finding the mean score for each category (the sum of the weighted scores divided by the number of commissioners).

E. The Role of Technical Experts

Reasonable priorities require reliable facts as well as authentic values. From fifty-four panels of health-care providers, the HSC solicited outcome-of-treatment information in order to connect its carefully gathered value information to reliable data about the effectiveness of specific health services. Since treatment occurs in response to a condition, HSC requested the information in the form of condition-treatment pairs developed from diagnoses listed in the ICD-9 (\textit{International Classification of Disease}) or DSM-III-R (\textit{Diagnostic and Statistical Manual of Mental Disorders}), which were linked to procedures listed in CPT-4 (\textit{Current Physician's Terminology}) or ADA (American Dental Association) codes for treatments.\textsuperscript{35} Providers would indicate: (1) median age at onset of diagnosis; (2) probability that the designated treatment would be used; (3) expected duration of benefits from the treatment; (4) outcome proba-

\textsuperscript{34} Personal communication with Paige Sipes-Metzler, Executive Director of the Oregon Health Services Commission (Nov. 14, 1991).

\textsuperscript{35} PRIORITIZATION, supra note 8, at 10, app. D, D15-D16.
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Abilities with and without treatment; and (5) cost to payer with and without treatment.

Providers next would identify outcomes as Death, Residual Effects (major symptoms, activity impairments, and mobility restrictions), or Asymptomatic Cure and determine the probability estimate of each outcome's occurrence given the condition-treatment pair under consideration. Their responses would take the form of a reference list comprising twenty-four symptoms and six measures of activity (two each for mobility, physical activity, and social activity) taken from the QWB scale.36

F. Net-benefit Formula

The Commission used the value weights (QWB scale) and the outcomes data from providers in a net-benefit formula; it considered cost information only when items in the same category had the same score or when the commissioners had doubts about the reasonableness of an item's location on the reference list.37 To construct the net-benefit ratio, the commissioners subtracted the numeric value for the probable outcome if a condition were not treated from the value from the probable outcome of treating it. They expressed all outcomes in terms of the QWB scale. The expert panels provided the probability estimates about outcomes resulting from treatment or nontreatment of specific conditions.38

G. Final Intuitive Adjustments of Individual Items

After using the net-benefit formula to rank-order items within each category, the commissioners examined the entire list line-by-line to identify any items that intuitively seemed "out of place." Commissioners who wanted to move

36. Thus, in the case of medical treatment of heart attack, a provider panel might have estimated that 30% of the untreated persons would die, 30% will have chest pain, 20% will have frequent shortness of breath and 20% will return to their former state of health within five years. Among treated persons 10% will die anyway, 30% will have chest pain, 30% will have shortness of breath, and 30% will return to their previous state of health. Each state has a QWB factor: death is 0, chest pain is .747, shortness of breath is .682 and good health is 1. Each factor is multiplied by its probability in the treated and untreated groups. Total value for the untreated group (.5605) when subtracted from total value for the treated group (.7287) gives a marginal-benefit index of .1682. These numbers are used to create the "within category" rank of individual condition-treatment pairs. See id. D at D3-D5.

37. Id. at 23-28, app. D. Since costs of treatment were finally not considered in the formula, its result is more properly called a "marginal benefit ratio." The "net-benefit" label is retained for consistency, since that is the designation used in the HSC's report. A persistent misunderstanding of Oregon's prioritization process is the belief that a cost-benefit or cost-effectiveness ratio was the primary determinant of position on the list. Although the earliest work with the formula included costs, acquiring reliable data proved so difficult that the HSC ultimately used costs only to make marginal adjustments in a small number of the items on the list. Whether inclusion of costs in the prioritization process would improve the technique or distort its social desirability continues to be a matter of dispute. See, e.g., Robert Veatch, Should Basic Care Get Priority? Doubts About Rationing the Oregon Way, 1 KENNEDY INST. ETHICS J. 187 (1991).

38. See supra note 36.
an item on the list were held to a "reasonableness" test, which consisted of evaluating the public-health impact, the cost of medical treatment, the incidence of the condition, the effectiveness of treatment, social costs, and cost of non-treatment. Thus, for example, medical therapy for intraventricular and subarachnoid hemorrhage of the newborn appears at line 687 among the items in category 17 although its "logical" place is among the items in category 2, "Maternity and newborn care." Why demote this medical therapy? Because such treatment generally is unsuccessful in saving the baby's life or in preventing devastating damage to the baby's brain. The commissioners made such justifications in open discussion and then collectively reached a final determination by consensus. Additionally, the following rule guided the proceedings: that services with a preventive effect should take precedence over items referring to the same diagnosis in a severe or exacerbated stage.

In summary, the Oregon Plan applies basic democratic principles to the complex field of health care. It stimulates active participation by the general citizenry in declaring the values on which new political choices should be based. It maintains a role for experts in describing the probable outcomes of specific medical interventions that, in the aggregate, would compose a package of benefits. It requires of legislators an accountable budget-making process that finally delivers to human-services agencies the resources necessary to organize and administer a valued set of health services.

The Oregon prioritization process functions first and foremost as an instrument for implementing rational budget management of Medicaid and for defining a basic-benefits package for small-business health insurance programs. As the United States moves toward a universal health-care guarantee, the need to define a basic-benefits level on which the guarantee should rest will continue to grow. The Oregon approach offers an innovative model for involving both experts and the general public in this task.
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II. PRIORITIZATION AND UNIVERSAL GUARANTEES

New proposals for universal coverage range from government-run health-insurance systems to a variety of mixed public-private systems. Mixed public-private proposals fall into three basic types: (1) those requiring compulsory, employment-based, private insurance with government insurance for nonworkers and the poor; (2) those requiring employers either to provide insurance or to pay into health insurance fund for uninsured workers, nonworkers and the poor ("play or pay"); (3) those requiring use of tax credits and vouchers to purchase private health insurance.

All of these proposals assume that the new program will define a "basic" set of health-care benefits which any private insurer or government program must contain. The following list shows how some popular proposals identify the requisite content of guaranteed level of health care envisioned by their authors.


# Proposals for Guaranteed Health-Care Access

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<tr>
<th>Proposal</th>
<th>Content of Guarantee</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMA Health Access</td>
<td>Minimum Benefits (broadly defined by AMA)</td>
<td>Multiple payers (MP)</td>
</tr>
<tr>
<td>Pepper Commission (PC)</td>
<td>Adequate Minimum Standard (broadly defined by PC)</td>
<td>MP</td>
</tr>
<tr>
<td>&quot;Physicians Who Care&quot;</td>
<td>Catastrophic Coverage for major illness (not defined)</td>
<td>MP</td>
</tr>
<tr>
<td>Medical Schools Section (AMA)</td>
<td>Medically Necessary Services</td>
<td>MP</td>
</tr>
<tr>
<td>Karen Davis</td>
<td>Current Medicare Coverage plus other categories</td>
<td>MP</td>
</tr>
<tr>
<td>Kansas Employer Coalition</td>
<td>Broad, Minimum Plan (like HMO Act (1973) or like Medicare)</td>
<td>MP</td>
</tr>
<tr>
<td>Enthoven and Kronick</td>
<td>Federal Standards</td>
<td>MP</td>
</tr>
<tr>
<td>Urban Institute</td>
<td>Minimum Standards</td>
<td>MP</td>
</tr>
<tr>
<td>Heritage Foundation</td>
<td>Basic Package (federally defined)</td>
<td>MP</td>
</tr>
<tr>
<td>U.S. Health (Roybal)</td>
<td>Broad Coverage</td>
<td>Single payer</td>
</tr>
<tr>
<td>Physicians' for National Health Program</td>
<td>Medically Necessary Services (national standards)</td>
<td>Single payer (each state)</td>
</tr>
<tr>
<td>Committee for National Health Insurance</td>
<td>Core Benefits (federally defined)</td>
<td>MP (state option)</td>
</tr>
</tbody>
</table>

This list illustrates that those who have recently stepped forward in the name of universal access to health care employ several different words carrying different assumptions. Debates among supporters and opponents of these plans tend to focus on the different philosophical visions of government and private insurance as agents of the transition to a universally guaranteed system of access. For instance, everyone talks about who will be responsible for controlling total expenditures in the new system. But few pay attention to the
task of defining the content of the universal guarantee: to what should we all have access?

The 1983 report on access to health care produced by the President's Commission for the Study of Ethical Issues in Medicine and Biomedical and Behavioral Research identified the critical social need for such a definition. The President's Commission's report made two significant conceptual moves in the then-languishing debate on "National Health Insurance." First, the Commission argued that the effort to base health care on some moral or human right created more problems than it solved, because such a right could neither be clearly grounded, nor its limits clearly set, nor the correlative duties appropriately assigned. Second, it introduced two key words into the customary formula about access to health care: equitable access and adequate care. "Society has a moral obligation to ensure that everyone has access to adequate care without being subject to excessive burdens." The report urged that the concept of "adequate health care" be used to guide social efforts to create a package of basic care available to all, nonetheless acknowledging that some persons may have the resources to privately purchase services in excess of the basic standard. Equity demands only that an adequate level be available to all, not that every kind of care be equally available to all. The Commission thus openly endorsed the concept of a two or many-tier system, provided that the bottom tier could meet some standard of equity.

The President's Commission pointed to four important health-care goals: (1) contributing to equality of opportunity in society, (2) reducing pain and suffering, (3) informing persons about their life prospects, and (4) associating health care with many central symbols of human existence. The Oregon approach adds to the array of values pointed to by the President's Commission. Through its community-meeting process, the Oregon approach evokes a rich articulation of "what makes health care important to us" and provides a broad base of values by which to judge the scope of "adequate" health care (the thirteen value themes discussed above).

The President's Commission did not offer a definition of adequate care, but discussed factors that require consideration: (1) which conditions merit

42. See SECURING ACCESS, supra note 7, at 35-42.
43. Id. at 22 (emphasis added).
44. See id. at 35-47.
45. See id. at 16-17. But see NORMAN DANIELS, JUST HEALTH CARE 81-83 (1985). Daniels argues for a narrow rationale, maintaining conditions for equality of opportunity, as the basis for claiming a societal duty to secure access to health care for everyone. The more-narrow rationale, Daniels argues, more clearly establishes a basis in justice for the social obligation. Daniels contends that other rationales are less forceful and less likely to sustain a critical perspective on the current structure of the health-care system. The Oregon approach of asking the community to help define what they believe makes health care a significant common good is even more broad than the President's Commission four-point basis. I believe this is a strength rather than a weakness.
46. See infra section I.D.
guaranteed access to treatment; (2) health conditions in relation to treatment options; (3) the costs and effectiveness of such treatments; and (4) the quality of guaranteed treatments. The President's Commission suggested several approaches to defining adequacy criteria, including relying on professional judgment, consulting average current use data, and compiling comprehensive lists of medical services.\footnote{47} Two caveats run through the President's Commission's remarks on adequacy. First, care must be taken to keep the definition dynamic: "adequacy" should not denote an uncritical endorsement of the status quo. Second, recognizing that the definition of adequate is not objective, the ultimate source of value determinations should be the public. In sum, "the appropriate values to be assigned to the consequences of policies must ultimately be determined by people expressing their values through social and political processes as well as in the marketplace."\footnote{48}

One principal equity issue embedded in the concept of adequate care is fairness. Fairness in a two-tier system rests on the content of the universally guaranteed level of service. But where will this basic-benefits package come from? Who will define it? What values will it encompass? By what process will it be reviewed for adequacy? I believe that it is in answering these questions that the Oregon Plan reveals its most interesting and nationally-useful feature.

A concerted effort over time with a broad selection of U.S. citizens could contribute information useful to the national task of identifying the content of the much-desired package of guaranteed medical benefits. Shedding light on the "black box" of basic health care, in turn, would give meaning to the phrase "equitable access to adequate health care." Since the virtual demise of the Health Planning Agencies—created in the 1970s to provide a national network for citizen input into the health-care system—any current national effort along the lines of the Oregon Plan would require some coalition building among civic groups such as those that make up American Health Decisions (a coalition of statewide organizations similar to Oregon Health Decisions),\footnote{49} League of Women Voters, AARP, and the like. A model around which such a nationwide outreach could be constructed already has been developed by the Public Agenda Foundation and was first attempted on a large scale in the spring of 1992.\footnote{50}

\footnote{47. SECURING ACCESS, supra note 7, at 37-42.}
\footnote{48. Id. at 37.}
\footnote{50. PUBLIC AGENDA FOUND., CONDITION CRITICAL: THE AMERICAN HEALTH CARE FORUM (1992) (available upon request from Public Agenda Foundation, 6 East 39th Street, Suite 900, New York, New York 10016). "Conducted in cooperation with the National Issues Forum and TV stations, newspapers, and educational organizations across the country, Condition Critical is intended to help citizens understand and take part in the debate on the country's health care system."}
A second equity issue concerns the level of financial burden required of someone seeking access to adequate care. Most of the current universal-access proposals pay a great deal of attention to this issue of financial burden, with regard both to those seeking care and to those called upon to contribute resources so as to lighten the burden of those in greatest need. Oregon's community meetings did not shed light on this dimension of equity because targeting the source of funding for the whole health-care system lay outside of the Oregon Plan's mandate. There is, however, no reason to believe that a community meeting process could not illuminate the values underlying community decisions about how to finance the new system. Indeed, if health-care reform aims to achieve equity goals (i.e., universal access to "adequate" care), then clearly-articulated values regarding the moral goals of third-party financing should guide the development of any fiscal plans.

The greatest challenge facing a search for consensus on the financing issue is how to keep the discussion from being overwhelmed by deeply-ingrained feelings about taxes independent of equitable goals. This discussion, though difficult and sensitive, nonetheless is essential to moving ahead on the march toward universal health insurance.

III. HEALTH CARE, SOLIDARITY, AND PUBLIC PARTICIPATION

The Oregon Plan presumes that the content of a socially-guaranteed "basic-benefits" package should unfold from an open, democratic process in which public values and technical expertise play complementary roles. This approach considers questions of justice and fairness, especially in terms of access to socially-guaranteed benefits. It also ensures social responsibility for the content of the common good (the basic health-care package) and promotes fairer distributions of the burden of sustaining that good.

Most universal-access proposals focus almost exclusively on how to finance their programs, such that they treat the content of the basic-benefits package as a near-negligible issue. Currently, public programs within the U.S. health-care system vary greatly as to basic benefits. Each of the public sector's fifty different Medicaid programs, Medicare, Veterans Administration, Department of Defense Medical Programs, the Native American Health Service, and state and local welfare programs insures a different benefits package. Private insurance plans likewise vary tremendously in terms of covered services. The system as a whole tends to define benefits broadly, deferring as much as possible to professional autonomy. In light of this tremendous variability, all reform proposals address the need to develop uniform national standards for benefit packages. Uniformity in the lower tier—the universally guaranteed tier—is seen as a prerequisite for fairness and equity in the system. To fulfill
this prerequisite, it will be necessary to say what is and what is not guaranteed as a basic benefit.

The Oregon approach treats the decision regarding benefit packages not merely as a technical choice within experts’ domain, but rather as a process encompassing public values and political accountability. Determining adequate health-care benefits certainly requires some degree of technical expertise. This determination should not be made without serious input from health-care experts—both service providers and those who are technically skilled in organizing and financing the endeavor. Yet the public also should have a role, since the health-care system aims to serve the public’s wants, needs, and expectations. The Oregon approach further demonstrates that synthesis of public values and technical knowledge requires a visible point of political accountability. Dedicating public resources to health care rather than some other use entails a significant political choice. The Oregon approach seeks to keep that choice out in the open with its decision-making rationale accessible to public scrutiny.

In addition to universal access, other major pieces of the national health-care puzzle include cost containment, quality assurance, and the political system’s capacity to assess the relative value of health care in comparison to other uses of collective resources. Defining the basic-benefits package using a public-involving method like Oregon’s does not solve these other dimensions of the national puzzle, but it does establish a frame of reference for approaching them as integrated problems. Cost-containment goals originate from community values about health care. Efficiency in health care is not an absolute concept, but rather one defined by society’s health-care goals. Quality is not objective, but subjective. The ultimate assessment of quality derives from the community’s sense of acceptable levels of hardship, inconvenience, and difficulty associated with the pursuit of health and health care.

Political assessment of the relative worth of health care depends largely on the capacity of community members to make their preferences accessible to those who manage public resources—both at the legislative and the executive level. The openness and public-involving nature of the Oregon Plan strives against the political cynicism and alienation that pervades the United States. Even if those with political power now behave wrongly, unfairly, or perversely, our political system will not improve by further isolating politicians from scrutiny or further decreasing their accountability to the communities they (at least nominally) serve. In a technologically-complex society such as ours, a romantic call to populist solutions seems doomed to fail. The system needs experts. But the experts need to understand the community’s values. What the Oregon approach attempts to do, and in many ways succeeds in doing, is to create an environment in which experts and the public can work together to
Light on the Black Box of Basic Health Care

promote politically-sound, technically-accurate and ethically-defensible collective decisions regarding the allocation of health care.

As we move into a universal-access system during the next decade, the need for integrated public and expert involvement in such decision-making will become even greater. As we seek rational ways to slow the rate of growth in total health-care expenditures, we also must render the public accountable for collective financing decisions. As we seek to identify which hardships, inconveniences, and difficulties attach to our expectations of quality in health care, we must strike a balance among professional, individual and collective values. And as we seek to decide which “other uses” of collective resources we reasonably might trade for more health care—or which health-care products we reasonably might forego in return for more of some other collective good—we must locate the honest priorities of the American public.

As a participating observer of the unfolding Oregon Plan, I have come to understand that it will forever remain a dangerous and unfinished project. Dangerous, because collectively financed health-care challenges our sense of community by making us face the consequences of our solidarity—or lack of it—in the face of common threats: death, disability, pain, suffering, and loss of vigor. Unfinished, because, while the source of the threats will change, our individual and collective fears never will disappear. Consider how the HIV epidemic has placed new challenges before patients, providers, and policymakers. Furthermore, underwriting the cost of universal access competes with private uses of discretionary income. That which promotes the collective health needs, priorities and values of the American community cannot possibly promote all the individual health needs, priorities, and values of American citizens. It simply will be impossible to guarantee access to every new medical therapy, every new medical technology, and every potentially life-saving drug.

The national march toward universal access to adequate health care thus will require continuous effort in the face of an unsettling challenge to our sense of national solidarity. Unfortunately, we citizens of the United States have not yet determined how we shall measure our solidarity with one another in the sphere of health care. We will take a critical step when we finally open the “black box” of basic health care and democratically define what should be the content of this guarantee from all of us to all of us.

POSTSCRIPT

As this article was going to press, Oregon Governor Barbara Roberts received a letter dated August 3, 1992 from the Secretary of the Department of Health and Human Services (HHS), Louis W. Sullivan, M.D. In that letter, the Secretary informed Governor Roberts that the waivers necessary to imple-
ment the Medicaid component of the Oregon Plan could not be given "final approval until a number of legal issues, which relate primarily to the Americans with Disabilities Act [(ADA)], are resolved." The Secretary invited Governor Roberts "to submit a revised application which addresses these concerns" and looked forward "to approving such a demonstration." Because the waiver refusal was not accompanied by substantive explanations of specific ways in which the Oregon Plan violated the ADA, Oregon leaders were left uncertain about what to do to accomplish a successful revision.

On August 26, 1992, a public meeting was held in Oregon at which Michael J. Astrue, General Counsel for HHS, pointed to the use of telephone survey data to rank services as the heart of the problem. According to General Counsel Astrue, the methodology of the telephone survey incorporated a prohibited process since it asked respondents to rate certain states of life (e.g., requiring a wheelchair for mobility, or having difficulty learning) on a scale of 0 to 100, with 100 representing perfect health. In Astrue's opinion, this aspect of the ranking methodology was discriminatory in principle, because it assigned a lower value to the life of a person with a disability as compared with the life of a healthy person. Astrue stated repeatedly at the meeting that the data from the telephone survey could not be used in the ranking process without automatically violating the ADA. Members of the Health Services Commission disputed whether Astrue adequately understood the ranking methodology or the impact of the telephone survey data on the ranking process.

Leaders of Oregon's Medicaid agency are preparing to submit a revised waiver application and have requested from HHS and the Department of Justice full documentation of the various legal issues. At the August meeting, General Counsel Astrue indicated that such formal documentation did not yet exist despite his statements that the waiver denial had been preceded by numerous internal memorandums. He also assured the Health Services Commission that the product of their work—the actual prioritized list of health services—was not objectionable from an ADA perspective, and that by merely eliminating the telephone survey data without significantly changing the list, the Oregon plan would, in all likelihood, win waiver approval from HHS. Oregon expects to resubmit its request for waiver after the November 1992 general elections.