

# Journal of Contemporary Health Law & Policy (1985-2015)

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Volume 10 | Issue 1

Article 27

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1994

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### Recommended Citation

Catherine G. Vachiere, *Stalled on the Road to Health Care Reform: An Analysis of the Initial Impediments to the Oregon Demonstration Project*, 10 J. Contemp. Health L. & Pol'y 405 (1994).

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## STALLED ON THE ROAD TO HEALTH CARE REFORM: AN ANALYSIS OF THE INITIAL IMPEDIMENTS TO THE OREGON DEMONSTRATION PROJECT

We are engaged in a great struggle to reform the American health care system, a system addicted to increasing costs and decreasing equity. The first tactic of someone suffering from addictive behavior is two-fold: to try to remove the bad habit with the least possible disruption to the ordinary way of life, and to try to change the undesirable behavior in a painless, incremental way. This tactic rarely works, as any reformed smoker or alcoholic can testify. The price of real change is harsher self-examination and the revision of basic values and habits.<sup>1</sup>

In his article explicating the merit and necessity of health care rationing,<sup>2</sup> philosopher Daniel Callahan argues that the time has come for the American health care system to engage in harsh self-examination, and to move forward toward true reform.<sup>3</sup> In Callahan's view, the problem underlying the American addiction to health care is the extraordinary amount of money spent without receiving commensurate value for the investment or increased equity in terms of access to care.<sup>4</sup>

Equity, efficiency, and consensus on health care priorities are the three elements that must be combined in order to attain "an economically sound health care system."<sup>5</sup> The difficulty in achieving meaningful re-

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1. Daniel Callahan, *Rationing Medical Progress - The Way to Affordable Health Care*, 322 NEW ENG. J. MED. 1810, 1810-11 (1990).

2. See, e.g., Daniel Callahan, *Symbols, Rationality, and Justice: Rationing Health Care*, 18 AM. J.L. & MED. 1 (1992); see also Richard D. Lamm, *Rationing of Health Care: Inevitable and Desirable*, 140 U. PA. L. REV. 1511 (1992); Paul T. Menzel, *Some Ethical Costs of Rationing*, LAW, MED. & HEALTH CARE, Spring-Summer 1992, at 57; Harry Schwartz, *We Need to Ration Medicine*, NEWSWEEK, Feb. 8, 1982, at 13.

3. Callahan, *supra* note 1, at 1811.

4. *Id.*

5. *Id.* Equity is understood as "access for all to a base level of health care." Efficiency is understood as "a means of limiting the use of procedures that are ineffective or marginally effective as well as some of the procedures that are effective but too expensive." Lastly, consensus on health care priorities encompasses both individual and social priorities. *Id.*

form<sup>6</sup> stems from the deeply ingrained values that characterize the present system: autonomy and freedom of choice, the idea of limitless medical progress, and the quest for increasing levels of quality in health care.<sup>7</sup> Both an effective "cost-containment movement and a shift in fundamental values" are needed to solve the American health care crisis.<sup>8</sup>

The State of Oregon attempted such a shift in values and cost-containment strategies. Faced with 400,000 citizens who did not have health insurance and lack of significant corrective action at the federal level,<sup>9</sup> Oregon enacted a comprehensive legislative package designed to ensure that all of its residents had access to health care.<sup>10</sup> With a shift in emphasis "from who is covered to what is covered,"<sup>11</sup> the Oregon experiment brought an array of issues to the forefront of the health care debate. These issues range from questions of social equity to medical ethics to states' rights.<sup>12</sup>

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6. Presumably, meaningful reform entails the incorporation of Callahan's three elements into the health care system.

7. Callahan, *supra* note 1, at 1811. Elsewhere, Callahan refers to the idea of limitless medical progress as the "moral logic of medical progress." Daniel Callahan, *Transforming Mortality: Technology and the Allocation of Resources*, 65 S. CAL. L. REV. 205, 207 (1991). Callahan identifies three historical steps which have transformed our basic thinking: (1) "the transformation of medicine from a caring but therapeutically ineffective calling to a scientific discipline centered on cure;" (2) "the transformation of the idea and scope of 'health;" and (3) the transformation of "our images and visions of what it means to live a life." *Id.* at 205-06. Embedded in these historical changes is the "moral logic" of medical progress: "what can be known, ought to be known, and what can be done, morally ought to be done." *Id.* at 207. In other words, medical progress, "in the initial sense of scientific possibility, becomes a moral imperative." *Id.*

8. Callahan, *supra* note 1, at 1812.

9. See Mark Moran, *Oregon Plan Forces Hard Choices, But Praised for Fairness*, *MH Coverage*, *PSYCHIATRIC NEWS*, May 3, 1991, at 15; see also Marian Freedman, *Stating the Case for Health Care Reform*, *BEST'S REV.*, April 1992, at 36, 37 (noting that in the absence of progress at the federal level "[v]irtually every state either has taken action on the problem or is considering legislation"); Daniel S. Greenberg, *State Action on Health Care Reform*, 339 *LANCET* 1101 (1992) (noting that "[w]ith Washington immobilised on the subject, several state governments are attempting their own solutions to the problems of access and cost control in health care services"); John E. McDonough, *States First: The Other Path to National Health Reform*, *AM. PROSPECT*, Spring 1992, at 61 (noting that states play a critical role in health care reform); Richard Soriano, *Stepping Up to Bat: States Take the Lead on Health Policy*, *J. AM. HEALTH POL'Y*, May/June 1992, at 14a (noting that while the federal government is "paralyzed" by election year politics and congressional corruption, the states bear the burden of health care reform).

10. See Julie Kosterlitz, *Oregon Wants a Little Medicaid Slack*, 12 *NAT'L J.* 2766 (1989).

11. John Kitzhaber, Presentation to the Conference on Health Care: The Oregon Solution 1, 6 (Aug. 9, 1991) [hereinafter Kitzhaber Presentation] (transcript on file with the *Journal of Contemporary Health Law & Policy*).

12. Kosterlitz, *supra* note 10, at 2766.

On August 3, 1992, Secretary of Health and Human Services Louis W. Sullivan denied the federal waiver necessary for full implementation of the Oregon Demonstration Project.<sup>13</sup> Citing potential legal conflicts with the Americans With Disabilities Act, Sullivan denied final approval and urged Oregon to submit a revised application addressing the legal concerns.<sup>14</sup> Oregon thereafter continued its dialogue with the Health Care Financing Administration,<sup>15</sup> and revised the Demonstration Project. While the revised project has now been approved by the Clinton Administration, this Comment examines the initial proposal and its rejection.

Putting aside questions of *whether* to ration,<sup>16</sup> this Comment focuses on the Oregon experience as a means of exploring *how* to ration health care. Part I lays out the Oregon plan in detail, exploring the social and political context from which the plan originated, the Medicaid system in Oregon, and the nuts and bolts of the Oregon Basic Health Services Act. Part II discusses the reasoning behind the denial of the federal waiver, paying particular attention to the Office of Technology Assessment's legal review of the Oregon project. Part III responds to and comments on the waiver denial. This Comment provides an in-depth examination and critique of one process utilized to ration health care at the state level.

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13. Letter from Louis W. Sullivan, M.D., Secretary of the United States Department of Health and Human Services, to the Honorable Barbara Roberts, Governor of Oregon (Aug. 3, 1992) [hereinafter Sullivan Letter] (on file with the *Journal of Contemporary Health Law & Policy*).

14. *Id.*

15. See Minutes of a Meeting of the Subcomm. on the Blind and Disabled, Oregon Health Services Commission (Aug. 26, 1992) [hereinafter Subcommittee Minutes] (on file with the *Journal of Contemporary Health Law & Policy*); Minutes of a Meeting of the Oregon Health Services Commission (Aug. 26, 1992) [hereinafter Commission Minutes] (on file with the *Journal of Contemporary Health Law & Policy*); Letter from Paige R. Sipes-Metzler, DPA, Executive Director of Oregon Health Services Commission, to Darrel J. Grinstead, Chief Counsel of the Health Care Financing Administration (Sept. 10, 1992) (on file with the *Journal of Contemporary Health Law & Policy*); Letter from Darrel J. Grinstead, Chief Counsel of the Health Care Financing Authority, to Paige R. Sipes-Metzler, DPA, Executive Director of Oregon Health Services Commission (Sept. 22, 1992) (on file with the *Journal of Contemporary Health Law & Policy*).

16. The author notes that there are many compelling arguments against rationing as an acceptable or necessary means of responding to the health care crisis. See, e.g., Joseph A. Califano, Jr., *Rationing Health Care: The Unnecessary Solution*, 140 U. PA. L. REV. 1525 (1992); Arnold S. Relman, *The Trouble With Rationing*, 323 NEW ENG. J. MED. 911 (1990).

## I. THE OREGON DEMONSTRATION PROJECT

### A. Context of the Oregon Plan

Medicaid, the largest government program for financing health care for the nation's poor, is jointly funded by state and federal governments.<sup>17</sup> Due to rising enrollment and soaring costs, the Medicaid program has increased dramatically.<sup>18</sup> Enrollment in Medicaid was projected to reach 30.1 million people in 1992.<sup>19</sup> Health care expenditures were expected to rise from \$92.1 billion in fiscal year 1991, to \$127.2 billion in fiscal year 1992.<sup>20</sup> Trends in rising enrollment and soaring costs show no sign of abating,<sup>21</sup> thereby increasing the strain on federal and state budgets.<sup>22</sup>

Debate over rationing health care as a means of handling increased fiscal strain began in Oregon in 1987 when the legislature decided to end Medicaid coverage for organ transplants.<sup>23</sup> The amount of funds previously intended for the transplants would provide basic health and prenatal services for 1500 pregnant women.<sup>24</sup> The state legislature reasoned that there were more effective ways to allocate scarce public resources than funding costly procedures for a few people, and that more lives could be saved per dollar by a shift in funding.<sup>25</sup> However, the case of Coby Howard, a seven-year old leukemia patient who died in 1988 be-

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17. See GENERAL ACCOUNTING OFFICE, OREGON'S MANAGED CARE PROGRAM AND IMPLICATIONS FOR EXPANSION 2 (1992) [hereinafter GAO REPORT].

18. *Id.*

19. *Id.* at 12. This rise in enrollment represents an increase of almost 28% between fiscal years 1989 and 1992, from 23.5 million clients to 30.1 million. *Id.* at 14.

20. *Id.* at 12. This is an increase of more than 38%. *Id.*

21. See GAO REPORT, *supra* note 17 at 14 (noting that the number of Medicaid clients and the costs of care are expected to continue rising in future years due to economic, social, and demographic trends, "coupled with already mandated program expansions").

22. *Id.* at 2. Estimated expenditures for the fiscal year 1993 total \$148 billion. *Id.* at 14. The report further notes that state governments view Medicaid as "a substantial financial burden." In fiscal year 1991, Medicaid constituted 13.6% of all state expenditures, second only to elementary and secondary education; state expenditures increased an average of 10% per fiscal year between 1984 and 1989, while revenues increased at a rate of only 8%; and increased funding for Medicaid strains funding of other social services, particularly in states requiring balanced budgets. *Id.* When Medicaid was introduced in 1965, funding for the program constituted only 5% of state budgets, as compared with the 15% it is expected to command in 1995. Eric L. Robinson, *The Oregon Basic Health Services Act: A Model for State Reform?*, 45 VAND. L. REV. 977, 988 (1992).

23. Julie Rovner, *Oregon Plan Sparks Emotional Debate Over Rationing Health Care*, 49 CONG. Q. 1278 (1991). Such medical services are considered "optional" under federal law. *Id.*

24. Robinson, *supra* note 22, at 988-89.

25. *Id.*

cause he was unable to afford a bone marrow transplant,<sup>26</sup> prompted a reexamination of Oregon's entire health care delivery system.<sup>27</sup>

In 1988, the governor of Oregon appointed a special task force to evaluate the state's health care problem.<sup>28</sup> The Governor's Commission on Uncompensated Care recommended that Oregon provide equitable access to health care to all citizens without imposing excessive financial burdens on the state, the taxpayers, or the medical community.<sup>29</sup> The Commission identified three main impediments to access to health care: "financial barriers to those unable to afford care," "limitations to Medicaid imposed by the state legislature," and "problems of availability of

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26. See Harvey D. Klevit et al., *Prioritization of Health Care Services: A Progress Report by the Oregon Health Services Commission*, 151 ARCHIVES INTERN. MED. 912 (1991); Robinson, *supra* note 25, at 989; Rovner, *supra* note 23, at 1278. Oregon no longer funded most organ transplants through its Medicaid plan. Klevit, *supra*, at 912. At the time of his death, Coby and his family had raised \$70,000 of the \$100,000 needed for the surgery through private contributions. Robinson, *supra* note 22, at 989. Coby's plight generated much publicity throughout the nation, and much discussion of the Oregon policy. *Id.* Opposition to the policy was so extreme that John A. Kitzhaber, Oregon Senate President, was labeled "Dr. Death" by his critics when he wanted to "maintain the no-transplant policy." Rovner, *supra* note 23, at 1278.

27. See Robinson, *supra* note 22, at 989. During debate over whether to overturn the no-transplant policy, Kitzhaber realized that "we had no framework for making the decision," prompting the chain of events leading up to the Oregon Basic Health Services Act. Rovner, *supra* note 23, at 1278. Kitzhaber further noted that the question of whether organ transplants have merit was not the primary issue, but that

[r]ather, the question was simply this: If the state was going to invest money in its health care budget, where should the next dollar go? What was the policy that would lead us to fund transplants as opposed to further expanding the availability of prenatal care? What was the policy that would lead us to offer transplants to eight individuals as opposed to nine - or to 19? Where was the equity in giving sophisticated and costly services to a few Oregonians covered under Medicaid before providing basic health care services to other equally needy citizens, including many of the "working poor," who lacked any public or private coverage? What became readily apparent was that Oregon had no health care policy.

John Kitzhaber, *A Healthier Approach to Health Care*, ISSUES SCI. & TECH., Winter 1990-91, at 59, 59-60.

28. See Richard Allen, *Caring for the Uninsured: The Oregon Experience*, 115 ARCHIVES PATHOLOGY & LABORATORY MED. 437 (1991).

29. *Id.* at 437-38. Some 400,000 Oregonians under the age of 65 do not have health insurance coverage. *Id.* at 437. Sixty-five percent of that total were employed workers and their families. The remaining one third were either unemployed, or earning more than 58% of the Federal Poverty Level (FPL), which is the cut-off point in Oregon for Medicaid qualification. An additional 15,000 uninsured individuals were considered high risks, and consequently uninsurable. Furthermore, providers were shifting costs to the insured in order to provide care for the uninsured. This created an expanding group of uninsured persons, since employers who provided health care for their employees became increasingly unwilling to bear this financial burden. *Id.*

services, mainly in rural areas."<sup>30</sup> The Commission further noted that due to barriers to access, the uninsured generally received "more expensive, acute, and episodic care that resulted in the shifting of cost to the insured and in higher healthcare costs."<sup>31</sup>

The Commission recommended as a starting point that Oregon adopt a mission statement recognizing "an obligation to ensure equitable access without excessive burdens to an adequate level of health care for all Oregonians."<sup>32</sup> The Commission also recommended six specific steps to:

solve the problem of equitable access without excessive financial burden: (1) an employee tax credit for small businesses; (2) a state-run high-risk pool; (3) an expansion of Medicaid to 100 [%] of the FPL [federal poverty line]; (4) a plan for continuation of benefits to the recently unemployed; (5) increased funding for primary clinics, especially in the more rural areas of the state; and (6) various cost-containment strategies, particularly managed care programs and tort reform.<sup>33</sup>

The Commission concluded that ensuring access to better health care would result in cost reduction and a healthier population.<sup>34</sup>

### *B. Oregon's Current System*

Oregon's current Medicaid program began in 1985 and utilizes a managed care approach.<sup>35</sup> As of April 1992, approximately 73,000 people in eleven counties were enrolled in managed care plans under Oregon's Medicaid program.<sup>36</sup> The current program is the result of a patchwork of

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30. *Id.*

31. *Id.*

32. *Id.* "This obligation should be balanced by people's obligation to provide for their own needs." *Id.* at 438.

33. *Id.* at 439.

34. *Id.*

35. GAO REPORT, *supra* note 17, at 2. Under managed care, health plans such as health maintenance organizations (HMO's) provide health services to enrolled clients for a fixed monthly fee. Because it encourages health plans to control service use and to deliver cost effective service, many view managed care as a hopeful approach to containing medical costs while providing access to care. The report notes, however, that safeguards are necessary to ensure that health plans do not limit patient services inappropriately or provide substandard services in an effort to save money. *Id.*

36. *Id.* GAO noted that Oregon's managed care plan has avoided many of the problems faced by other states: Oregon's plan is well accepted by providers and clients, has many safeguards to "prevent inappropriate restriction in access to health care," and has quality assurance monitoring in place which meets federal requirements. *Id.* at 3. While generally sound, the Oregon program could be improved in terms of child health screening services, client satisfaction surveys, and intensification of oversight. *Id.*

state and federal laws defining who is eligible and the extent of their eligibility.<sup>37</sup>

Approximately 200,000 people are eligible for the Medicaid program in Oregon.<sup>38</sup> More than twice that number, however, have no health insurance at all.<sup>39</sup> An estimated 120,000 uninsureds with incomes below the Federal Poverty Line (FPL) do not qualify for Medicaid because their income is nonetheless too high or their family status excludes them from the program.<sup>40</sup> In 1990, the program cost \$230 million, of which sixty-

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37. David M. Eddy, *What's Going on in Oregon?*, 266 JAMA 417, 418 (1991). Eddy recognized six main building blocks to determine eligibility: "the presence of children in a family, the ages of the children, whether a woman is pregnant, whether someone is aged, the presence of a major disability, and income." *Id.* Federal law defines the groups for whom coverage is mandatory, optional, and forbidden based on varying combinations of these six categories. *Id.* Once eligibility is determined, one qualifies for generous coverage due to the fact that federally mandated services are defined by broad categories, with few restrictions within these categories. *Id.* States have few choices in the face of increasing costs of Medicaid programs: they can raise taxes, but this is often blocked by public perception that taxes are already too high; they can reduce payments to providers, but this simply shifts the costs to others or prompts providers to refuse to treat Medicaid patients; they can pull money from other social programs in the state budget, but this not only deprives recipients of those programs, but also has a negative, indirect effect on health; or lastly, they can tighten or limit criteria for coverage by lowering the threshold that qualifies a family for coverage, by dropping optional groups, or by dropping optional categories of services. *Id.* at 419. States most frequently choose the last option. *Id.* The net effect of the legislative patchwork is "a program that covers virtually every medical service for a subset of poor people but covers nothing for a far larger number of people who are poor or nearly poor." *Id.* at 418. The results can be extreme, as in Alabama where the income threshold for Aid to Families With Dependent Children (AFDC) is set at 14% of FPL. *Id.* at 419.

38. *Id.* at 418.

39. *Id.* The statistic cited in this article is 450,000, or 18% of the state's population. *Id.* Based on a 1986 survey by the State Health Planning and Development Agency (presently the Office of Health Policy), it is estimated that 16% of households where the head is under 65 years of age are uninsured; uninsured heads of households and their spouses are less likely to see a doctor; uninsureds who do see a doctor make more visits to the doctor than insureds; average out-of-pocket expenditures for hospitalization are higher among the uninsured; the uninsured tend to be younger, single, less educated, of lower financial status, and unemployed or only marginally employed; uninsured persons are less likely to have a regular source of care, and more likely to delay needed care because of cost; the uninsured are more likely to report disabling medical conditions, and to experience days away from work because of illness. OREGON HEALTH SERVICE COMMISSION, *PRIORITIZATION OF HEALTH SERVICES: A REPORT TO THE GOVERNOR AND LEGISLATURE*, at xviii (1991) [hereinafter HSC REPORT] (on file with the *Journal of Contemporary Health Law & Policy*).

40. Eddy, *supra* note 37, at 418. By "not poor enough," Eddy means that these uninsured persons have incomes above 50% of the FPL. In terms of "right family status," Eddy indicates that these persons have no children, are not pregnant, or the children are too old. Eddy notes that "[a] family of four with an income of \$541 a month is 'too rich' to



three percent was covered by the federal government and thirty-seven percent by the state.<sup>41</sup> Under current laws, costs continue to grow without control.<sup>42</sup> In the face of increasing fiscal pressures and limitations, Oregon “covertly” rationed health care in its system by “decreasing the number of individuals eligible for Medicaid services.”<sup>43</sup>

### C. *The Oregon Basic Health Services Act*

#### 1. *Overview of Purpose and Goals*

The Oregon Basic Health Services Act (OBHSA) was envisioned as a means of addressing the lack of a cohesive and comprehensive health care policy.<sup>44</sup> OBHSA was prompted by a desire to create a new system that recognized the reality of fiscal limitations, carefully defined public policy objectives, and established a sense of accountability for resource allocation decisions.<sup>45</sup> Dr. John Kitzhaber, an emergency physician and former President of the Oregon Senate, characterized the effort as a systemic approach to the health care problems of Oregon that addresses the problems identified by the 1988 Governor’s Commission on Uncompensated Care.<sup>46</sup>

A clear policy objective that evolved was “to keep all Oregonians healthy,” as opposed to simply providing them with access to health

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qualify, even though private insurance would cost them about \$204 a month.” *Id.* Presently, a person must fall into a federally specified need category *and* have income much lower than the FPL in order to qualify for Medicaid in Oregon. OFFICE OF TECHNOLOGY ASSESSMENT, SUMMARY: EVALUATION OF THE OREGON MEDICAID PROPOSAL 1 (1992) [hereinafter OTA SUMMARY]. For example, Oregon residents who receive AFDC assistance must have incomes of less than 50% of FPL. *Id.* FPL was defined in 1992 as an annual income of \$11,570 for a family of three. *Id.* at 1 n.1.

41. Eddy, *supra* note 37, at 418.

42. *Id.* Part of the increasing costs is tied to the inflation of medical care in both the public and private sectors. The remainder is tied to new requirements at the federal level mandating additional services for eligible recipients. *Id.*

43. Klevit et al., *supra* note 26, at 912. Kitzhaber argues that there are actually three ways in which the present system arbitrarily rations health care: by adjusting Medicaid income levels to disqualify certain individuals; by age; and by inappropriate and ineffective application of resources. BUREAU OF NATIONAL AFFAIRS, SPECIAL REPORT: OREGON PLAN SPARKS DEBATE 172 (1990) [hereinafter SPECIAL REPORT]. As an example of this last means of rationing, Kitzhaber points to the fact that nearly one half of the Medicaid budget is spent on care for people during their last 30 days of life. *Id.*

44. Kitzhaber, *supra* note 27, at 60.

45. *Id.*

46. Kitzhaber Presentation, *supra* note 11, at 13. The initial intent was to address the twin problems of access and cost, in a manner that encompassed public and private components. *Id.* at 1.

care.<sup>47</sup> Underlying this distinction is the realization that “health care is not necessarily synonymous with health.”<sup>48</sup> Health care is important only if it furthers the goal of maintaining, restoring, or improving health.<sup>49</sup> Other social problems, such as housing, education and environmental factors, affect health as well.<sup>50</sup> Therefore, in order to promote health as a policy objective, Oregon realized that it must reform its health care system in a comprehensive manner.<sup>51</sup> Putting greater resources into increasing access to health care at the expense of other important social programs would not advance the overall goal of health.<sup>52</sup> Stated more succinctly, “[t]he Oregon proposal represents an effort to develop not simply a *health care* policy, but a *health* policy: an integrated approach in which resource allocations for health care are balanced with allocations in related areas which also affect health.”<sup>53</sup>

In terms of the need for accountability in the decision making process, Kitzhaber notes that the current system “allows us to make these allocation decisions in a vacuum — responding to the emotionalism of a highly visible individual in need, while ignoring thousands of others equally in need . . . simply because they are *not* highly visible.”<sup>54</sup> OBHSA recognizes that an explicit decision to allocate money for one set of medical services necessarily entails an implicit decision not to allocate money for another set of services.<sup>55</sup> OBHSA requires that policymakers make health care allocation decisions explicitly, weighing the overall social costs and benefits and assuming accountability for these decisions and their consequences.<sup>56</sup>

## 2. Ethical Foundations

In his article analyzing the Oregon plan, Michael Garland identified three central ethical commitments that serve as guiding principles for OBHSA.<sup>57</sup> The first commitment is to the idea that “it is more equitable

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47. *Id.* at 5.

48. *Id.*

49. *Id.*

50. *Id.* at 5-6.

51. *Id.* at 6.

52. *Id.*

53. *Id.*

54. *Id.* at 5.

55. *Id.* Such implicit decisions, in essence, constitute rationing of health care with no real means of accountability. Kitzhaber, *supra* note 27, at 61.

56. Kitzhaber Presentation, *supra* note 11, at 5.

57. Michael J. Garland, *Justice, Politics and Community: Expanding Access and Ra-*

to assure everyone basic health care than to offer a larger but unevaluated collection of benefits to some of the poor while excluding others from anything but emergency care."<sup>58</sup> The second is that "explicit, publicly accountable choice is better than the hidden rationing that now occurs."<sup>59</sup> The third commitment is that "health care priorities should combine authentic values of the community with expert technical judgments about health services."<sup>60</sup>

Additional underlying principles of the Oregon plan have been identified. The state's citizens must have universal access to a basic level of care, and a process must be established for determining this basic level.<sup>61</sup> The criteria used in the process must be publicly debated, reflect societal values, and consider the common good.<sup>62</sup> Society must provide resources for those who cannot finance an acceptable level of care.<sup>63</sup> The health care distribution system must provide effective and appropriate treatments, rather than those with marginal or unproven benefit.<sup>64</sup> Lastly, allocations for health care must be part of a broader policy that encompasses other social programs that affect health.<sup>65</sup>

### 3. The Legislation

In 1989, the Oregon legislature adopted "sweeping initiatives" to increase access to health care.<sup>66</sup> The OBHSA consists of three complimentary bills, each targeting a specific segment of the uninsured population.<sup>67</sup> First, Senate Bill 534 establishes a high risk, state subsidized insurance pool for the uninsurable and the chronically ill.<sup>68</sup> Second, Senate Bill 935 targets persons who are employed but have no employer-based health

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*tioning Health Services in Oregon*, LAW, MED. & HEALTHCARE, Spring-Summer 1992, at 67, 68.

58. *Id.* Many criticisms of the Oregon plan are aimed at this premise. Callahan phrases the question as: "Do you cut back on people, or do you cut back on services? . . . It's at least a moral toss-up." Moran, *supra* note 9, at 15.

59. Garland, *supra* note 57, at 68.

60. *Id.*

61. Judith P. Rooks, *Let's Admit We Ration Health Care - Then Set Priorities*, AM. J. NURSING, June 1990, at 39, 39-40.

62. *Id.*

63. *Id.*

64. *Id.*

65. *Id.*

66. Klevit et al., *supra* note 26, at 912.

67. *Id.*; see also OTA SUMMARY, *supra* note 40, at 2, Box A. The three bills are S. 534, S. 935, and S. 27, and are codified at OR. REV. STAT. §§ 414.705-.750 (1990).

68. HSC REPORT, *supra* note 39, at xvii.

insurance.<sup>69</sup> This bill mandates that employers provide health insurance to their employees and dependents.<sup>70</sup> The minimum benefit package offered by employers under S. 935 must match that provided for the Medicaid population.<sup>71</sup> Employers who fail to provide insurance to their employees after 1994 are required to make mandatory contributions to a state fund from which uninsured employees may purchase insurance.<sup>72</sup> Senate Bill 27, which establishes the Oregon Medicaid Demonstration Project, is the third and most controversial part of OBHSA.<sup>73</sup>

#### 4. Senate Bill 27 - The Oregon Medicaid Demonstration Project

Under S. 27, income is the sole test for Medicaid eligibility.<sup>74</sup> This shift in eligibility criterion increases Medicaid coverage to 100% of the FPL.<sup>75</sup> S. 27 also dramatically alters the way in which benefits are defined, and expands the use of managed care.<sup>76</sup> S. 27 "mandates a prioritized health service list,"<sup>77</sup> which is the key innovation of the project.<sup>78</sup> Cutting services rather than people in the face of fiscal constraints is a "sharp departure" from existing federal law.<sup>79</sup>

Under S. 27, the governor appointed an eleven member body to serve

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69. OTA SUMMARY, *supra* note 40, at 2, Box A.

70. *Id.*

71. *Id.*

72. *Id.*

73. Klevit et al., *supra* note 26, at 912.

74. HSC REPORT, *supra* note 39, at xvii.

75. Klevit et al., *supra* note 26, at 912.

76. OTA SUMMARY, *supra* note 40, at 2, Box A.

77. HSC REPORT, *supra* note 39, at xvii.

78. Garland, *supra* note 57, at 67. Prioritization encompasses the notion that "from a societal perspective, some health services can be declared more important than others." *Id.* Further, the whole range of services can be arranged to reflect the priorities of a given society. *Id.* Although novel, prioritization is not without precedent. McDERMOTT, WILL & EMERY [ON BEHALF OF THE DEPT. OF HUMAN RESOURCES OF THE STATE OF OREGON], ISSUE BRIEF: DOES THE PROPOSED OREGON HEALTH PLAN DEMONSTRATION PROJECT VIOLATE THE AMERICANS WITH DISABILITIES ACT? 1 (July 1, 1992) [hereinafter ISSUE BRIEF] (on file with the *Journal of Contemporary Health Law & Policy*). In the face of budget constraints, most states have set priorities concerning which of the optional Medicaid services would be funded. Oregon's novelty is in ranking and prioritizing *all* health services covered by Medicaid, including services ordinarily considered "mandatory services" under federal law. *Id.*

79. Kosterlitz, *supra* note 10, at 2766. Traditionally, federal law requires that states offer "all necessary medical services" to Medicaid patients. With appropriate waivers of federal law, Oregon would instead exercise the right to choose which medical procedures patients can receive. *Id.*

as the Oregon Health Services Commission (HSC).<sup>80</sup> The legislature assigned to the HSC the task of reporting “a list of health services ranked by priority from the most important to the least important, representing the comparative benefits of each service to the entire population to be served.”<sup>81</sup> With this general mission and no established procedures for carrying it out,<sup>82</sup> the HSC divided “tasks and responsibilities among the general public, the commission, the legislature, and specific agencies.”<sup>83</sup>

The methodology employed by the HSC was “a four step process for health resource allocation.”<sup>84</sup> In the first step, the HSC was required to develop a prioritized list of all health services covered by Medicaid.<sup>85</sup>

80. Klevit et al., *supra* note 26, at 912. The HSC was composed of five physicians, one public health nurse, one social worker, and four laypersons. *Id.* at 913.

81. *Id.* at 912. Additional fundamental provisions include:

- (1) active solicitation of public involvement in a meeting process to build a consensus on the values to be used to guide health resource allocation decisions;
- (2) implementation through contracting with managed-care systems;
- (3) the legislature, at a time of budgetary shortfall, would . . . be obliged to decrease the number of available services or make more funds available to cover the existing services;
- (4) the reimbursement or capitation rates for providers and plans . . . could not be reduced at a time of insufficient resources . . . .

*Id.*

82. HSC REPORT, *supra* note 39, at 4.

83. Garland, *supra* note 57, at 68. The division of responsibilities was a critical element of the plan, and allowed for a “separation of value considerations from technical facts” during initial phases of the prioritization. The division further allowed development of the priority list unimpeded by political pressures commonly felt in the legislature. *Id.*

84. *Id.*

85. *Id.* This first step can be broken down into three stages. The first stage entailed the categorizing and ranking of condition/treatment pairs. The HSC assembled a list of 709 condition/treatment pairs. These pairs were then organized into 17 general categories that were created and ranked by HSC. See ISSUE BRIEF, *supra* note 78, at 1; OTA SUMMARY, *supra* note 40, at 4. “Essential services” include: acute fatal where treatment prevents death with full recovery; maternity care including most disorders of newborns and obstetrical care for pregnancy; acute fatal where treatment prevents death without full recovery; preventive care for children; chronic fatal where treatment improves life span and quality of life; reproductive services; comfort care which includes palliative therapy for conditions where death is imminent; preventive dental care for adults and children; and proven effective preventive care for adults. OTA SUMMARY, *supra* note 40, at 6; HSC REPORT, *supra* note 39, at 18-19. “Very important services” include: acute nonfatal where treatment causes a return to previous health state; chronic nonfatal where one-time treatment improves quality of life; acute nonfatal where treatment does not return to previous health state; and chronic nonfatal where repetitive treatment improves quality of life. OTA SUMMARY, *supra* note 40, at 6; HSC REPORT, *supra* note 39, at 19. Services that are “valuable to certain individuals” include: acute nonfatal where treatment expedites recovery of a self-limiting condition; infertility services; less effective preventive care for adults; and fatal or nonfatal where treatment causes minimal or no improvement in quality of life. *Id.* The ranking of these categories by the HSC was the primary factor in how the condition/treatment pairs ultimately were ranked in the priority setting process. For each condition/treat-

This list was based on community values about health care and technical information about the effectiveness of health services.<sup>86</sup> The second step commenced upon completion and delivery of the list to the legislature.<sup>87</sup> In this step, the legislature set the budget, which *de facto* established the benefit package for the new Oregon Medicaid Program.<sup>88</sup> Activity in the third step was twofold: the Office of Medical Assistance Programs (OMAP) requested the necessary waivers of federal Medicaid regulations, and the agencies established the administrative and evaluative elements necessary to run the complex social program.<sup>89</sup> The fourth step

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ment pair, the HSC gathered information concerning "(1) the expected probability of successful treatment of the condition; (2) the duration of treatment benefits; and (3) the costs of treatment." *ISSUE BRIEF*, *supra* note 78, at 1-2.

The second stage consisted of the actual ranking of the condition/treatment pairs. *Id.* at 2. This, in turn, entailed three concurrent processes. First, the HSC prepared a net benefit comparison for each pair. Based on medical literature and clinician input, the HSC determined the extent to which treatment results in an improved condition, as compared to expected condition without treatment. Condition/treatment pairs were quantified by whether the outcome, with or without treatment, resulted in death, a return to prior condition, or other symptoms or functional impairments. Second, the HSC solicited public opinion on the importance of health states and medical conditions covered by the condition/treatment pairs. *Id.* After 47 community meetings conducted by Oregon Health Decisions, a consensus of 13 health-related values emerged. *HSC REPORT*, *supra* note 39, at 21. These were grouped by the HSC into three attributes: value to society, value to an individual at risk of needing the service, and essential to basic health care. *Id.* at 21-22. Various social advocates gave testimony at a series of 12 public hearings, which proved useful for understanding the general tone of public needs and concerns. *Id.* at 22. In addition, a telephone survey gauged public reaction to the symptoms and functional impairments of specific health states. *ISSUE BRIEF*, *supra* note 78, at 2. Third, a preliminary ranking was undertaken, utilizing net-benefit comparisons and social value input. *Id.* at 4.

The third stage consisted of a line by line reexamination of the list of condition/treatment pairs. Using professional judgment, an interpretation of community values, cost benefit ratios, and costs to altering the order of the pairs, the HSC manually adjusted the list. *Id.* Using a "reasonableness" test, Commissioners re-ranked "out-of-position" items on the draft list. *HSC REPORT*, *supra* note 39, at 28.

86. Garland, *supra* note 57, at 68.

87. *Id.*

88. *Id.* Based on actuarial analysis, the legislature funded the program through line 587 of the prioritized list of condition/treatment pairs for the first year. *OTA SUMMARY*, *supra* note 40, at 4. All diagnostic visits and evaluations would be covered under the plan. Richard C. Wopat, *The Oregon Health Plan: To Cover All Diagnostic Visits*, 268 *JAMA* 790 (1992). "For the vast number of conditions below line 587, there is either no effective treatment, or the treatment only expedites recovery and recovery would occur either with or without treatment." *Id.*

89. Garland, *supra* note 57, at 69. Waiver of certain statutory and regulatory requirements in the federal Medicaid program was necessary for the implementation of S. 27. *HSC REPORT*, *supra* note 39, at 39. These waivers would allow Oregon to operate a demonstration program that varies from the traditional Medicaid program. *Id.* Oregon's application for the federal waiver was denied by the Health Care Financing Administration

entailed actual implementation of the new services in the community.<sup>90</sup>

There are three common misconceptions about the Oregon plan.<sup>91</sup> First, the plan is not concerned only with Medicaid.<sup>92</sup> Rather, the plan is part of a trio of bills, designed to address the problem of the state's uninsured.<sup>93</sup> Second, the plan is not proposed as a final solution.<sup>94</sup> Instead, it is envisioned as a stop gap remedy to bring short term relief to the uninsured while moving in a direction to make a national solution more likely.<sup>95</sup> Third, rather than an extension of the 1987 "no transplant" policy, the plan represents reform of the policy on which that decision was based.<sup>96</sup> This reform encourages funding choices based on a comprehensive review of the entire range of services, rather than tradeoffs on optional services.<sup>97</sup>

## II. THE DENIAL OF THE FEDERAL WAIVER

### A. *The Office of Technology Assessment Review*

#### 1. *Overview*

In response to a request by United States Representatives John Dingell and Henry Waxman, the Office of Technology Assessment (OTA) conducted a study to analyze the Oregon Medicaid proposal and to discuss potential implications for the federal government, the state of Oregon, and Medicaid beneficiaries.<sup>98</sup> The request was prompted by concerns about the effects of the proposal on program recipients, and its potential ramifications on the national health care debate.<sup>99</sup> Among other topics,

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(HCFA) on August 3, 1992. See Sullivan Letter, *supra* note 13 and discussion *infra* part II.B. The HCFA manages the Medicaid program. Kitzhaber, *supra* note 27, at 64. HCFA has the authority to grant an administrative waiver of the Medicaid regulations so that Oregon can redesign the current package of Medicaid benefits. *Id.*

90. Garland, *supra* note 57, at 69.

91. *Id.* at 67.

92. *Id.*

93. *Id.*

94. *Id.*

95. *Id.* at 67-68; see also Kitzhaber Presentation, *supra* note 11, at 14.

96. Garland, *supra* note 57, at 68.

97. *Id.* "The object of the plan is to create a public policy tool for determining, for purposes of collective funding, the worth of all forms of health service, not just life-saving interventions, or high technology services, or high cost services." *Id.*

98. OTA SUMMARY, *supra* note 40, at 3-4. John Dingell is Chairman of the House Committee on Energy and Commerce, and Henry Waxman is Chairman of the House Subcommittee on Health and the Environment. *Id.* at 3.

99. *Id.*

OTA analyzed potential violations of constitutional and statutory law.<sup>100</sup>

In its analysis, OTA noted that “[f]ederal statutes prohibiting recipients of [f]ederal funds from discrimination on the basis of race, handicap, or age clearly apply to the Oregon proposal.”<sup>101</sup> Additionally, federal implementing regulations make further prohibitions on certain kinds of “disparate-impact” discrimination.<sup>102</sup> While noting that the effects of the anti-discrimination statutes are “not entirely clear cut,” OTA concluded that “the proposal is probably not very vulnerable to a challenge on the basis of these [anti-discrimination] statutes unless in its implementation the denial of benefits falls disproportionately on protected groups.”<sup>103</sup> OTA further concluded that a disparate impact on protected groups is unlikely to occur at the proposed level of funding.<sup>104</sup>

## 2. *Americans with Disabilities Act Analysis*

Because the waiver denial was based in large part on perceived violations of the Americans with Disabilities Act (ADA),<sup>105</sup> it is important to

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100. See OFFICE OF TECHNOLOGY ASSESSMENT, CONGRESS OF THE U.S., EVALUATION OF THE OREGON MEDICAID PROPOSAL, Ch. 7, 175-89 (1992) [hereinafter OTA REPORT]. The study analyzed federal and state constitutional issues. *Id.* at 175-80. In terms of federal statutory issues, the study looked at “anti-dumping” and other federal laws that relate to health care access, and the protection of human research subjects. *Id.* at 180-83. The study also examined five federal civil rights statutes: Title VI of the Civil Rights Act of 1964, the Rehabilitation Act of 1974, the Americans With Disabilities Act of 1990, the Child Abuse Prevention and Treatment and Adoption Act, and the Age Discrimination Act of 1975. *Id.* at 183-88.

101. *Id.* at 188. The federal statutes referred to here are the federal civil rights statutes listed *supra* note 100.

102. *Id.* at 188.

103. OTA SUMMARY, *supra* note 40, at 16. Such a disparate impact might be shown by a demonstration that the services that the protected group uses tend to fall below the cutoff point on the list. *Id.*

104. *Id.* OTA also notes that if the cutoff line were to move upward due to budgetary shortfalls, the potential for such a disparate impact challenge would increase. *Id.*

105. See 42 U.S.C. § 12101 (West Supp. 1991). The ADA is the culmination of more than two decades of legislative activity designed to safeguard the civil rights of persons with disabilities. David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454 (1992). In broad terms, the ADA “prohibits discrimination against otherwise qualified persons with disabilities in employment, public services and transportation, public accommodations, and telecommunications.” ISSUE BRIEF, *supra* note 78, at 5. The precursor legislation to the ADA was Title V of the Rehabilitation Act of 1973. *Id.* at 5-6.

The ADA establishes a national mandate and enforceable standards for the elimination of discrimination against persons with disabilities. 42 U.S.C. § 12101(b)(1)-(2). The legislation is intended to ensure that the federal government plays a key role in this effort, and invokes the full sweep of congressional authority in addressing such discrimination. § 12101 (b)(3)-(4).



examine OTA's assessment of that statute in greater detail.<sup>106</sup> OTA reviewed the ADA along with section 504 of the Rehabilitation Act of 1973, the model legislation for the ADA.<sup>107</sup> The language of the regula-

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Title II, concerning public services, would be the relevant section for challenging the Oregon Health Plan for discrimination on the basis of disability. *ISSUE BRIEF, supra* note 78, at 6. Title II states, in relevant part, that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. OTA notes that although the focus of the law is on access of persons with disabilities to transportation, employment, and places of business, this section of the Act can be construed to place a broader interpretation on its reach. *OTA REPORT, supra* note 100, at 186.

Disability is defined under the statute as "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." 42 U.S.C. § 12102(2). Implementing regulations reiterate this broad definition, stating that disabilities are considered to include "any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genitourinary; hemic and lymphatic; skin; and endocrine; [or] any mental or psychological disorder." Hadorn, *supra*, at 1454-55 (citing 28 C.F.R. § 35.104 (U.S. Dept. of Justice regulations for state and local government services, 56 Fed. Reg. 35,717 (1992))). An exhaustive list of disabilities does not exist, but legislative reports and implementing regulations have identified at least the following: "such contagious and noncontagious diseases and conditions as orthopedic, visual, speech, and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV . . . disease (whether symptomatic or asymptomatic), drug addiction, and alcoholism." *Id.* at 1455. Persons are considered disabled under the ADA if one or more major life activities are impaired by any of the conditions or illnesses listed. *Id.*

"Qualified individual with a disability" means "an individual with a disability who, with or without reasonable modifications . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity." 42 U.S.C. § 12131(2). Hadorn notes that although the phrase "otherwise qualified" was dropped, the Supreme Court interpretation of this phrase under section 504 is instructive on the meaning of "qualified individual with a disability." Hadorn, *supra*, at 1457. Section 504's language

meant that a person must be qualified in spite of, rather than apart from, his or her disability. Therefore, it was ruled permissible to withhold benefits if a person's disability-causing condition rendered him or her unfit or unqualified for receiving a benefit, providing that reasonable accommodation could not be made for that disability.

*Id.*

It is also important to note that the preamble to the implementing regulations of Title II, the Department of Justice stated that "[t]he standards of Title V of the Rehabilitation Act apply for purposes of the ADA to the extent that the ADA has not explicitly adopted a different standard than Title V." *ISSUE BRIEF, supra* note 78, at 6.

106. For a discussion of the reasoning behind the waiver denial, see *infra* part II.B.

107. See *OTA REPORT, supra* note 100, at 185.

tions interpreting the scope of section 504 indicates that intentional or overt discrimination, as well as acts or practices that have a disparate impact on the handicapped, are prohibited.<sup>108</sup> The Supreme Court defined the scope of section 504 in *Alexander v. Choate*.<sup>109</sup>

OTA indicates that while a state may limit or restrict Medicaid covered services in a facially neutral manner, even if it disadvantages groups who qualify as handicapped under section 504, a state may be in violation of section 504 if it explicitly defines or categorizes services such that non-handicapped persons qualify for and receive medical treatment, but handicapped persons are denied comparable services.<sup>110</sup> Even if this situation were not regarded as a *per se* violation, "it may be regarded as the kind of disparate impact discrimination described in *Choate*."<sup>111</sup> In such a case, a court would have to apply the *Choate* balancing test.<sup>112</sup> OTA concluded that "[i]t is simply not possible under current law to anticipate how future courts would answer these questions."<sup>113</sup>

Likewise, in the specific context of the ADA, OTA concluded that "[a]ny assumption regarding how Oregon's proposal would fare under a Disabilities Act challenge is necessarily speculative, since there is no case law."<sup>114</sup> OTA concluded that the legislation places "no additional burden on the discretion of a State Medicaid program beyond those already in place" under section 504.<sup>115</sup> However, OTA recognized that at least one legal advocate suggested that there are additional requirements for Medicaid programs under the ADA.<sup>116</sup> Specifically, "the use of the public survey to assign values to health states gives inadequate weight to the opinions of persons with disabilities and therefore biases the ranking pro-

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108. *Id.*

109. 469 U.S. 287 (1985). The Supreme Court upheld a Tennessee Medicaid limit on the length of a hospital stay "because it did not overtly distinguish between handicapped and nonhandicapped beneficiaries" and "both categories have 'meaningful' access to the same benefits." OTA REPORT, *supra* note 100, at 185.

110. OTA REPORT, *supra* note 100, at 185. Such categorization would amount to differential treatment of similarly situated individuals, and would be considered intentional discrimination under the statute. *Id.*

111. *Id.*

112. *Id.* Under *Choate*, "concerns of 'disparate impact' . . . must be balanced by 'the need to keep section 504 within manageable bounds' and avoid unduly burdensome 'Handicapped Impact Statements.'" *Id.* (quoting *Alexander v. Choate*, 469 U.S. 287, 299 (1985)). Determinative issues would include reasonable justifications, and the level of judicial review required under the balancing test. *Id.*

113. *Id.*

114. *Id.* at 186.

115. *Id.*

116. *Id.*

cess against services for disabled persons."<sup>117</sup> Under this argument, the additional burden for Oregon presumably would be to rid the prioritization process of any impermissible bias.<sup>118</sup> It is unclear how much weight OTA gave to this argument in its analysis.<sup>119</sup>

### B. Decision of the Department of Health and Human Services

On August 3, 1992, Louis W. Sullivan, Secretary of Health and Human Services (HHS), wrote a letter denying Oregon's application for a waiver of federal Medicaid laws.<sup>120</sup> In the letter, Sullivan expressed the Bush Administration's commitment to encouraging innovation in state health care programs and its favorable view of using states as "laboratories for democracy."<sup>121</sup> Sullivan denied final approval of the application, however, pending resolution of legal issues relating primarily to the ADA.<sup>122</sup> Sullivan stressed that because of the "real possibility" that Oregon's ap-

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117. *Id.*; see also Letter from Thomas J. Marzen, General Counsel, and Daniel Avila, Staff Counsel, National Legal Center for the Medically Dependent & Disabled, to the Honorable Christopher H. Smith, United States Representative 1 (Dec. 5, 1991) [hereinafter Marzen & Avila Letter] (on file with the *Journal of Contemporary Health Law & Policy*). The OTA report cites this letter as providing the basis of this argument. OTA REPORT, *supra* note 100, at 186. Ultimately, this is the argument used to deny Oregon's waiver application. For a discussion of denial of Oregon's waiver application, see *infra* part II.B.

118. Note, however, Oregon's observation to the contrary:

To the extent that courts have found non-employment related violations of the Rehabilitation Act by state and local governments, these cases involved circumstances where individuals were found to have been *deliberately* excluded or segregated by reason of their disability or handicap. In contrast, *no case* has held that a state or local government violated the Rehabilitation Act based on a defective or discriminatory decision-making process.

ISSUE BRIEF, *supra* note 78, at 6 n.1 (emphasis added).

119. OTA concluded that potential ADA challenges were "necessarily speculative." OTA REPORT, *supra* note 100, at 186. Additionally:

OTA analysis of the list showed that the weights from the public survey had relatively little effect on the final rankings on the list . . . Furthermore, where survey responses differed according to the health experiences of the respondent, the result in at least a few cases could be to increase the relative weight assigned to a given treatment that would reduce the disability. However, because the Oregon Health Services Commission has not made its ranking process explicit and because it is possible that in future revisions of the list public survey information could be more determinate, the Oregon plan might still be vulnerable to challenge under the act.

*Id.* OTA thus seems to conclude that the argument should not impede implementation of the project, but also leaves the door open for future claims on these grounds.

120. Sullivan Letter, *supra* note 13.

121. *Id.*

122. *Id.*

proach would serve as a model for other states, "it is critically important that [the OBHSA] go forward only with strict adherence to the legal protections" of the ADA.<sup>123</sup>

In an attachment to Sullivan's letter, the reasoning behind the decision was set forth.<sup>124</sup> It was noted that the record of the process by which the prioritization list was compiled contained "considerable evidence that it was based in substantial part" on a premise inconsistent with the ADA.<sup>125</sup> The inconsistent premise was that "the value of the life of a person with a disability is less than the value of the life of a person without a disability."<sup>126</sup> Further, there would be no approval of the waiver until HHS and the Health Care Finance Administration were persuaded that the program was revised to exclude such value of life considerations.<sup>127</sup>

Following this general overview was a series of five suggestions and observations to assist Oregon in its revision of the plan. First, the rankings of the condition/treatment pairs should be redone without using data derived from the telephone survey.<sup>128</sup> HHS determined that there were "substantial indications" from the record that "the quality of life data derived from the Oregon telephone survey quantifies stereotypic assumptions about persons with disabilities."<sup>129</sup> Oregon did not dispute that the

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123. *Id.*

124. DEPT. OF HEALTH & HUMAN SERVICES, ANALYSIS UNDER THE AMERICANS WITH DISABILITIES ACT ("ADA") OF THE OREGON REFORM DEMONSTRATION, Aug. 3, 1992 [hereinafter HHS ANALYSIS] (on file with the *Journal of Contemporary Health Law & Policy*).

125. *Id.*

126. *Id.*

127. *Id.* The Health Care Finance Administration is the division of HHS which oversees the Medicaid program.

128. *Id.* at 2. The telephone survey at issue

was done to collect numeric values from the public which would represent their feelings about impaired health states. The same symptoms and functional impairment modifiers were used in the survey that the health services providers selected to describe residual effects, death, and return to former state of health. Symptoms ranged from loss of consciousness due to seizure, fainting, or coma to wearing eyeglasses or contact lenses. Functional impairments consisted of six scenarios depicting mobility, physical activity and social activity. Survey respondents, numbering 1,001, scored the severity of symptoms and functional impairments on a scale of 0 (death) to 100 (perfect health). The lower the score, the more serious the problem. Weights for each of the symptoms and functional modifiers were computed for use in the benefits portion of the cost-benefit ratio.

HSC REPORT, *supra* note 39, at 26; *see also* HSC REPORT, *supra* note 39, at App. C.

129. HHS ANALYSIS, *supra* note 124, at 1; Three sources are cited for support of this proposition: scholarly research concluding that "persons without disabilities systematically undervalue the quality of life of those with disabilities" in quality of life surveys; the OTA "found this bias against persons with disabilities in the Oregon survey results;" and the

survey allowed bias to be taken into account, or that the survey affected the final ranking.<sup>130</sup> Instead, Oregon argued that the impact of the survey on the final ranking of health services was "real but limited."<sup>131</sup> In contrast, HHS characterized the impact as "appreciable."<sup>132</sup> Thus the analysis concluded that "[u]nless Oregon funds all of the health services on its prioritized list every year, it is unlikely . . . that the Commission could demonstrate that the telephone survey data will have no effect on which medical conditions are treated."<sup>133</sup>

Second, Sullivan observed that other aspects of the ranking process reflected discrimination on the basis of disability.<sup>134</sup> Therefore, the rankings should be redone without taking certain community values into account.<sup>135</sup> The ranking of health service categories by the commissioners and the hand adjustments to the prioritized list were seen as problematic by HHS.<sup>136</sup> "[Q]uality of life" and "ability to function" were the two community values used impermissibly.<sup>137</sup> These two values placed importance on "'restored health' and functional 'independence' and thus expressly value[d] a person without a disability more highly than a person with a disability in the allocation of medical treatment."<sup>138</sup> The analysis

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HSC stated that "those who had experienced the problem [impaired health state] did not feel it was as severe as those who had not experienced the problem." *Id.*

130. *Id.*

131. *Id.* More precisely, Oregon argued that "statistical analysis demonstrates that the survey has virtually no effect on the ultimate rankings of condition/treatment pairs." *ISSUE BRIEF, supra* note 78, at 7. Oregon characterized the impact as "negligible," and emphasized that the data was used "only as a general barometer of the public's attitudes toward certain morbidities." *Id.* at 4. Oregon noted that a re-ranking of the list, using alternative morbidity scores in the calculations, produced a virtually identical prioritization list. *Id.* This serves to "underscore the insignificance of the morbidity score in the HSC's overall calculation of net benefits." *Id.*

132. HHS ANALYSIS, *supra* note 124, at 1. The analysis based this characterization on Oregon's own data indicating that "120 services would move at least 30 places . . . and more than 50 services would move at least 50 places on the list if constant values of 0.5 were substituted for values generated by the survey." *Id.* at 1-2.

133. *Id.* at 2.

134. *Id.*

135. *Id.*

136. *Id.*

137. *Id.* at 2. After a series of 47 community meetings, the full list of values which were arrived at by consensus included prevention, cost-effectiveness, equity, effectiveness in treatment, benefits many, mental health and chemical dependency, personal choice, community compassion, impact on society, length of life, and personal responsibility. HSC REPORT, *supra* note 39, at App. F.

138. HHS ANALYSIS, *supra* note 124, at 2. Quality of life was discussed at all community meetings. OREGON HEALTH DECISIONS, HEALTH CARE IN COMMON: REPORT OF THE OREGON HEALTH DECISIONS COMMUNITY MEETINGS PROCESS 11 (1990), *reprinted in*

noted that “any methodology that would intentionally ration health care resources by associating quality of life considerations with disabilities does not comport with the mandate of the ADA.”<sup>139</sup>

A third observation was that under *Alexander v. Choate*,<sup>140</sup> Oregon may consider “any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities.”<sup>141</sup> Factors which Sullivan suggested Oregon consider in allocating medical resources included “the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases.”<sup>142</sup>

Fourth, Sullivan expressed concern with the rankings of two specific condition/treatment pairs that fell below the funding cutoff line.<sup>143</sup> The first was liver transplants for alcoholic cirrhosis of the liver.<sup>144</sup> Sullivan stated that there is no “medical underpinning” for a distinction between transplants for alcoholic and non-alcoholic cirrhosis of the liver.<sup>145</sup> Thus, the Medicaid coverage decision violated the ADA because it rested entirely on the presence of alcoholism, which is considered a disability under Title II.<sup>146</sup> “Decisions with respect to coverage of such treatment could, however, be made based on an appropriate record.”<sup>147</sup> For exam-

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HSC REPORT, *supra* note 39, at App. F. [hereinafter OHD REPORT]. Services which enhance quality of life “are those which enhance a person’s productivity and emotional well being, restore an individual’s health, reduce pain and suffering, and allow one to function independently.” *Id.* “A high quality of life was felt to be valuable because it increases emotional well being, reduces pain and suffering, and increases productivity, independence, and length of life.” *Id.*

Ability to function was discussed at 75% of the community meetings. *Id.* at 14. Ability to function “includes emotional well being, productivity (not necessarily economic), independence, and restored quality of life.” *Id.* Ability to function is valuable “because it implies restoring a person to a preillness state (or as close as possible) and to independence.” *Id.*

139. HHS ANALYSIS, *supra* note 124, at 2.

140. 469 U.S. 287 (1985).

141. HHS ANALYSIS, *supra* note 124, at 2; *see also Choate*, 469 U.S. at 302.

142. HHS ANALYSIS, *supra* note 124, at 2. The permissible factors are not limited to the four listed. *Id.*

143. *Id.*

144. *Id.*

145. *Id.* at 3. Liver transplants for alcoholic cirrhosis of the liver are ranked at line 690, while such transplants for non-alcoholic cirrhosis are ranked at line 366. *Id.* at 2-3. A “medical underpinning” that would substantiate the need for differential treatment would be that a transplant is a more successful treatment for one type of cirrhosis but not the other. *Id.* at 3.

146. *Id.*

147. *Id.*

ple, Oregon could adopt a Medicaid standard that requires "evidence of sufficient social support to assure assistance in alcohol rehabilitation" before the procedure is funded.<sup>148</sup>

The second condition/treatment pair involved treatment of extremely low birth weight babies with gestation periods of less than 23 weeks.<sup>149</sup> The concern here was similar to the concern for transplants for alcoholic cirrhosis of the liver: the possibility of differential treatment of similarly situated individuals.<sup>150</sup> Under the Oregon proposal, medical therapy was available for low birth weight babies that exceeded 499 grams and apparently for low birth weight babies less than 500 grams but with gestation periods of more than 23 weeks.<sup>151</sup> Presuming that low birth weight with a gestation period less than 23 weeks was a protected disability under the ADA, Oregon's distinction in prioritization violated Title II.

Sullivan's fifth observation also involved low birth weight babies. The Child Abuse Amendments of 1984 "established standards relating to the withholding of treatment for medically fragile infants."<sup>152</sup> Those amendments gave "substantial deference to the medical judgment of the treating physician" and presupposed the rendering of certain life support services.<sup>153</sup> Concluding that the low priority ranking of such medical therapy amounts to a refusal to cover life support for medically fragile infants, the ranking was found to be inconsistent with the provisions of the Child Abuse Amendments.<sup>154</sup>

### III. RESPONSE AND COMMENT

#### A. *Public Values and Political Accountability*

In formulating the prioritization process, Oregon understood that the

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148. *Id.*

149. *Id.* at 2.

150. *Id.* at 3.

151. *Id.* Medical therapy for low birth weight babies who exceed 499 grams is ranked at line 22. *Id.*

152. *Id.* In 1984, Congress amended the Child Abuse Prevention and Treatment and Adoption legislation, giving HHS additional authority for regulating discrimination against handicapped newborns. OTA REPORT, *supra* note 100, at 186. The amendments defined "the withholding of medically indicated treatment and nutrition from handicapped infants as a type of child abuse," and conditioned the receipt of federal funds on a state's enforcement of its laws prohibiting such child abuse. *Id.* at 186-87. Exceptions to the withholding of "medically indicated treatment" are permitted under the implementing regulations only under narrowly defined circumstances. *Id.* at 187.

153. HHS ANALYSIS, *supra* note 124, at 3. Such life support services include medication, nutrition and hydration. *Id.*

154. *Id.*; see OTA REPORT, *supra* note 100, at 187 (supporting this conclusion).

composition of a basic benefit package “should result from an open, democratically driven process in which public values and technical expertise play complementary roles.”<sup>155</sup> Indeed, any health resource allocation decision ought to involve public values and political accountability, as well as technical choice.<sup>156</sup> Understanding that “[s]omeone’s values necessarily play a role in defining basic benefits,” and “[w]ho supplies those values is the question,” Oregon allowed its citizens to play a definitive role.<sup>157</sup> Instead of deferring to expert opinion and judgment, Oregon sought to balance technical expertise with values from a “common good perspective.”<sup>158</sup> Oregon envisioned the public’s role as a means of ensuring political accountability for explicit rationing in health resource allocation.<sup>159</sup>

The rationale underlying HHS’s denial of the necessary waivers for full implementation of the Oregon Demonstration Project strikes at the very heart of Oregon’s innovation. The key criticisms of Oregon’s process for developing the prioritized list are aimed at the public opinion surveys and the community meetings. Yet these are precisely the innovations that allow for open debate, explicit decision-making, and political and social accountability. HHS’s mandates for changes in the prioritization process would take decisions out of the hands of the people and place them back in the hands of the few, the experts. These few are far removed from accountability and, arguably, just as susceptible to inappropriate bias. This reallocation of decision-making effectively leaves Oregon where it began: without any real accountability for the health resource allocation decisions that must be made.

## B. *Rebuttal of Waiver Denial*<sup>160</sup>

### 1. *HHS’s First Mandate*

HHS’s first mandate requires that the prioritization process be redone without taking into account data derived from the phone survey. According to HHS, three sources of information demonstrate that the quality of life information gleaned from the surveys quantify stereotypic assumptions about persons with disabilities.<sup>161</sup> However, none of these sources

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155. Garland, *supra* note 57, at 74.

156. *Id.*

157. *Id.*

158. *Id.*

159. See discussion *supra* part I.C.1.

160. For a full discussion of the reasons behind the HHS denial, see *supra* part II.B.

161. HHS ANALYSIS, *supra* note 124, at 1.



support HHS's conclusion.

The first source relied upon is a body of scholarly research indicating that "persons without disabilities systematically undervalue the quality of life of those with disabilities."<sup>162</sup> As an example of such scholarly work, HHS specifically cited an article in the Hastings Center Report by David C. Hadorn.<sup>163</sup> However, this same author more recently concluded that "[t]here is no evidence that ratings for health states (e.g., a specified state of pain or of limited activity) differ with ability level."<sup>164</sup> Furthermore, Hadorn concluded that "there is little evidence that the ratings obtained from the Oregon poll differ systematically from the ratings that would have been obtained from disabled people."<sup>165</sup> Hadorn found that Oregon's data on respondents' health and ability levels reveal no substantial differences in values based on these levels.<sup>166</sup> He thus concluded that "a disabled person's assessment of his or her own personal quality of life, while often higher than might be expected, cannot necessarily serve to indicate how that person would rate different levels of disability in the abstract."<sup>167</sup> Moreover, it is likely that even disabled persons prefer nondisabled states, and that they would rate nondisabled states higher than disabled states.<sup>168</sup>

The OTA report is the second source relied on by HHS. HHS argued that OTA found a bias against persons with disabilities in the Oregon survey results.<sup>169</sup> Yet this same report states that:

[i]ronically, OTA analyses of the list showed that the weights from the public survey had relatively little effect on the final rankings on the list . . . . Furthermore, where survey responses differed according to the health experiences of the respondent, the result in at least a few cases could be to increase the relative weight assigned to a given treatment that would reduce the disability.<sup>170</sup>

Relying in part on this passage from the OTA Report, Oregon argued in its issue brief to HHS that the use of the results of the telephone survey

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162. *Id.*

163. See David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy*, HASTINGS CENTER REP., May-June 1991, 11, 11 (citing other studies).

164. Hadorn, *supra* note 105, at 1455.

165. *Id.*

166. *Id.*

167. *Id.*

168. *Id.*

169. HHS ANALYSIS, *supra* note 124, at 1.

170. OTA REPORT, *supra* note 100, at 186.

as *one* of several factors in the prioritization process did not bias the final list.<sup>171</sup> In addition to statistical analysis demonstrating that the survey had virtually no effect on the final rankings, there is no evidence to suggest that the survey was flawed or biased.<sup>172</sup>

The Oregon Health Services Commission Report is the third source cited by HHS. The HSC Report indicates that "those who had experienced the problem [impaired health state] did not feel it was as severe as those who had not experienced the problem."<sup>173</sup> This conclusion, however, is limited to five specific health states: (1) difficulty in learning, remembering or thinking clearly; (2) coughing, wheezing, or difficulty breathing; (3) taking prescribed medication or following a diet for health reasons; (4) wearing glasses or contact lenses; and (5) difficulty in sexual performance.<sup>174</sup> The HSC conclusion therefore only applies to these five health conditions.

HHS attempted to cite the HSC Report out of context and to create the impression that Oregon's own report indicates discriminatory and impermissible bias in the telephone survey results. This is not a proper conclusion to be drawn from the material cited by HHS.<sup>175</sup> Furthermore, reliance on the OTA Report and scholarly research to support the proposition that the survey results were biased is misplaced. While such evidence may very well exist, HHS failed to employ its use in the denial of the federal waiver.

One should also observe that the impact of the telephone surveys on the final prioritized list is really a matter of characterization. Oregon called the impact "real but limited," and "negligible."<sup>176</sup> Oregon based these characterizations on its comparison of the prioritized list with a re-ranked list that substituted constant values for the survey results.<sup>177</sup> But HHS called the impact "appreciable," based on *its* assessment of the *same comparison*.<sup>178</sup> Such disparity in interpretation leaves the validity of

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171. ISSUE BRIEF, *supra* note 78, at 7 (emphasis added).

172. *Id.*

173. HHS ANALYSIS, *supra* note 124, at 1 (citing HSC REPORT, *supra* note 42, at app. C-11).

174. HSC REPORT, *supra* note 42, at app. C-11.

175. See discussion *supra* at note 131 (indicating that the survey's impact on the final rankings was negligible at best).

176. ISSUE BRIEF, *supra* note 81, at 4, 7.

177. *Id.*

178. For a full discussion of the community meeting process, see *supra* notes 85, 137 and 138, and accompanying text.

either standard and the actual significance of the survey in the prioritization process in question.

## 2. *HHS's Second Mandate*

HHS's second mandate required that the prioritized list be redone without taking into consideration the community values of "quality of life" and "ability to function." These two values were among the fourteen values identified by Oregonians as important in making health resource allocations, based on a series of forty-seven community meetings held throughout the state.<sup>179</sup> HHS criticized the role these two values played in the ranking of categories and hand adjustments to the prioritized list.

Disallowing the use of these two values in the prioritization process further undermined Oregon's goal of achieving real accountability in its health resource allocation decisionmaking. It is important to note that HHS did not object to the actual process used to rank the condition/treatment categories and the making of hand adjustments to the list. HHS also did not object to HSC's role as the entity to carry out this part of the process. The objection was limited solely to the roles that the values of "quality of life" and "ability to function" played.

Arguably, values play a role in assessing quality of life whenever medical treatment decisions are made. HHS simply shifted whose values play that role from the community to the Commission members. Rather than community values, derived from consensus and thus more likely to reflect some degree of objectivity, serving as general guiding principles for the Commission, the Commission members are confined to their own perceptions and perspectives. The subjective judgments of these few members effectively undermines Oregon's effort to create a decision-making process that holds all Oregonians accountable for health resource allocation.

Furthermore, several factors keep the potential negative effects of "quality of life" and "ability to function" in check. Twelve other values were identified in the community meetings, including the values of equity, effectiveness, and community compassion.<sup>180</sup> These values reflect

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179. For a full discussion of the community meeting process, see *supra* notes 88, 140 and 141 and accompanying text.

180. The concept of equity stem[s] from a basic premise that no person should be excluded from receiving health care when they need it. This was often voiced as feeling that government should take more responsibility in the health care arena to work towards the assurance that everyone has equal access to an adequate level of health care. Eq-

community insistence that health care must be available to all, that compassion must be shown to those with debilitating conditions, and that effectiveness must be measured by improvement in quality of life as well as by cure. Coupled with the general goal of promoting health in terms of maintaining, restoring, or improving health,<sup>181</sup> these values check potential abuses of "quality of life" and "ability to function" considerations.

Recognition by Oregon citizens of the potential hazards of making quality of life assessments is another factor that limits the potential negative effect of considering the the values of "quality of life" and "ability to function." Oregon Health Decisions (OHD), a community organization that conducted the community meetings for OHS, noted that citizens had difficulty articulating objective criteria for measuring quality of life.<sup>182</sup> OHD also noted citizen concern "about who had the right to make decisions regarding one's quality of life."<sup>183</sup> HSC knew of these concerns as it ranked the categories and made line by line adjustments. Thus, HSC was aware that its decision-making authority could be abused. Arguably, this served as a second check on the negative consequences of including quality of life and ability to function in this part of the process.

### 3. HHS's Third Mandate

The third mandate required that the factors considered when prioritizing health care services be content neutral, not take disability into account, and not have a particular exclusionary effect on disabled persons.<sup>184</sup> Accordingly, HHS would have the ranking process devoid of any reference to quality of life and limited to a set of "neutral" criteria.

Regarding content neutrality, Oregon may consider factors such as cost of medical procedures, length of hospital stays, prevention of death, and prevention of contagious diseases.<sup>185</sup> HHS also suggested that methodol-

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uity was felt to be valuable because it encompasses justice and humaneness in health care . . . .

OHD REPORT, *supra* note 138, at 15. Effective treatment includes "an indication of success rate which incorporates a cure rate, improvement in quality of life, and length of success, with priority going to long term success over short term success." *Id.* at 17. Community compassion includes "a community concern for life, preserving the integrity of an individual and a family, and compassion for the vulnerable such as children and the elderly. Community compassion was felt to be valuable because it encourages humaneness in caring, and a sense of community support." *Id.* at 21.

181. See *supra* part I.C.1 for the relevant policy discussion.

182. See OHD REPORT, *supra* note 138, at 11.

183. *Id.*

184. See HHS ANALYSIS, *supra* note 124, at 2.

185. *Id.*

ogies that intentionally ration health care resources by associating quality of life considerations with disabilities will not conform to the mandates of the ADA.<sup>186</sup> Oregon, however, associated quality of life considerations with *all* health states, not just disabilities. There is no disparate treatment of similarly situated individuals because all persons are treated the same. Furthermore, by disallowing quality of life as a consideration in the prioritization process, HHS actually hinders some treatments utilized by the disabled from receiving higher rankings.<sup>187</sup> “Failing to differentially value states of disability vs. nondisability would result in a policy that failed to value ability-restoring treatments.”<sup>188</sup>

Regarding the requirement that factors not take disability into account, HHS has essentially proposed a new standard for measuring exclusion of a qualified individual “by reason of such disability.”<sup>189</sup> The standard set forth in *Alexander v. Choate* for determining when disability has been taken into account requires that the disabled not be denied access to or excluded from the Medicaid services that a state has chosen to provide for all Medicaid recipients on the basis of their present disability.<sup>190</sup> HHS implied that the Oregon plan discriminates based on an individual’s fu-

186. *Id.*

187. See ISSUE BRIEF, *supra* note 78, at 7 (quoting OTA REPORT, *supra* note 100, for the proposition that “[w]here survey responses differed according to the health experience of the respondent, the result in a[t] least a few cases could be to increase the relative weight assigned to a given treatment that would reduce the disability”).

188. Hadorn, *supra* note 105, at 1455.

The actual use of differential preference judgments for quality-of-life states (including functional status) lies in the consequent ability of the prioritization process to identify - and ensure coverage for — services that restore function (or prevent the loss of function) . . . . These treatments would not be valued very highly if disabled persons’ post hoc preferences were used as the standard of valuation, since (according to the Center report, at least) disabled people consider states of limited functioning to be virtually as desirable as states of full function . . . . If limited function isn’t so bad after all, in other words, services that improve function will not be considered particularly worthwhile.

*Id.* at 1456.

189. See 42 U.S.C. § 12132 (West Supp. 1991).

190. ISSUE BRIEF, *supra* note 78, at 8. In *Choate*, the Supreme Court noted:

The new limitation does not invoke criteria that have a particular exclusionary effect on the handicapped; the reduction, neutral on its face, does not distinguish between those whose coverage will be reduced and those whose coverage will not on the basis of any test, judgment, or trait that the handicapped as a class are less capable of meeting or less likely of having . . . . The reduction in inpatient coverage will leave both handicapped and nonhandicapped Medicaid users with identical and effective hospital services fully available for their use, with both classes of users subject to the same durational limitation.

*Id.* (quoting *Alexander v. Choate*, 469 U.S. 287, 302 (1985)).

ture disabled state.<sup>191</sup> No regulations have been promulgated to support this expanded interpretation articulated by HHS. Furthermore, under the Oregon plan, a person's present disability has no impact on whether a particular health care service is covered by the plan, or on whether an otherwise qualified individual is eligible for a particular medical treatment.<sup>192</sup> Oregon thus meets the standard set forth in *Alexander v. Choate*, and does not unlawfully take disability into account.

The presence of bias in the prioritization process is debatable. Some argue that no service was left unfunded because of bias against the disabled.<sup>193</sup> The next section will demonstrate that these concerns can be addressed without dismantling the entire Oregon project.

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191. For example, picture the following scenario:

Patient A and Patient B are both injured in an accident. Treatment A is recommended for Patient A, while Treatment B is recommended for Patient B. Both treatments cost the same. However, Treatment A will sustain Patient A's life but will not restore the abilities A lost after the accident (such as an ability to walk), while Treatment B will sustain B's life and restore his ability to walk. If the basis for funding B but not A is a quality-of-life judgment that being able to walk is of greater benefit than not being able to walk, for example, then a decision to deny treatment for A would be discrimination based on A's *resulting level of disability*. In effect, B's life would be considered more valuable than A's life because B will regain an additional function while A would not. Under the second scenario, a distinction between two effective treatments would be based not on treatment effectiveness, because both treatments would sustain life, but on an inappropriate assessment of the underlying quality-of-life each patient will have after treatment. This scenario describes the Oregon Plan.

Marzen & Avila Letter, *supra* note 117, at 6 (emphasis added).

192. ISSUE BRIEF, *supra* note 78, at 7. Thus, under the Oregon plan,

the amputee who requires treatment for a ruptured spleen will be treated exactly the same as an individual without such a disability. The deaf individual who has an upper respiratory infection and common cold will likewise be treated the same under the OHP as an individual who can hear. In sum, whether or not a participant in the OHP has a disability has no bearing on whether a particular condition is covered. All OHP participants are subject to the same benefits and limitations imposed by the OHP, regardless of whether or not they are disabled.

*Id.* Further, "[t]he 587 funded condition/treatment pairs will be available uniformly to all participants with or without disabilities." *Id.* at 8. "The existence or non-existence of a disability simply is not a factor in determining whether a participant is covered for a particular health service; what is determinative is whether the health service is one that the Oregon legislature has determined to fund." *Id.* at 9.

193. See Virginia Wilson, *Woe the Reformers*, NEWSWEEK, Oct. 19, 1992, at 55. "If even a hint of such a judgment infects a health-insurance plan, its provisions may now be fatally flawed. That's chiefly what nailed the Oregon proposal, although [Michael] Astrue [general counsel at HHS] can't name any service left unfunded because of bias against the disabled." *Id.*

#### 4. *HHS's Fourth Mandate*

HHS's fourth mandate is specific to the placement of two condition-treatment pairs: liver transplants for alcoholic cirrhosis of the liver and life support for extremely low birth weight babies under twenty-three weeks gestation.<sup>194</sup> HHS's concern is that the ADA is violated because individuals with these disabilities will not receive treatment, while similarly situated individuals without these two conditions will be treated.<sup>195</sup>

The ranking of low birth weight babies under twenty-three weeks gestation is easily resolved without rejecting or dismantling the entire prioritization process. HSC is required to update the prioritized list every two years.<sup>196</sup> Additionally, the Commission is authorized to adjust the list in the interim to make technical changes due to errors, omissions, advances in medical technology, or new data regarding health outcomes.<sup>197</sup> This authority means that "[t]o the extent an advocacy group can point to the ranking of a specific condition/treatment pair as somehow discriminating against the disabled, the group [can] request that the condition/treatment pair be specifically evaluated by the HSC."<sup>198</sup> This approach allows the Commission to revise and modify the Demonstration Project to accommodate particular concerns when reasonable, without invalidating the entire plan.<sup>199</sup>

#### 5. *HHS's Fifth Mandate*

In its fifth mandate, HHS responded to concerns over potential violations of the Child Abuse Amendments of 1984, which established standards relating to the withholding of treatment for medically fragile infants.<sup>200</sup> Presumably, this mandate could be addressed in the same manner as the fourth mandate. Therefore, instead of dismantling the entire prioritization process, this particular legal concern could be addressed through the HSC authority to adjust the prioritized list.

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194. HHS ANALYSIS, *supra* note 124, at 2.

195. See Commission Minutes, *supra* note 15, at 3.

196. ISSUE BRIEF, *supra* note 78, at 5.

197. *Id.*

198. *Id.* at 9.

199. *Id.*

200. See *supra* note 152 for a discussion of these amendments.

### C. Further Comments and Considerations

#### 1. Impact on State Reform

In recent years, increased activity has occurred at the state level with regard to health care reform. With the severity of the health care crisis increasing and the absence of federal action, states are taking the lead in health care reform.<sup>201</sup> While some argue that the state level is the appropriate level for change, others believe that the only way to make significant progress is through reform at the national level.<sup>202</sup> All recognize, however, that states play a critical role in health care reform.

Many leaders look to the Oregon Demonstration Project as a model that might be duplicated in other states.<sup>203</sup> However, the denial of the federal waivers and the reasoning behind HHS's decision have created heightened tension among many state reformers. Alicia Pelrine, Director for Human Resources for the National Governor's Association, stated that "it has certainly created a sense of nervousness among the other states about whether the administration is really interested in allowing the states to move forward on comprehensive reform efforts."<sup>204</sup> Likewise, there has been concern that the ultimate message "is that if you use the democratic process and you thrash this out among the citizens of the state, you run the risk of getting a negative answer. Whereas if you . . . do it in secret . . . you may have a better shot at getting your waiver approved."<sup>205</sup>

While the final impact on state reform efforts is unclear, HHS's denial of the federal waivers may have a chilling effect on a state's willingness to engage in innovative projects, which may ultimately endanger efforts at the national level. States are often looked to as "laboratories" for engaging in social experimentation. Without state activity, national reform will lack an important resource for creativity and innovation in solving health

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201. Freedman, *supra* note 9, at 36-37. "Virtually every state either has taken action on the problem or is considering legislation." *Id.* at 37; *see also* Greenberg, *supra* note 9, at 1101 (describing reform efforts in Minnesota, Florida, Hawaii, and Oregon).

202. Compare McDonough, *supra* note 9, at 61 (arguing that "[s]tates occupy a critical role in the debate about health care"), with Deborah Stone, *Why the States Can't Solve the Health Care Crisis*, AM. PROSPECT, Spring 1992, at 51 (arguing that "states cannot do it alone, however, because of fundamental impediments in the federal system").

203. *See, e.g.*, Sullivan Letter, *supra* note 13.

204. Interview: *A View from the National Governor's Association*, Health Line, American Political Network, Inc., Aug. 7, 1992 [hereinafter *Pelrine Interview*](on file with the *Journal of Contemporary Health Law & Policy*).

205. *Id.*



care problems, as well as a forum to test new ideas before national implementation.

## 2. *The Oregon Plan as One Step Forward*

It is important to remember that Oregon does not intend the Demonstration Project to serve as a final solution for the state's health care crisis. Rather, it is intended as a temporary means of combatting the twin problems of accessibility and affordability in a limited context. Efforts to find a national solution must continue. Many of the criticisms of the Oregon Demonstration Project have been directed at Oregon's failure to create an ideal solution.<sup>206</sup> However, the Oregon Demonstration Project must be evaluated as "an improvement over the status quo."<sup>207</sup> Thus, although the Oregon plan may fall short of the ideal in many regards, its efforts ought to be encouraged.

## 3. *A Guaranteed Minimum Benefits Package*

A major criticism of the Oregon Demonstration Project is that because the cutoff line for coverage is based on financial considerations, the level of coverage can rise and fall with budgetary pressures.<sup>208</sup> Arguably, Oregon's approach is just as arbitrary as the current means of dealing with budgetary shortfalls.<sup>209</sup> One solution is to require Oregon to increase the number of services funded,<sup>210</sup> and to commit to a minimum level of coverage for the entire period of the demonstration project.<sup>211</sup> By going somewhat further down the list in its commitment to funding, Oregon

206. See John A. Kitzhaber, *Constructive Debate in a Real World*, HMQ, First Quarter 1991, at 16.

207. *Id.* Kitzhaber states:

Will the Oregon plan resolve all inequities and inefficiencies and produce the perfect system? Of course not. In an ideal system . . . everyone would have access to every medical service and procedure, and no one would have to pay. But contrary to the intimations of our critics, we have never claimed that our proposal represents the best system. We claim only that it represents a better one, that it is both more equitable and more effective in promoting the general health of the population, and that it adheres to a clearly defined policy, which we are prepared to defend . . . .

*Id.* at 17.

208. Robert Steinbrook & Bernard Lo, *The Oregon Medicaid Demonstration Project - Will It Provide Adequate Medical Care?*, 326 *NEW ENG. J. MED.* 340, 343 (1992).

209. *Id.* Such current methods include "further restricting Medicaid eligibility criteria, underfunding services, or setting artificially low rates of reimbursement to providers." *Id.*

210. *Id.*; see also Joshua M. Wiener, *Oregon's Plan for Health Care Rationing*, *BROOKINGS REV.*, Winter 1992, at 26, 31.

211. Wiener, *supra* note 210, at 31.

might achieve an "adequate benefit package."<sup>212</sup> Such a package would encompass most of the eight condition/treatment pairs classified as "essential to basic care," and the fifty-one pairs the Commission assessed as "very important," but which are not currently slated for funding.<sup>213</sup> This kind of approach is more acceptable than redrawing lines according to politics and finances.<sup>214</sup> Even more importantly, "[i]f Oregon lengthens the list and guarantees maintenance of that level of coverage, it might be the demonstration that helps us end our national disgrace in health care."<sup>215</sup>

#### IV. CONCLUSION

Under current case law and regulations promulgated pursuant to section 504 of the Rehabilitation Act of 1974 and the Americans With Disabilities Act, there is no legal precedent for invalidating as discriminatory a decision-making process in a non-employment related context. The Oregon Demonstration Project is neutral on its face, and does not impermissibly "take disability into account," as the Supreme Court currently interprets this phrase. Furthermore, the Oregon Demonstration Project already has procedures to correct any instances of discrimination that might occur and to accommodate specific concerns as to exclusionary effects. Therefore, dismantling the entire prioritization process is unnecessary. Without supporting case law or implementing regulations, the Department of Health and Human Services proposed a new standard for finding disability-based discrimination when it denied the necessary waivers to implement the Oregon Demonstration Project. Arguably, this is beyond the scope of HHS's authority. Ironically, this misapplication of the ADA could weaken its strength and effectiveness in protecting the rights of the disabled.

While not perfect, the Oregon Demonstration Project *is* a step forward from the status quo. The true innovation of the Oregon plan is its ability to achieve accountability in the health resource allocation decision-making process. The specific mandates of HHS and the reasoning behind them have undermined efforts to attain this goal, and stalled one of the first significant steps down the road to health care reform.

*Catherine Grace Vanchiere*

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212. *Id.*

213. *Id.*

214. Steinbrook & Lo, *supra* note 208, at 343.

215. Wiener, *supra* note 210, at 31.

