

# COMBINING DELIBERATION AND FAIR REPRESENTATION IN COMMUNITY HEALTH DECISIONS

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Among the many controversial innovations of Oregon's basic health services reform, perhaps the most favorably received was the state's effort to involve citizens in the prioritization process. Through public hearings, community meetings, and an opinion survey, the legislature and the Health Services Commission (HSC) sought to elicit directly from Oregonians the "public values" on which the ranking of health treatments would in part depend. Observers hailed the effort as "an open, public moral debate,"<sup>1</sup> "an experiment with health-care-by-democracy,"<sup>2</sup> and "a classic exercise of American democracy."<sup>3</sup> Despite these glowing notices, defects in design undercut Oregon's participatory process, and it fell short of achieving all the benefits for which its initiators hoped. This paper offers a sympathetic critique of Oregon's pioneering experiment in order to help improve future programs that similarly try to involve citizens in making vital decisions.

An orientation to the future is especially appropriate because the Oregon participatory planning process could be the first of many comparable efforts in bioethics and health policy. The Oregon Basic Health Care Act requires the HSC to update its priority listing of health services every two years, and the statutory mandate of public hearings and community meetings appears to apply to future HSC reports, not just the initial list approved by the legislature in 1991.<sup>4</sup> Oregon Health Decisions (OHD), the group that organized community meetings for the HSC, is the prototype for a nationwide Community Health Decisions (CHD) movement, which seeks to bring "a cross-section of the citizenry together with health care professionals, state and local officials, consumer

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<sup>1</sup> *Oregon Medicaid Rationing Experiment: Hearing Before the Subcomm. on Health and the Env't of the House Comm. on Energy and Commerce*, 102d Cong., 1st Sess. 102-49 (1991) [hereinafter *Hearings*]; *id.* at 24 (statement of Leonard Fleck).

<sup>2</sup> Timothy Egan, *New Health Test: The Oregon Plan*, N.Y. TIMES, May 6, 1990, § 1, at 31.

<sup>3</sup> Daniel M. Fox & Howard M. Leichter, *Rationing Care in Oregon: The New Accountability*, HEALTH AFF., Summer 1991, at 7, 7.

<sup>4</sup> See OR. REV. STAT. § 414.720 (Supp. 1990).

activists, and members of the academic world in neighborhood, regional, and statewide forums to grapple with the hard choices facing health care."<sup>5</sup> Supported by several foundations, the CHD movement has spawned projects in at least a dozen states.<sup>6</sup> If other jurisdictions uncritically adopt the Oregon process as a model, its shortcomings could be unfortunately replicated. Conversely, if attention focusses only on Oregon's mistakes without recognition that they are correctable, then the burgeoning CHD movement might be unnecessarily nipped in the bud.

Nor is the relevance of the Oregon experience limited just to health policy. In its reliance on widespread, small-scale community meetings, the Oregon project exemplifies the intensified participatory politics envisioned and vigorously advocated by communitarian theorists and reformers.<sup>7</sup> Resonating with archetypal images of New England town meetings and Jeffersonian grassroots democracy, this ideal has always had a strong appeal in the American psyche. Unfortunately, carried out in a relatively unstructured fashion, intensified voluntary participation can prove antithetical to the egalitarian values on which democracy ultimately rests.

The paper that follows is divided into three main sections: Part I is a general analysis built around four questions that shape evaluative judgments about citizen-participation programs; Part II is an account and critique of the participatory components of Oregon's prioritization process; and Part III suggests improvements for similar endeavors in the future. To emphasize that my critique of the Oregon process is not ad hoc, I begin with an analysis couched in general terms. The problems that Oregon's well-intentioned enterprise encountered were entirely predictable; any future community decision program, in Oregon or elsewhere, that is constructed along the same lines can be expected to exhibit similar shortcomings.

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<sup>5</sup> Bruce Jennings, *A Grassroots Movement in Bioethics*, HASTINGS CENTER REP., Special Supp. June-July 1988, at 1, 4.

<sup>6</sup> See Brian Hines, *Health Policy on the Town Meeting Agenda*, HASTINGS CENTER REP., Apr. 1986, at 5, 5-7; Jennings, *supra* note 5, at 1-16; Robert J. Slater, *State Networks for Citizen Participation in Health Care Decisions*, NATIONAL INST. FOR DISP. RESOL. FORUM, Summer/Fall 1991, at 4, 4-6.

<sup>7</sup> Most notably, see BENJAMIN R. BARBER, *STRONG DEMOCRACY: PARTICIPATORY POLITICS FOR A NEW AGE* 139-212 (1984).

## I. GENERAL ISSUES IN THE DESIGN AND EVALUATION OF CITIZEN-PARTICIPATION PROGRAMS

Debate in this area often focusses on whether responsible governmental entities should or should not enlist ordinary citizens—unofficial, unelected, and unaccountable—to help shape public policy, especially in areas such as health care that involve complex choices dependent on arcane technical information and entailing life-or-death consequences. Devotees of direct democracy reflexively answer yes; conversely, admirers of guardian elites and strict defenders of electoral accountability issue automatic negatives. I take a more pragmatic position by proposing that the desirability of any particular instance of citizen participation depends on answers to four questions:

- (1) How conducive is the participatory process to informed deliberation and stable judgment?
- (2) How representative are participants, both of the citizenry in general and of groups especially affected by the policies at stake?
- (3) How binding are the recommendations that participants make?
- (4) For what purposes do officials seek to encourage citizen participation?

The answers to these questions are strongly interdependent, whether viewed from the perspective of democratic philosophy or practical politics.

### A. *Deliberation and Its Costs*

The alleged incompetence of ordinary citizens to deal with public questions, especially those dependent on technical knowledge, has always been a major argument in favor of reserving policy-making to bureaucratic, scientific, judicial, or other elites. Schumpeter expressed the usual doubts more frankly than most: “the typical citizen drops down to a lower level of mental performance as soon as he enters the political field.”<sup>8</sup> For this reason, among others, “democratic elitists” like Schumpeter would confine mass political activity to the occasional, simple act of voting. In their view, citizens’ judgments about more complex issues would be dangerously ill-founded and ill-considered.

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<sup>8</sup> JOSEPH A. SCHUMPETER, *CAPITALISM, SOCIALISM, AND DEMOCRACY* 262 (3d ed. 1950).

If participatory policymaking is not to merit such scorn, then those citizens who become involved must be atypically well-informed and willing to grapple with complexities. Either they must possess previously acquired expertise, or the public-involvement program must devote time and resources to educating them, or both. Ideal deliberative processes require people to talk with one another, speaking their own minds and listening to others so that all can understand how fellow citizens think and feel about the issue.<sup>9</sup> As a process of sequential interaction, deliberative discussion inherently demands more time than potentially simultaneous acts of preference-assertion, such as voting; and, as the number of active participants grows, the time needed for all to be heard rises at least proportionately.<sup>10</sup> Consequently, if citizens are to be involved in a satisfactorily deliberative process, then those who participate must be willing to pay substantial costs in time, mental effort, and social interaction.

### B. *The Conflict Between Deliberation and Representativeness*

Other things being equal, the greater the costs of an activity, the smaller the number of people who will engage in it. Applied to political participation, this axiom produces a general rule: The more intensive (or costly) the activity a system asks its members voluntarily to perform, the less extensive their actual participation—i.e., the smaller the proportion who will act.<sup>11</sup> As an intensive form of participation, deliberation will be confined to relatively small numbers. Given the other virtues of deliberation, this prospect would not be troubling if we could count on the few who take part to resemble in policy-relevant characteristics the many who do not. Unfortunately, that hope is usually untenable.

Because the deterrent to intense, deliberative participation is the high cost of such activity, those who take part must either find that cost easier to bear than their inactive fellow citizens or have stronger countervailing incentives to offset it, or both. Whether by design or inadvertence, unequal costs for different citizens are

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<sup>9</sup> See BARBER, *supra* note 7, at 175, 202.

<sup>10</sup> See ROBERT A. DAHL, *AFTER THE REVOLUTION? AUTHORITY IN A GOOD SOCIETY* 68 (1970). See generally Bertrand de Jouvenel, *The Chairman's Problem*, 55 AM. POL. SCI. REV. 368 (1961) (offering an example of how the right of free speech may be limited by time constraints).

<sup>11</sup> See JACK H. NAGEL, *PARTICIPATION* 54 (1987). This section generally draws on chapter five of that book. See *id.* at 53-68.

always built into the logistics of participation programs—for example, the time and place of a meeting may make it harder for some people to attend than for others. The effects of such details on differential costs of participation can be idiosyncratic, but it is possible to make one reliable generalization. Educated, well-informed persons usually have less difficulty participating, because they are more likely to know when and how to participate, they can more easily cope with or even enjoy the cognitive challenges of learning about complex issues, they are more confident about expressing themselves in discussion and debate, and their arguments tend to be more impressive and influential.

If policymaking were always just a matter of finding neutral, technical solutions to common problems, then disproportionate involvement of educated persons would be desirable because of their superior competence. More often, however, policy choices depend on interests and values that are not universally shared. Education is statistically associated with higher income and occupational status, as well as with distinctive cultural tastes. Thus, policy decisions based on intensive, deliberative forms of citizen participation will usually neglect the needs and desires of more plebeian members of the population, unless the process is carefully structured to counteract the normal bias in favor of the well-educated.

Just as education biases participation by reducing costs, atypical inducements and motivational patterns will also spur a fraction of citizens to pay the price of intensive participation. These patterns are of three types: (1) special interests, as when an individual has an unusual financial or other stake in a public decision; (2) “selective incentives,” as when an organization (e.g., an employer) makes individual rewards or punishments contingent on participation;<sup>12</sup> and (3) zealous devotion to a particular policy, which can have any number of causes—ranging from ideological, religious or ethical conviction to mere eccentricity. All these motives will entail distinctive policy positions, and it is exceedingly unlikely that the persons they impel to act will accurately mirror the distribution of preferences among the inactive bulk of the population.

The preceding argument is not meant to deny that some citizens will take part because of a disinterested sense of civic obligation.

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<sup>12</sup> See MANCUR OLSON, *THE LOGIC OF COLLECTIVE ACTION: PUBLIC GOODS AND THE THEORY OF GROUPS* 51 (1971).

But even that seemingly most benign of motives is statistically associated with education (and therefore with social class), with ethnicity, and with a preference for public-regarding, future-oriented, good-government policies and procedures—a taste not equally prevalent among all segments of the population.<sup>13</sup> Thus, on all counts, we can expect voluntary, self-selected participants to be unrepresentative of the citizenry as a whole.

### C. *Should Citizens Advise or Decide?*

A basic issue to determine, preferably in advance, about any citizen-involvement program is whether to give participants binding authority to decide the issues put before them or just to consult them for opinions and advice.<sup>14</sup> Their normal role is advisory, but American governments have often delegated control over public resources to participatory entities. Usually, however, the participants who actually decide are elected from a geographical or functional constituency especially affected by the program in question.<sup>15</sup> The persons thus chosen are no longer ordinary citizen-participants, but instead acquire quasi-official status, power, and responsibility. Confining authority to a relatively small subset of participants promotes better deliberation, and choosing them through elections helps make them representative of, as well as accountable to, the larger population of affected persons.

Deliberation and representation are, of course, virtues that elected legislatures are designed to combine and from which they derive much of their legitimacy. From the standpoint of democratic theory, serious questions should arise whenever elected officials or administrators they appoint delegate binding decisions to ordinary citizens, unless the participatory arrangements are both deliberative

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<sup>13</sup> See EDWARD C. BANFIELD & JAMES Q. WILSON, CITY POLITICS 234-40, 329-46 (1966); James Q. Wilson & Edward C. Banfield, *Political Ethos Revisited*, 65 AM. POL. SCI. REV. 1048, 1048 (1971).

<sup>14</sup> Elsewhere, I characterize four modes of citizen involvement in public administration: advising, deciding, supporting, and doing. See NAGEL, *supra* note 11, at 146. Vroom and Jago emphasize that a crucial choice in participative management is whether subordinates are to be entrusted with making decisions, or merely consulted. See VICTOR H. VROOM & ARTHUR G. JAGO, THE NEW LEADERSHIP: MANAGING PARTICIPATION IN ORGANIZATIONS 33 (1988).

<sup>15</sup> Examples at various times and places have included elected boards of community action programs during the war on poverty, local boards administering federal grazing lands, neighborhood councils disbursing community development block grants, and district school boards under community control programs.

and representative—preferably, superior to the legislature on at least one of these counts, and not markedly inferior on the other.

When citizens are involved in a purely consultative mode, the tests of deliberation and representation may apply less stringently. However, many advisory bodies that lack formal authority nevertheless substantially affect final decisions. The greater the de facto influence of such groups, the more we should be concerned about whether they satisfy both criteria.

#### D. *What Are the Purposes of Participation?*

Thus far I have analyzed citizen participation from a purely normative perspective, but politicians and officials who resort to such devices usually do so for practical reasons. From their standpoint, tests derived from democratic theory are relevant only to the extent they affect the ability of a participatory process to achieve pragmatic goals. Four such purposes, singly or in combination, commonly motivate authorities to involve citizens.

##### 1. Shifting Responsibility

When policy choices are especially divisive, authorities may pass the buck to ordinary citizens. Thus many countries, including Finland, Iceland, Norway, Sweden, and New Zealand, have used referendums to resolve the inflammatory issue of prohibition.<sup>16</sup> In the United States, government agencies have often established grassroots committees to handle hard choices involving the allocation of individual benefits and deprivations; local draft boards were a conspicuous example.

Officials can most plausibly shift the burden of decision by giving citizens binding authority. Although officials may still share responsibility if the status of participants is nominally advisory, the ploy is more successful when citizens' advice is both unequivocal and heeded. In either case, if the criteria of deliberation and representativeness are operative ideals in the political culture, attempts to transfer responsibility may meet with condemnation if the participatory process seems inadequate on either count.

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<sup>16</sup> See REFERENDUMS: A COMPARATIVE STUDY OF PRACTICE AND THEORY 227-37 (David Butler & Austin Ranney eds., 1978).

## 2. Testing the Waters

Citizen participation in the advisory mode often helps officials devise programs that are substantively acceptable to groups that have the power to upset plans, or punish their authors, at later stages—legislative, administrative, or electoral. When citizens are consulted for this purpose, ensuring that participants fairly represent the entire population may seem irrelevant or counterproductive, since the powerless can be neglected with impunity. Such a cavalier attitude toward involving the weak often backfires, however. Political power is neither static nor easily predictable, and seemingly powerless groups may acquire unexpected strength, especially when the decision moves to a different arena or new forces enter the struggle.<sup>17</sup>

## 3. Achieving Consensus

The idea that participation properly understood offers the best way to both build unified judgment and reach amicable agreement is a recurring theme in the theory and practice of participatory democracy and participatory management. Although this faith is especially common (and more often justified) at the small-group level,<sup>18</sup> some enthusiasts extrapolate consensus as a goal and expectation to larger polities.<sup>19</sup> Regardless of scale, participationists recognize deliberation as the key to consensus, which they believe emerges only after people fully understand the logic of the situation, interact empathetically, and engage in protracted discussion. On the other hand, participationists are inclined to give short shrift to representation. Because many subscribe to the unitary assumption that all interests are ultimately compatible, they tend to see public decisions as a problem-solving process in which everyone should eventually arrive at the same answers. Superior competence and special knowledge therefore matter more than political equality in deciding who should participate.<sup>20</sup>

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<sup>17</sup> See E.E. SCHATTSCHNEIDER, *THE SEMISOVEREIGN PEOPLE* (1960).

<sup>18</sup> See JANE J. MANSBRIDGE, *BEYOND ADVERSARY DEMOCRACY* 278-89 (1980); SIDNEY VERBA, *SMALL GROUPS AND POLITICAL BEHAVIOR: A STUDY OF LEADERSHIP* 222-25 (1961).

<sup>19</sup> For example, although Benjamin Barber accepts the centrality of conflict in the political process, he advocates "a politics that can transform conflict into cooperation through citizen participation, public deliberation, and civic education." BARBER, *supra* note 7, at 135.

<sup>20</sup> This logic is best explicated (but not unconditionally endorsed) by Mansbridge.



#### 4. Legitimation

A long tradition of small-group research and practical action supports the "participation hypothesis"—the generalization that people are more likely to accept change if the persons who are expected to change take part in deciding what the change will be and how it will be made.<sup>21</sup> The preceding three purposes, if achieved, certainly facilitate acceptance, but participatory processes per se have a legitimizing effect, even when they are advisory or fall short of achieving substantive consensus. In large polities, a parallel notion exists in the belief that elections establish consent, both as constitutional fiction and as sociological reality.<sup>22</sup> In an age when so many people distrust politicians, officials seeking extra legitimacy for policies turn to citizen participation. Whether or not their hopes will be realized depends on the perceived quality and fairness of the process—especially whether all affected groups can be persuaded that "people like us" had a fair hearing.

All four of the goals listed in this section appear to have motivated the architects of Oregon's health care reform to enlist citizens in the prioritization process. Although the planners achieved a measure of success, difficulties in combining deliberation and representation prevented them from fulfilling their hopes.

## II. THE OREGON EXPERIMENT AND ITS PROBLEMS

The Oregon Basic Health Care Act assigns the biennial task of developing prioritized lists of treatments to an eleven-member Health Services Commission (HSC), appointed by the Governor and confirmed by the Senate; by law, seven of the Commissioners must be health professionals. The legislature forbids itself from altering HSC reports but retains responsibility for deciding how much, if

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See MANSBRIDGE, *supra* note 18, at 233-51. Sophisticated participationists often emphasize that true consensus depends on hearing all points of view. Barber explicitly repudiates the unitary assumption, yet he emphasizes quality of participation over equality. See BENJAMIN R. BARBER, *THE DEATH OF COMMUNAL LIBERTY: A HISTORY OF FREEDOM IN A SWISS MOUNTAIN CANTON* 5, 273 (1974). I weight values differently. See NAGEL, *supra* note 11, at 66 ("[E]galitarian democrats must assign ultimate legitimacy to those methods that encourage the most extensive participation").

<sup>21</sup> This is a paraphrase of Herbert Simon's original formulation. See VERBA, *supra* note 18, at 206.

<sup>22</sup> On the effect of elections in expanding the capacity of governments to win compliance, see BENJAMIN GINSBERG, *THE CONSEQUENCES OF CONSENT: ELECTIONS, CITIZEN CONTROL AND POPULAR ACQUIESCENCE* 181-85 (1982).

anything, to appropriate in order to implement the HSC's recommendations.<sup>23</sup> In other words, the legislature can either reject the report in toto or accept it and decide where on the treatment list to draw the line.

Before preparing the list, the HSC is compelled by the Act to conduct public hearings, which are a standard requirement in such situations. Both the legislature and the HSC appear to have regarded the hearings as a predictable opportunity for special-interest groups, which the state takes the trouble to enumerate: "advocates for seniors; handicapped persons; mental health services consumers; low-income Oregonians; and providers of health care, including but not limited to physicians licensed to practice medicine, dentists, oral surgeons, chiropractors, naturopaths, hospitals, clinics, pharmacists, nurses and allied health professionals."<sup>24</sup> The HSC dutifully held twelve hearings. Although 1500 people attended and hundreds testified, the Commissioners appear not to have been impressed by this routine form of citizen participation. Their otherwise voluminous report devotes only two perfunctory pages to the hearings. One tabulates testimony by topic and city; the other offers the sketchiest of accounts and this conclusion:

Testimony generally was not useful in measuring treatment effectiveness objectively but was useful for understanding the general tone of public needs and concerns. The message was delivered that dental, preventive and mental health care and chemical dependency services should be a part of the health services available.<sup>25</sup>

As does everyone else interested in the Oregon reform, the Commission devotes far more attention to the two more novel components of its public participation program, community meetings and a telephone survey.

#### A. *Community Meetings and the Problem of Representation*

Like the hearings, these sessions were mandated by the Act, though in much more positive and hopeful language: "[T]he Commission shall actively solicit public involvement in a community meeting process to build a consensus on the values to be used to

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<sup>23</sup> See OR. REV. STAT. § 414.720 (Supp. 1990).

<sup>24</sup> *Id.* § 414.720(1).

<sup>25</sup> OREGON HEALTH SERVS. COMM'N, THE 1991 PRIORITIZATION OF HEALTH SERVICES app. E at 1 (1991) [hereinafter OHSC, PRIORITIZATION].

guide health resource allocation decisions.”<sup>26</sup> To organize the community meetings, the HSC engaged Oregon Health Decisions (OHD), a nonprofit organization that serves as a model for the nationwide community health decisions movement. Founded in 1982, OHD attracted 5000 participants to 300 meetings during 1983 and 1984, culminating in a Citizens Health Care Parliament in October of 1984.<sup>27</sup> OHD’s efforts undoubtedly had a significant influence on the Oregon Basic Health Care Act, including the provision for community meetings.

In early 1990, OHD organized forty-seven meetings ranging in size from three to 120 persons, with a total attendance of 1048 citizens.<sup>28</sup> Each meeting lasted at least two hours and followed a standard format. The first half hour was devoted to an informative briefing, including a slide show. For the next hour, participants were divided (if necessary) into discussion groups of six to ten members. Led by trained volunteer facilitators, the groups warmed up by discussing eight prototypical cases of individuals in need of health services. They were then asked collectively to classify nine sample health care categories into three priority groups—essential, very important, and important.<sup>29</sup> In the last half hour, the small groups reported their judgments to a plenary gathering. OHD compiled facilitators’ reports of the frequency with which various values were discussed in this last stage of the forty-seven meetings in order to derive a ranking of thirteen values “Oregonians want the Health Services Commission to use in guiding the process of prioritizing health care services.”<sup>30</sup> Prevention and quality of life topped the list; length of life and personal responsibility (for health problems) were at the bottom.<sup>31</sup>

The HSC originally had hoped to ask attendees at community meetings to fill out a survey that would yield quantifiable data about health values and service preferences. OHD recommended instead that the two-hour meetings be reserved for the interactive “consen-

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<sup>26</sup> OR. REV. STAT. § 414.720(2) (Supp. 1990).

<sup>27</sup> See Hines, *supra* note 6, at 5.

<sup>28</sup> See OREGON HEALTH DECISIONS, HEALTH CARE IN COMMON: REPORT OF THE OREGON HEALTH DECISIONS COMMUNITY MEETINGS PROCESS (1990), in OHSC, PRIORITIZATION, *supra* note 25, app. F at 5.

<sup>29</sup> Categories included: “Treatment of conditions which are fatal and can’t be cured;” “Treatment for alcoholism or drug addiction;” and “Preventive care which definitely can prevent early death or a reduction in quality of life.” *Id.* app. A.

<sup>30</sup> *Id.* at 5.

<sup>31</sup> *Id.* at 5-6.

sus building" process.<sup>32</sup> The decision not to use the community meetings as a source of more definite and therefore possibly binding data was fortunate, because, as both OHD and the HSC frankly disclose, the community meetings failed to attract anything like a representative sample, either of Oregonians in general or of people most affected by the Medicaid reform.

As might have been predicted from the general analysis of intensive participation sketched in the preceding section, most participants at these "grassroots" meetings were well-educated and occupationally involved with health care. Two-thirds were college graduates, and another 22% had some college education.<sup>33</sup> No fewer than 69.2% were mental health and health care workers.<sup>34</sup> Over a third (34%) had incomes of \$50,000 or more, whereas only about 8% of participants were below the federal poverty level, compared with 11% of Oregon's population.<sup>35</sup> Potential beneficiaries of the reform—the uninsured—numbered just 9.4%, and current Medicaid recipients were only 4.4%; all other participants had medical insurance.<sup>36</sup>

### B. *The Telephone Survey and the Problem of Deliberation*

The HSC evidently recognized the drawbacks of the unrepresentative turnout at the community meetings. They also continued to hope that public participation could yield more definitive data that would relieve them of the responsibility for making value decisions—a prudent tack, as the predominance of health professionals on the Commission otherwise made it politically vulnerable to charges of favoring providers. Acting now on their own initiative rather than in accordance with statutory instructions, the HSC commissioned a telephone survey.

Contacted through random-digit dialing, 1001 Oregonians responded to a seventy-seven-item questionnaire. The key section

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<sup>32</sup> See OHSC, PRIORITIZATION, *supra* note 25, at 9.

<sup>33</sup> See OREGON HEALTH DECISIONS, *supra* note 28, at 30.

<sup>34</sup> See *id.* at 29. Persons working in the mental health and chemical dependency (MHCD) fields turned out in force, probably because they wanted the plan to cover their services. The Commission responded by recommending that the legislature include MHCD representatives on the Commission in the future and integrate MHCD services into the prioritized list for 1993-95. For a lengthy supplement to the HSC report suggesting how this might be done, see OHSC, PRIORITIZATION, *supra* note 25, at app. H.

<sup>35</sup> See OHSC, PRIORITIZATION, *supra* note 25, app. C at 3.

<sup>36</sup> See OREGON HEALTH DECISIONS, *supra* note 28, at 29-30.

of the survey consisted of thirty-one hypothetical health outcomes, which respondents were asked to rate on a Quality of Well Being (QWB) scale from 0 ("as bad as death") to 100 ("the situation describes good health"). Each outcome represented a different combination of twenty-three symptoms and six categories of functional impairment.<sup>37</sup> By assuming that the overall scores for outcomes were an additive function of underlying values for symptoms and impairments, the Commission calculated "weighting factors" for each symptom and impairment category. The relevant weights were then added together to obtain QWB scores for health outcomes represented as combinations of symptoms and impairments.<sup>38</sup>

In its first attempt to develop a prioritized list of condition-treatment (CT) pairs (which at that point numbered nearly 2000), the HSC used a mathematical cost-benefit formula in which QWB scores derived from the survey defined the degree of benefit associated with treatment outcomes.<sup>39</sup> This ingenious attempt to incorporate "public values" into a technocratic algorithm failed. Because numerous rankings defied common sense, the "[d]eeply embarrassed" Commission "hastily withdrew" the computer-generated list.<sup>40</sup> "I looked at the first two pages of that list and threw it in the trash can," said one member.<sup>41</sup>

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<sup>37</sup> For example, item D involved functional and physical impairment but no symptoms: "You can be taken anywhere, but have to be in bed or in a wheelchair controlled by someone else, need help to eat or go the bathroom, but have no other health problems." OHSC, PRIORITIZATION, *supra* note 25, app. C at 14. By contrast, item M combined a severe symptom with the absence of functional, physical, or social impairments: "You can go anywhere and have no limitations on physical or other activity, but have a bad burn over large areas of your body." *Id.* at 15. Apparently, the survey designers were untroubled by the improbability of the latter combination. We have no way of knowing whether respondents were similarly willing to suspend disbelief.

<sup>38</sup> For example, the QWB score for a heart attack victim who survives but continues to experience frequent chest pain is 0.747, which is the sum of 1.0 (return to former state of health) plus -0.253 (the weight for chest pain). *See id.* app. D at 4; *see also id.* app. C at 5 (describing the general QWB methodology).

<sup>39</sup> Another key input to the cost-benefit analysis came from panels of physicians, who supplied probabilities of outcomes conditional on treatments. *See id.* app. D at 17-18.

<sup>40</sup> Virginia Morell, *Oregon Puts Bold Health Plan on Ice*, 249 SCI. 468, 468 (1990).

<sup>41</sup> *See id.* (quoting Harvey Klevit). Oft-cited examples of perverse priorities include treatments for thumb-sucking and acute headaches outranking those for cystic fibrosis, viral pneumonia, and AIDS. *See id.*; Timothy Egan, *Oregon Shakes Up Pioneering Health Plan for the Poor*, N.Y. TIMES, Feb. 22, 1991, at A12; Bruce C. Vladeck, *Unhealthy Rations*, THE AM. PROSPECT, Summer 1991, at 101, 102.

Although explanations for these unacceptable results emphasize faulty cost data, QWB weights derived from the survey also provide a shaky foundation for such an important decision. As the HSC report notes, the Oregon results for three impairment states and two symptoms differ substantially from those previously obtained elsewhere by researchers who used interviews rather than telephone surveys.<sup>42</sup> The Quality-of-Well-Being questionnaire is difficult enough to answer at one's leisure using pencil and paper, with the ability to compare and revise answers. It is hard to imagine that citizens having no advance preparation can maintain consistent, well-considered responses when they attempt to scale thirty-one complicated items presented sequentially over the telephone. Thus, even if there were no conceptual objections to the QWB and cost-benefit methodologies, the survey data would have been questionable because respondents had insufficient opportunity to deliberate.

Having failed in its attempt to shift responsibility for value judgments to this novel mechanism for making citizen-participants decisive, the Commissioners fell back on a mixed process in which their own judgment played a significant role. After consolidating the CT pairs down to 709, they devised and ranked seventeen categories of health services, an approach that, in the Commission's words, allowed the HSC "to take into account the full range of values expressed at community meetings and public hearings."<sup>43</sup> The category rankings do reflect the values most often expressed at community meetings: prevention and quality of life. Five of the top nine categories were for various preventive services, and the lowest priorities went to conditions for which available treatments offer minimal or no improvements in quality of life.<sup>44</sup>

After sorting CT pairs into categories, the HSC applied its "net-benefit" formula to rank pairs within categories.<sup>45</sup> Here, as one component of the net-benefit analysis, QWB weights from the telephone survey came into play again, but only as part of the second criterion of a lexicographic ordering in which categorization came first.<sup>46</sup> Even this modest influence was substantially diluted

<sup>42</sup> See OHSC, PRIORITIZATION, *supra* note 25, app. C at 11. The QWB technique was based on the work of Dr. Robert M. Kaplan and his collaborators. See *id.*

<sup>43</sup> *Id.* at 15.

<sup>44</sup> See *id.* at 18-19.

<sup>45</sup> See *id.* app. D at 23-24. The HSC calls its version of cost benefit a "net benefit value" because it omits economic (but not QWB) costs associated with failure to treat, though it does include economic costs of treatment. See *id.* at 2.

<sup>46</sup> See *id.* app. D at 26-27.

in the final stage of prioritization, when the HSC conducted a line-by-line review. Applying their own judgments of "reasonableness,"<sup>47</sup> the Commissioners moved 40% of the CT pairs up or down at least fifty places.<sup>48</sup> According to a review by the Congressional Office of Technology Assessment (OTA), the two most important determinants of where CT pairs finally ended up were the categories to which they were assigned and the Commissioners' judgments in the final review, which "overshadowed the initial net-benefit-based rankings" within categories.<sup>49</sup>

### C. *Political Effects of Oregon's Participation Process*

By normal political standards, Oregon's prioritization program was a success. The HSC's second list was widely viewed as reasonable; even severe critics of the program found it an improvement over the first attempt.<sup>50</sup> The state legislature accepted the Commission's report and appropriated an extra \$33 million for Medicaid so that 85% of treatments on the list could be covered.<sup>51</sup> Within the state and before Congress, the reform won backing from an impressively broad and diverse coalition, including the Associated Oregon Industries, the Oregon AFL-CIO, the Oregon Association of Hospitals, the Oregon Medical Association, and the state's entire congressional delegation.<sup>52</sup>

Nevertheless, the political consequences of the program fell short of the more ambitious objectives of its architects. Despite its attempt at an inclusive consensus, the process failed to satisfy all potential opponents. Although critics had a weak base within Oregon, they had powerful champions in Washington, with the result that the fate of Oregon's waiver application remains uncertain.

Instead of universally legitimating the program, the defects of the participation process provided opponents with openings that they exploited vigorously. One commentator called "[t]he Oregon proposal . . . an experiment, applying . . . the opinions of eleven Commission members . . . [to] life-and-death decisions for hundreds

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<sup>47</sup> See *id.* app. D at 28.

<sup>48</sup> See *Hearings*, *supra* note 1, at 177.

<sup>49</sup> See *id.* at 175-76 (testimony of Clyde J. Behney, Health Program Manager, OTA).

<sup>50</sup> See *id.* at 38 (statement of Families USA).

<sup>51</sup> See *id.* at 74 (statement of Oregon Governor Barbara Roberts).

<sup>52</sup> See *id.*

of thousands of poor Oregonians."<sup>53</sup> A representative of the Oregon Human Rights Coalition noted that her group has "very little confidence in the fairness of a list which was based ultimately on the personal experiences and judgment of the 11 members of the Oregon Health Services Commission."<sup>54</sup> The HSC, critics alleged, is "dominated by health professionals"<sup>55</sup> who would deprive "non-consenting poor women and children" of "medically necessary care and services"<sup>56</sup> in "a scheme that preys on [their] limited political clout."<sup>57</sup> Children's rights advocates argued that "[t]o ask 1,000 healthy upper middle class people with no risk to their benefits what they'd take away and when they'd pull the plug is silly. And how many poor children were at those meetings?"<sup>58</sup> In short, Oregon imposed "a line drawn by us for them."<sup>59</sup>

The legislature, the Commission, and their advisors had awkwardly straddled the basic participatory dilemma. One part of their program was deliberative but not representative; the other was representative but not deliberative; and the two combined to influence the final list in a way that, although mysterious, was obviously not decisively authoritative.

### III. SUGGESTIONS TO IMPROVE COMMUNITY DECISIONS PROGRAMS

If the community health decisions movement and similar citizen-participation projects are to achieve the elusive combination of deliberation and fair representation, they must accept two guiding principles.

First, whenever the goal is to determine "the values of the people," and especially when those values are to play a decisive or strongly influential role in public policy, *participants must be systematically chosen to meet representational goals*. Voluntary, self-selected participants will invariably overrepresent better-educated, higher-status members of society and groups with special interests

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<sup>53</sup> *Id.* at 49 (letter of Bishop James W. Malone, Chairman, Domestic Policy Committee, U.S. Catholic Conference).

<sup>54</sup> *Id.* at 110 (statement of Anita Hendrix, Oregon Human Rights Coalition).

<sup>55</sup> Vladeck, *supra* note 41, at 101.

<sup>56</sup> *Hearings, supra* note 1, at 49 (letter of Bishop James W. Malone).

<sup>57</sup> *Id.* at 56 (statement of Senator Albert Gore, Jr.).

<sup>58</sup> Lawrence D. Brown, *The National Politics of Oregon's Rationing Plan*, HEALTH AFF., Summer 1991, at 28, 40 (quoting Sara Rosenbaum of the Children's Defense Fund).

<sup>59</sup> Charles J. Dougherty, *Setting Health Care Priorities: Oregon's Next Steps*, HASTINGS CENTER REP., Supp. May-June 1991, at 5, 5 (summarizing arguments of opponents).



in the policy at stake. This is not to say that such persons should be denied the opportunity to express views. Public hearings and other open forums remain essential, both so people will not feel excluded and so officials can realistically assess political forces. But if any part of the citizen-participation process is to have binding authority or special influence—as the Oregon community forums and telephone survey did—then those participants must be selected using a well-structured, consciously designed framework.

Second, to ensure that the persons thus selected will consent to take part in an intensive, deliberative process, *participants must be compensated for their time, earnings foregone, and other costs*. Techniques for selecting representative samples have been highly developed in survey research, but respondents in ordinary polls are uncompensated volunteers. Too much cannot be asked of them, or else the response rate falls and answers obtained are of questionable quality, as in the Oregon telephone survey. If persons invited to take part in an important, interesting process are also protected against material losses and (if necessary) given modest incentives, then it should be possible to induce reasonably representative samples to engage in satisfactorily deliberative efforts.

As examples of how representation and deliberation might be combined, I sketch below two possibilities. Neither is original. My modest purpose is only to help disseminate good ideas in a context where they might be helpful.

#### A. Focus Groups to Represent Specially Affected Groups

Focus groups are carefully selected small groups that meet face-to-face under the guidance of a trained moderator.<sup>60</sup> Their small size (usually eight to twelve members) and extended meeting times (up to two hours or more) enable them to engage in genuine discussion.<sup>61</sup> Participants are normally compensated up to \$75 per session and often receive help with travel and babysitting.<sup>62</sup> Originally derived from the “focussed interview” technique developed during World War II by the renowned sociologist Robert

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<sup>60</sup> See generally DAVID W. STEWART & PREM N. SHAMDASANI, FOCUS GROUPS: THEORY AND PRACTICE (1990) (supplying a good, clear introduction to focus groups); R.E. Petersen, Consumer Participation in Health Care Decision Making in Oregon: Evolution, The Current Situation and Ideas for the Next Step (January 1992) (unpublished manuscript, on file with the author).

<sup>61</sup> See STEWART & SHAMDASANI, *supra* note 60, at 17.

<sup>62</sup> See Petersen, *supra* note 60, at 13-14.

K. Merton, focus groups have become a standard, widely used method in marketing and political research.<sup>63</sup>

Because they are too small to constitute an adequate sample of a diverse population, focus groups are used mainly to generate qualitative insights that can then be tested with larger samples using less intensive, more quantifiable techniques. If, however, the problem is well-defined and the groups are drawn from a relatively homogeneous population of interest, focus groups alone may suffice to test a proposition.<sup>64</sup>

How might focus groups function in future versions of the Oregon prioritization process? Discussion in such groups is less inhibited when participants have similar socioeconomic status, and research shows that lower-status persons have less influence in mixed-status groups.<sup>65</sup> Therefore, focus groups would have greatest value in exploring the desires of specially affected, lower-status groups. The two obvious categories from which separate focus groups could be drawn are current Medicaid recipients who are putative losers in the reform and the uninsured who stand to gain coverage. Oregon State Senator John Kitzhaber, chief sponsor of the Oregon plan, described the latter group as "[t]he people who really don't have a voice in this issue" because they neither participate nor have strong advocates.<sup>66</sup> Appropriate focus groups could help give them the voice they lack.

Such groups might be convened at three stages in the process. First, at the very beginning, they could be probed to learn if affected groups have distinctive values or special concerns that might be taken into account by program planners, providers, and forums representing the general public. Second, if scales such as ranked health-service categories or QWB weights are derived from broader samples, focus groups representing specially affected populations might be asked the same questions to test whether their values are indeed similar.<sup>67</sup> Finally, once a prioritized list is

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<sup>63</sup> See *id.* at 9-10. On the history of focus groups, see generally Robert K. Merton, *The Focused Interview and Focus Groups: Continuities and Discontinuities*, 51 PUB. OPINION Q. 550 (1987).

<sup>64</sup> See STEWART & SHAMDASANI, *supra* note 60, at 17.

<sup>65</sup> See *id.* at 38, 45.

<sup>66</sup> Julie Kosterlitz, *Rationing Health Care*, 22 NAT'L J. 1590, 1592 (1990).

<sup>67</sup> While noting that the small number of low-income participants was "perhaps our chief concern," OHD President Richard H. Grant emphasized that meetings that were attended by larger numbers of poor people showed "no striking differences in values discussed." *Hearings, supra* note 1, at 150. On a county basis, however, the percentage of Medicaid recipients attending meetings never exceeded 14.3% and the

complete, the affected groups might be asked their reactions to the proposed reform as it affects them.

This last possibility is especially intriguing. As Stewart and Shamdasani point out, one good use of focus groups is to test whether program planners are right in believing they know what their clients want or should need.<sup>68</sup> The debate over the Oregon waiver application contains much fruitless argument over whether Medicaid recipients are really helped or hurt by the reform. The plan deprives them of treatment for numerous conditions ranging from myasthenia gravis to varicose veins, with the possibility that coverage will contract still further in the future; on the other hand, the plan provides valuable new benefits—including expanded hospitalization, preventive services for adults, dental services, mammograms, and hospice care—plus perhaps most significantly, the security of continued basic coverage if their incomes rise or their children pass the age of dependency.<sup>69</sup> As ethicist Leonard Fleck observes, “the most powerful moral consideration that could be used to justify” the Oregon program would be provided if the poor themselves autonomously chose the reform over the status quo.<sup>70</sup> Yet apparently no one thought to pose this question to them. Focus groups of recipients could provide an ideal vehicle for doing so, and if used in this way they might even resolve the strongest objections to Oregon’s waiver request.

B. *DARBs: Establishing Deliberative Assemblies  
on a Random Basis*

Because of their small numbers, focus groups can never reliably represent a large diverse population. For this purpose, we need new hybrid devices that simultaneously offer representation and deliberation—a merger, in effect, of the HSC’s telephone survey and community forums. In recent years, political theorists have advanced several proposals designed to achieve such a synthesis. Because the particular labels and details of these proposals vary, I

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largest turnout of uninsured persons was just 50%. See OREGON HEALTH DECISIONS, *supra* note 28, at 28-29. Given the usual dynamics of mixed-status groups, we cannot be confident that distinctive concerns of poorer people were sufficiently heard.

<sup>68</sup> See STEWART & SHAMDASANI, *supra* note 60, at 103.

<sup>69</sup> See *Hearings*, *supra* note 1, at 73 (statement of Governor Barbara Roberts); *id.* at 135-36 (testimony of Representative Ron Wyden); *id.* at 179 (testimony of Clyde J. Behney).

<sup>70</sup> See *id.* at 242 (letter from Leonard M. Fleck to Henry A. Waxman and Ronald Wyden (Sept. 11, 1991)).

propose the generic acronym DARB for "deliberative assembly on a random basis."<sup>71</sup>

One of the earliest DARB plans is Robert Dahl's "minipopulus," a paid advisory panel of about 1000 citizens chosen by the same means as public opinion polls. With the help of a scientific advisory board and an administrative staff, members of the minipopulus would study difficult technical policies, such as the control of nuclear weapons, for as long as a year.<sup>72</sup> They would stay in their home communities but would be connected through telecommunications and perhaps occasional assemblies. Although the minipopulus would not have binding authority, its purpose would be to advise the legislature by "reflect[ing] public opinion at a higher level of competence."<sup>73</sup>

Recently, James Fishkin proposed that a DARB of briefer duration be employed to influence Presidential nomination contests. His "deliberative opinion poll" would consist of about 600 citizens, chosen by standard sampling methods and offered sufficient compensation to gather for a long weekend in a single site. There, acting as "a national caucus" or a sort of "giant focus group," they would interact with Presidential candidates through forums, discussion, debates, and informal gatherings. At the end of three days, members of the deliberative poll would express their opinions about issues and candidates. Although unofficial, Fishkin hopes these results would influence opinion leaders, politicians, and the general public as the expression of "a microcosm of the entire nation [given] the opportunities for thoughtful interaction and opinion formation that are normally restricted to small-group democracy."<sup>74</sup>

Applied to the Oregon prioritization problem, the DARB concept need not entail so great a commitment of time as Fishkin's proposal, let alone Dahl's. If two hours were the minimum time for community forums, a half day or at most one full day should suffice

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<sup>71</sup> By a fortunate coincidence, "darb" is Canadian slang for "something considered especially excellent or outstanding." THE AMERICAN HERITAGE DICTIONARY OF THE ENGLISH LANGUAGE 335 (William Morris ed., 1970).

<sup>72</sup> ROBERT A. DAHL, CONTROLLING NUCLEAR WEAPONS: DEMOCRACY VERSUS GUARDIANSHIP 88 (1985).

<sup>73</sup> *Id.* at 88. Dahl first introduced the idea in AFTER THE REVOLUTION? AUTHORITY IN A GOOD SOCIETY, *supra* note 10, at 149; *see also* ROBERT A. DAHL, DEMOCRACY AND ITS CRITICS 340 (1989).

<sup>74</sup> JAMES S. FISHKIN, DEMOCRACY AND DELIBERATION: NEW DIRECTIONS FOR DEMOCRATIC REFORM 4 (1991).

for a well-planned DARB designed to do the work of both the forums and the telephone survey. The monetary and organizational costs of a DARB would be substantial, but possibly quite comparable to what the HSC expended on 47 forums and a statewide poll. In any case, the end products of the DARB would be far more valuable. A QWB questionnaire administered to well-briefed, unhurried DARB participants would be less likely to yield questionable data, and "community values" derived from their discussions could not be depicted as the wishes of an unrepresentative elite. The skills already learned by the Oregon Health Services Commission, Oregon Health Decisions, and other groups in the community health decisions movement could easily be applied within the framework of a DARB. Let us hope that these organizations adopt the concept, so that the next time citizens are enlisted to influence difficult issues of health policy, the process will be both deliberative and fairly representative of the entire community.

