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Health Care Rationing and Disability Rights

PHILIP G. PETERS, JR.*

"Should somebody at some level be in a position to say no?"¹

—Senator John C. Danforth

INTRODUCTION

By publicly suggesting to Hillary Rodham Clinton that potentially beneficial health care should sometimes be rationed, Senator Danforth touched "one of the rawest nerves in the health-care debate."² The examples he used frame the issue nicely:

- A baby kept alive in Virginia by respirator although she has almost no brain;³
- Siamese twins surgically separated by a procedure that would kill one and give the other only a one percent chance of survival;⁴
- Aggressive treatment of very low birth weight babies with a less than fifteen percent chance of functioning;
- Providing a pacemaker to a ninety-two-year-old man.

Danforth could easily have given other examples, such as the Florida family which insisted upon dialysis for a family member in a persistent vegetative state⁵ or the suggested protocol of taking six sequential stool guaiacs to test for colon cancer detected by the final sample at a cost of forty-seven million dollars per case.⁶

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1. Charlotte Grimes, *Some Health Rationing Needed, Danforth Says*, ST. LOUIS POST-DISPATCH, Oct. 1, 1993, at 5C (quoting from proceedings before the Senate Finance Committee on the previous day). Ms. Clinton responded: "I would agree for both moral and ethical reasons, as well as economic ones, there has to be the kind of difficult conversation that you are suggesting." *Id.* She suggested that the debate should wait until passage of a bill providing all Americans with insurance coverage. See also Melinda Beck, *Rationing Health Care*, NEWSWEEK, June 27, 1994, at 30.

2. Grimes, *supra* note 1, at 5C.

3. He may have had in mind the recent case of Baby K. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). Her care reportedly cost \$246,000 through mid-June for hospital care alone; she resides in a nursing home when not hospitalized. Jane B. Quinn, *Taking Back Health Care*, NEWSWEEK, June 27, 1994, at 36.

4. Danforth may have been referring to the Lakeberg Siamese twins, whose unsuccessful care reportedly cost \$1.3 million. See Beck, *supra* note 1, at 30.

5. Judith W. Ross, *The Puzzle of the Permanently Unconscious*, HASTINGS CTR. REP., May-June 1992, at 2, 3.

6. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 232 (3d ed. 1989) (discussing stool guaiacs). This is a sequential testing procedure used for colon cancer which, on

Any criterion suggested for rationing health care will be controversial. The stakes are high and no popular or ethical consensus has emerged. But allocation decisions are omnipresent and their continuation is inevitable. Common sense tells us to give priority to services that do the most good. As a result, an approach which would eliminate only the least beneficial or least cost-effective treatments has considerable potential appeal. It offers both the promise of maximizing health care outcomes from limited resources and the surface allure of scientific objectivity and nonpartisan neutrality. Not surprisingly, both the use and the advocacy of effectiveness measurements have expanded significantly in recent years.

But rationing the least effective care has a dark side beneath its veneer of objectivity. Any health care allocation scheme which attempts to maximize health care outcomes by giving priority to the most effective treatments has the potential to disfavor disabled patients and others, such as the elderly and the frail, whose quality of life is most impaired or whose conditions are most resistant to cure. As a result, the use of effectiveness criteria to allocate health resources may be challenged as violating society's commitment to equality in general, and to protection of those with the greatest need in particular.

The resolution of this conflict between efficiency and equality has dramatic implications for health policy. Although it surfaced most prominently when the State of Oregon attempted to obtain federal waivers for its health care rationing plan, the conflict is not unique to Oregon's plan or even to government programs. It arises whenever effectiveness or cost-effectiveness is used by health care providers or insurers to determine which treatments to provide or insure. Those instances range from bedside decisions by clinicians to macroallocation decisions by benefit plans about coverage of conditions such as AIDS, infertility, or mental illness. In each setting, allocations based on medical utility have the potential to disfavor some patients on the basis of their disability.

This Article explores the extent to which federal disability rights law limits the use of effectiveness criteria to allocate health care, either alone or as a part of cost-effectiveness analyses. To be more precise, it considers the circumstances in which disability-based classifications by health plans which would otherwise violate the anti-discrimination laws can be legally and ethically defended by proof that the excluded treatments are less effective than those which are provided.

Part I introduces the expanding use of effectiveness analysis in health care, explains its discriminatory potential, and reviews the Oregon experience. Part II outlines the current federal law protecting the rights of disabled persons to health care. The remaining portions of this Article examine, first, whether measures of effectiveness that do not take quality of life into account, such as survival rates, violate the rights of disabled persons (Part III), and, second,

the sixth try, detects three cases for each one million patients tested. Each case detected costs \$47 million (in 1975 dollars). See Duncan Neuhauser & Ann M. Lewicki, *What Do We Gain From the Sixth Stool Guaiac?*, 293 NEW ENG. J. MED. 226, 227 tbl. 2 (1975).

whether the additional issues raised by quality of life considerations preclude their use (Part IV). While the arguments for prohibiting the use of measures of effectiveness such as survival or success rates are surprisingly powerful, they are not sufficient to outweigh the ethical and legal arguments for permitting their use in proper circumstances. Quality of life considerations are more troublesome. When used to rank life-sustaining care, they would place a lesser value on the life of a disabled person than on the life of a person who could be restored to full function. If used in that way, quality of life considerations will probably be held to violate the existing disability rights laws. But because quality of life is relevant, even in the context of life-extending care, it is time to begin discussing the circumstances in which to authorize its use.

The objective of this essay is to make a preliminary exploration of the legal and ethical legitimacy of using medical effectiveness as a criterion for the allocation of health resources. The vulnerability of health-care plans which take the effectiveness of treatments into account, however, will also depend upon the resolution of several other crucially important legal issues not addressed here. For example, some court opinions appear to suggest that plans which favor one disability over another are less vulnerable to challenge than those which treat people without disabilities more favorably than persons with disabilities.⁷ Also, considerable confusion currently exists as to the vulnerability of exclusions which have a disproportionately unfavorable impact on disabled patients but which do not make facial classifications on the basis of disability (e.g., a limit on blood transfusions that disproportionately affects hemophiliacs).⁸ Health insurers have also suggested, so far unsuccessfully, that the anti-discrimination statutes do not apply to coverage restrictions

7. See, e.g., *Turnage v. Turner*, 485 U.S. 535, 549 (1988) ("There is nothing in [Section 504] that requires that any benefit extended to one category of handicapped persons also be extended to all other categories of handicapped persons."); *Doe v. Colautti*, 592 F.2d 704, 708-10 (3d Cir. 1979); *Duquette v. Dupuis*, 582 F. Supp. 1365, 1370-72 (D.N.H. 1984); *Doe v. Devine*, 545 F. Supp. 576, 585 (D.D.C. 1982) (noting that equal benefits are not required, but in fact were provided), *aff'd*, 703 F.2d 1319 (D.C. Cir. 1983). But see *McGuire v. Switzer*, 734 F. Supp. 99, 114-15 (S.D.N.Y. 1990) (holding that the plaintiff had established a cause of action under § 504 based on the state's higher tuition and maintenance reimbursement to blind individuals as compared to reimbursement to other disabled individuals).

8. Compare 42 U.S.C. § 12182(b)(2)(A)(i); *Alexander v. Choate*, 469 U.S. 287, 292-302 (1985) (assuming without deciding that Section 504 reaches "at least some conduct that has an unjustifiable disparate impact upon the handicapped" and making a powerful argument that this assumption is appropriate, but imposing a novel "meaningful access" test); and 28 C.F.R., pt. 35, app. A § 35.130, at 449 (1994) with EQUAL EMPLOYMENT OPPORTUNITY COMM'N, INTERIM GUIDANCE ON DISABILITY-BASED DISTINCTIONS IN HEALTH CARE PLANS (June 6, 1983) [hereinafter EEOC, INTERIM GUIDANCE], reprinted in 2 Accommodating Disabilities (CCH) ¶ 140,150, at 140,022 n.1, 140,024 n.7 (assuming that the disparate impact theory is unavailable under the ADA or Section 504). The Equal Employment Opportunity Commission ("EEOC") has since indicated that it might change its position as to the availability of the disparate impact theory. FACILITY HEALTH MANAGEMENT, HEALTH LAW FOCUS (CCH), Dec. 21, 1993, at 2, 2-3 (reporting remarks to the Labor Relations Section of the District of Columbia Bar by Peggy Mastroianna, director of EEOC's Americans with Disabilities Act policy division (Nov. 23, 1993)).

placed on private health insurance.⁹ The resolution of each of these issues could have a profound impact on the freedom of health plans to prioritize health services and deserves separate and extended analysis. In addition, the discussion which follows examines rationing at the level of health benefit plans. Bedside rationing by physicians raises many of the same issues, but it also poses additional issues which justify separate consideration and which may limit the application of my conclusions in that setting.¹⁰

I. RATIONING THE LEAST BENEFICIAL CARE

Health economists have worked for decades on methodologies for calculating both the effectiveness and the cost-effectiveness of health care expenditures.¹¹ Originally utilized to compare the value of different treatments for the same disease, these methods were later used to compare the cost-effectiveness of treatments for different diseases. Cost-effectiveness calculations have the appeal of incorporating outcomes research, patient

9. See *Carparts Distrib. Ctr., Inc. v. Automotive Wholesaler's Ass'n*, 37 F.3d 12 (1st Cir. 1994) (holding that the district court erred when it dismissed the plaintiff's claim on the ground that insurance plans were not public accommodations under the ADA and remanding the case for further determination on the issue); *Mason Tenders Dist. Council Welfare Fund v. Donaghey*, 2 AD Cases 1745 (S.D.N.Y. 1993) (holding that such plans are covered entities under the ADA); see also 28 C.F.R., pt. 36, app. B. § 36.212 (1994) (discussing industry comments on the issue and concluding that insurance plans are covered by the ADA). But see DISTRICT OF COLUMBIA BAR TASK FORCE, REPORT ON THE EFFECT OF THE AMERICANS WITH DISABILITIES ACT ON EMPLOYER-SPONSORED HEALTH PLANS 83-85 (1993) (questioning the applicability of the ADA to the terms of insurance policies). Monica McFadden's analysis of the legislative history, statute, and regulations strongly suggests that private insurance plans should be treated as covered public accommodations. Monica E. McFadden, *Insurance Benefits under the ADA: Discrimination or Business as Usual?*, 28 TORT & INSUR. L.J. 480, 485-86 (1993).

10. Unless physicians possess comparative data about other borderline treatments and about the cut-off dictated by current resources, they will be poorly positioned to make defensible judgments about relative cost-effectiveness. In addition, the necessity of their making these decisions is placed in doubt if the treatment is covered by a health benefits plan. On the other hand, physicians have traditionally been delegated substantial responsibility in the health sector to act as stewards of societal resources. In addition, they will ordinarily be in the best position to make individualized assessments of treatment effectiveness. Whether the disability rights laws should restrict their authority to make these decisions is therefore a difficult question which requires separate discussion. See also *infra* notes 195 (discussing satisfaction of the individualization requirement) and 231 (discussing other differences between health plan and bedside rationing in the context of quality of life considerations).

11. The history of Quality-Adjusted Life Years ("QALYs") is briefly described in John La Puma, *Quality-Adjusted Life Years: Ethical Implications and the Oregon Plan*, 7 ISSUES L. & MED. 429, 433-34 (1992) (expanding upon John La Puma & Edward F. Lawlor, *Quality-Adjusted Life-Years: Ethical Implications for Physicians and Policymakers*, 263 JAMA 2917 (1990)). American researchers initially derived the methodology from operations research in engineering and mathematics, using it in the health care setting to measure the tradeoff between survival and quality of life that is implicated by some treatment choices such as conservative care versus aggressive care. See *id.* The British, most notably Alan Williams, then borrowed the concept as a way of suggesting priorities in their national health care system. See, e.g., Alan Williams, *Economics of Coronary Artery Bypass Grafting*, 291 BRIT. MED. J. 326 (1985). More recently, QALYs have been calculated for a number of treatments in the United States. See, e.g., Michael J. Barry et al., *Watchful Waiting vs Immediate Transurethral Resection for Symptomatic Prostatism: The Importance of Patients' Preferences*, 259 JAMA 3010, 3011 (1988) (discussing Quality-Adjusted Life Months ("QALMs")); Milton C. Weinstein, *Estrogen Use in Postmenopausal Women—Costs, Risks and Benefits*, 303 NEW ENG. J. MED. 308 (1980).

preferences, and expected costs into a rational and potentially sophisticated scheme for maximizing health care outcomes from the available resources.

A. Effectiveness Analysis

Theoretically, at least, calculating the effectiveness of a medical service is relatively straightforward. This calculation involves both an estimate of the likely outcomes and an assignment of value to those outcomes. The value assigned to an outcome is determined by the impact which the treatment is expected to have on a patient's quality of life. That value is then adjusted to reflect the probability and duration of the expected benefit.¹² The product of this calculus is a single unit which expresses the number and quality of additional years that the treatment is likely to confer. These outcome units have been called both Quality-Adjusted Life Years ("QALYs")¹³ and Well Years.¹⁴ Oregon's controversial prioritization was the first large-scale effort to use QALYs for resource allocation in the United States.¹⁵

The theoretical value of these calculations cannot be overstated. They provide a common unit of measurement which permits treatments for different diseases to be compared on the basis of their expected benefit or their cost-effectiveness.¹⁶ Using QALYs or their equivalents, comparisons can be made between such disparate treatments as AZT, autologous bone marrow

12. E.g., OREGON HEALTH SERVS. COMM'N, *PRIORITIZATION OF HEALTH SERVICES: A REPORT TO THE GOVERNOR AND LEGISLATURE* apps. C, D (1991); Robert M. Kaplan & John P. Anderson, *A General Health Policy Model: Update and Applications*, 23 HSR: HEALTH SERVICES RESEARCH 203 (1988); La Puma, *supra* note 11, at 429; Milton C. Weinstein & William B. Stason, *Foundations of Cost-Effectiveness Analysis for Health and Medical Practices*, 296 NEW ENG. J. MED. 716, 718-19 (1977).

13. E.g., Williams, *supra* note 11, at 326-27; Weinstein & Stason, *supra* note 12, at 719.

14. E.g., Kaplan & Anderson, *supra* note 12, at 207-08; Robert M. Kaplan & James W. Bush, *Health-Related Quality of Life Measurement for Evaluation Research and Policy Analysis*, 1 HEALTH PSYCHOL. 61, 64-65 (1982).

15. David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy*, HASTINGS CTR. REP., May-June 1991, at Supp. 11, 14 [hereinafter Hadorn, *Oregon Priority-Setting Exercise*]; see David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 JAMA 2218 (1991) [hereinafter Hadorn, *Setting Health Care Priorities*] (describing the original Oregon methodology and the modifications undertaken before submission to the Federal Government for approval).

16. La Puma, *supra* note 11, at 431; Alan Maynard, *Logic in Medicine: An Economic Perspective*, 295 BRIT. MED. J. 1537, 1540 (1987). John Rawles includes several helpful illustrations of comparisons based on cost-effectiveness:

For example, a patient with severe arthritis of the hip who is unable to work and is in severe distress scores a quality of life of 0.7 [using a Rosser and Kind scale]. His expectation of life of 10 years is reduced to seven quality adjusted life years. Successful hip replacement, by eliminating disability and distress, restores 3 QALYs to his total, at an average cost of £750 per QALY.

Another example is a patient with renal failure undergoing renal dialysis twice a week in hospital for a year. He is unable to work and suffers moderate distress with a quality of life of 0.9. However, hemodialysis is life-saving, so every year adds 0.9 to the number of QALYs he would otherwise enjoy, at a cost of £14000 per QALY.

John Rawles, *Castigating QALYs*, 15 J. MED. ETHICS 143, 144-45 (1989) (citations omitted); see also George W. Torrance, *Measurement of Health State Utilities for Economic Appraisal*, 5 J. HEALTH ECON. 1, 6 tbl. 1 (1986); Williams, *supra* note 11, at 328 (comparing coronary artery bypass grafting with heart transplantation, treatment of end stage renal failure, and hip replacement).

transplants, infertility treatments, mammography screening, early CT scans for head pain, and heroic care for patients in persistent vegetative states. As a result, QALYs provide information that is potentially very useful when deciding which costly or marginally effective treatments to provide.

As the health economist David Hadorn has emphasized, reliable cost-effectiveness data will help health care providers minimize human suffering to the maximum extent possible with the resources society allocates to health care.¹⁷ They do so by directing available resources to their most beneficial use.

Current insurance and clinical practices often make the same kinds of calculations regarding treatment value and cost, albeit in a more intuitive manner.¹⁸ Today, these untutored perceptions not only influence the choice of treatments and conditions to exclude or restrict (such as mental health problems, AIDS, and infertility), but they can also play a role in decisions about whether a treatment is "experimental,"¹⁹ "medically necessary,"²⁰ or "futile."²¹ Prioritization is not a new idea, but current practices leave considerable room for faulty assumptions and for prejudice against some diseases. They may also rely on cost without considering effectiveness. QALYs can help improve the process, making it more rational and, therefore, more just.

QALYs also help us to reexamine old assumptions, habits, and biases.²² They permit health planners to ask whether our current allocation practices have given too much or too little priority to research on lethal diseases such as cancer or heart disease, as compared to debilitating diseases such as arthritis and dementia. They provide a tool for examining whether our current slighting of chronic disease, preventive care, or mental health is defensible

17. Hadorn, *Setting Health Care Priorities*, *supra* note 15, at 2225; *see also* Williams, *supra* note 11, at 328-29.

18. *See, e.g.*, David M. Eddy, *What Care Is 'Essential'? What Services Are 'Basic'?*, 265 JAMA 782, 788 (1991); Gavin Mooney, *QALYs: Are They Enough?: A Health Economist's Perspective*, 15 J. MED. ETHICS 148 (1989).

19. Insurers are reportedly increasing their scrutiny of new medical technologies, demanding stronger proof that they will provide significant benefits. Examples include some bone marrow transplants (costing \$150,000 to \$200,000), the drug taxol for treatment of breast and other cancers (\$18,000), and photopheresis for lymph cancer (\$22,800). Roger Signor, *Cost Curbs High-Tech Health Care*, ST. LOUIS POST-DISPATCH, Nov. 21, 1993, at D1, D17.

20. For example, fewer resources are expended on intensive care units for patients with poorer prognoses. Albert G. Mulley, *The Allocation of Resources for Medical Intensive Care*, in PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, in 3 SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES 285, 302, 306 (1983) [hereinafter SECURING ACCESS TO HEALTH CARE].

21. Mildred Solomon points out that physicians use medical language such as "futility" and "medically indicated" to mask value judgments about the adequacy of benefits conferred by treatments. Mildred Z. Solomon, *How Physicians Talk About Futility: Making Words Mean Too Many Things*, 21 J.L. MED. & ETHICS 231 (1993). The result is to empower physicians and disempower patients and families. *Id.* at 236; *see also* S. Van McCrary et al., *Physicians' Quantitative Assessment of Medical Futility*, 5 J. CLINICAL ETHICS 100, 102 (1994) (noting that physicians consider lifesaving treatment futile if the odds of success fall below a cutoff point, but they lack a consensus about where the cutoff point should be).

22. *See* Maynard, *supra* note 16, at 1540-41.

and for questioning the legitimacy of restrictions on treatments for AIDS or mental illness.

QALYs may also help health decision-makers to avoid what David Eddy has called "rationing by meat ax."²³ By excluding the least effective treatments for conditions that ordinarily are covered by insurance, savings could be generated to fund more comprehensive coverage of treatments for conditions such as mental health that are typically excluded or restricted. Blanket restrictions on treatments for infertility or mental health, for example, could be replaced by narrower exclusions of only those treatments which are least effective.

In addition, the exclusion of whole groups of uninsured persons from programs such as Medicaid could be replaced by the exclusion of marginally effective care. Oregon, for example, replaced a Medicaid system in which a six-year-old child was eligible when a seven-year-old was not, in which pregnant women had coverage but other women did not, and in which single adults with children were covered but those without children or with a spouse were excluded. In its place, the State has instituted a system that provides protection for more *people* by prioritizing the *treatments* covered.²⁴

QALYs make the basis for those choices more explicit and, in the case of Oregon, more public. Consequently, they force conscious confrontation of the difficult value judgments that must be made in order to compare the benefits of one treatment, such as hip replacement, against those of another quite different treatment, such as AZT.²⁵ This explicit attention to the difficult choices is in marked contrast to current practices, such as those of physicians who use neutral terms such as "futility" to mask intuitive judgments about the value of treatment to the patient.²⁶ These judgments should be made explicit and should be defended.²⁷ QALYs provide a framework for structuring that debate.

At the same time, effectiveness analysis need not replace all other bases for allocating health care. It can be combined with more egalitarian strategies for

23. David M. Eddy, *Rationing by Patient Choice*, 265 JAMA 105, 106 (1991).

24. Norman Daniels, *Is the Oregon Rationing Plan Fair?*, 265 JAMA 2232, 2232 (1991); David M. Eddy, *What's Going on in Oregon?*, 266 JAMA 417, 419 (1991) ("Oregon proposes to expand who is . . . but to contract what is covered . . ."). Compare the approach of Missouri, which spent nearly \$1 million keeping Nancy Cruzan alive in a persistent vegetative state, while providing Medicaid for only 40% of its citizens below the poverty level. Leonard M. Fleck, *Just Health Care Rationing: A Democratic Decisionmaking Approach*, 140 U. PA. L. REV. 1597, 1611 (1992).

25. See Maynard, *supra* note 16, at 1540 (shifting the debate to the accuracy of the measurements of cost and benefit).

26. See Ronald Cranford & Lawrence Gostin, *Futility: A Concept in Search of a Definition*, 20 L. MED. & HEALTH CARE 307, 308 (1992); Solomon, *supra* note 21, at 236 (criticizing physicians' use of language such as "futility" and "medically indicated" to mask value judgments about treatment decisions).

27. See, e.g., Daniels, *supra* note 24, at 2234 (arguing that fairness requires public scrutiny); La Puma, *supra* note 11, at 431-32. *Contra* James F. Blumstein, *Rationing Medical Resources: A Constitutional, Legal, and Policy Analysis*, 59 TEX. L. REV. 1345, 1354, 1373 (1981); see also GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* 34-41, 49, 78, 145, 195-99 (1978) (arguing that public political choices endanger basic values about the sanctity of life, but advance values of openness and honesty).

distributing health care to obtain the desired mix of medical utility and equity.²⁸ For example, patients with the greatest need could be given preferential access to treatment whenever their expected benefit is the same or sufficiently close to that of other patients who are better off. Alternatively, expected benefit could establish a threshold for eligibility after which allocation could be based on urgency or priority in time.

Finally, the measurement of treatment effectiveness is potentially useful in many different contexts. Most obviously, it could be used by state or federal governments, as Oregon initially attempted, to determine which treatments will be funded. Prior to Oregon's skirmish with the Federal Government in 1991, eighteen states had proposed preliminary health care reforms modeled after the Oregon plan.²⁹ Employers, private insurers, and patients are also likely to find cost-effectiveness information helpful when making decisions about the kind of coverage to offer or purchase. Indeed, Ellman and Hall have made the intriguing suggestion that consumers be permitted to select between health plans whose principal difference would be variations in cost-effectiveness standards.³⁰ Cost-effectiveness models could also help managed care plans design protocols to determine which diagnostic tests to perform and when to refer patients to specialists. The data may play a similar role in the design of clinical practice guidelines.³¹ Furthermore, cost-effectiveness has always played a role in decisions about preventive care, such as when and

28. Maynard, *supra* note 16, at 1540. For example, a Massachusetts task force endorsed a tradeoff between equity and utility in its organ transplantation program by using a two-tier process for selecting recipients. Dan W. Brock, *Ethical Issues in Recipient Selection for Organ Transplantation*, in ORGAN SUBSTITUTION TECHNOLOGY: ETHICAL, LEGAL, AND PUBLIC POLICY ISSUES 86, 96 (Deborah Mathieu ed., 1988) (citing MASSACHUSETTS TASK FORCE ON ORGAN TRANSPLANTATION, DEP'T OF PUB. HEALTH, REPORT (1984)). First, an initial pool would be selected on "objective medical grounds," and second, selection from the pool would be made on a first-come, first-served basis. The precise tradeoff would depend on how restrictively the initial medical criteria are drawn. *Id.* at 96-97.

29. Eric L. Robinson, Note, *The Oregon Basic Health Services Act: A Model for State Reform?*, 45 VAND. L. REV. 977, 978-79 (1992) (citing B.D. Colen, *Strong Medicine*, HEALTH, May 1991, at 32, 34). Florida may act to prioritize treatments and limit payment for those with low priority such as treatments for flu and premature infants of less than 20 weeks. See *Florida Legislator Outlines State's Next Reform Steps*, CCH PULSE: THE HEALTH CARE REFORM NEWSLETTER, Aug. 26, 1993, at 7.

30. Ira Mark Ellman & Mark A. Hall, *Redefining the Terms of Health Insurance to Accommodate Varying Consumer Risk Preferences*, 20 AM. J.L. & MED. 187, 193 (1993). This would be accomplished by marketing plans with different fixed budgets to be used for treatment (e.g., \$2 million per 1000 subscribers per year). Higher budget plans could fund less cost-effective care. These budgets would define the plan's contractual obligations and replace the standard policy language requiring payment of all appropriate medical care not excluded. *Id.* at 194. Decisions about how to allocate the finite resources of a particular plan would raise the same disability rights issues discussed in this Article.

31. See, e.g., *Florida Legislator Outlines State's Next Reform Steps*, *supra* note 29, at 7 (reporting that an architect of Florida's health care reform plan wishes to pass legislation to establish "cost-effective" practice parameters as an affirmative defense to malpractice suits); Hadorn, *Setting Health Care Priorities*, *supra* note 15, at 2223-24 (recommending the use of effectiveness data for setting practice guidelines and suggesting that practice guidelines serve as a basis for allocating health care). For an introduction to the subject of practice parameters, the impetus for increasing their number, and the issues raised by their use, see John D. Blum, *Hospitals, New Medical Practice Guidelines, COI, and Potential Liability Outcomes*, 36 ST. LOUIS U. L.J. 913 (1992). Congress has charged the Forum for Health Care Policy Research—an entity within the Agency for Health Care Policy and Research—with the development of practice guidelines based on current medical research. *Id.* at 919. The medical community itself is also moving toward more outcome measurements and guidelines. *Id.* at 921-22.

whom to screen for diseases such as breast cancer, diabetes during pregnancy, sickle cell disease, and Tay-Sachs disease.³² In all of these contexts, decision-making could potentially improve with the benefit of valid, reliable measurements of treatment effectiveness.

But measurement of medical effectiveness also presents serious methodological and ethical problems which must be surmounted before its use expands. The methodological problems arise both from the difficulty of obtaining adequate data about outcomes, benefits, and costs and also from predictable issues of study design.³³ Problems of this kind contributed to the failure of Oregon's initial attempt to prioritize medical treatments entirely on the basis of net benefit.³⁴ Unquestionably, the field is still in its infancy, but there is reason to believe that the data will improve in both quality and quantity.³⁵ And because even crude effectiveness measurements have the

32. See CHARLES H. HENNEKENS & JUNE E. BURING, *EPIDEMIOLOGY IN MEDICINE* 328-30 (1981) (stating that cost-effectiveness is one criterion for deciding when to perform medical screening).

33. For a taste of the issues, see Norman Daniels, *Four Unsolved Rationing Problems*, 24 *HASTINGS CTR. REP.*, July-Aug. 1994, at 27, 28 (discussing the Aggregation Problem); David M. Eddy, *Oregon's Plan: Should It Be Approved?*, 266 *JAMA* 2439 (1991); Eddy, *supra* note 23; Eddy, *supra* note 18; Hadom, *Oregon Priority-Setting Exercise*, *supra* note 15; La Puma, *supra* note 11, at 430-31, 434; Mooney, *supra* note 18 (describing generally issues such as the assumption of risk-neutrality and nonconstant marginal utilities, and suggesting refinements using weighting, regret theory, and prospect theory); Rachel Rosser & Paul Kind, *A Scale of Valuations of States of Illness: Is There a Social Consensus?*, 7 *INT'L J. EPIDEMIOLOGY* 347 (1978) (providing an example of an attempt to develop a scale representing the relative degrees of undesirability of certain health conditions and of death); Torrance, *supra*, note 16, at 18 (explaining the choice between rating scales, standard gamble, and time trade-off). For a further discussion of methodological problems, see *infra* notes 34, 200, and 202-03.

34. Problems with an initial list proposed in May, 1990, led Oregon to abandon pure cost-effectiveness and substitute a more subjective, multifactorial methodology before submitting its plan for federal approval in 1991. David M. Eddy, *Oregon's Methods: Did Cost-Effectiveness Analysis Fail?*, 266 *JAMA* 2135 (1991); Eddy, *supra* note 33, at 2444. In David Eddy's view, Oregon's inability to estimate accurately either costs or benefits precluded reliance on its initial list. *Id.* at 2444. Categories of services and outcomes were defined too broadly. See *id.*; Eddy, *supra*, at 2138. For example, "trouble speaking" could range from mild lisp to mutism. *Id.* Duration of treatment benefits was poorly differentiated. Eddy, *supra* note 24, at 417. Cost data were incomplete or inaccurate. *Id.*; Eddy, *supra*, at 2138. And the list generated serious doubts whether the values assigned to treatment outcomes, especially lifesaving treatments, had been accurately measured. Eddy, *supra* note 24, at 417; Eddy, *supra*, at 2138-41.

Counter-intuitive rankings resulted from these problems. Reportedly, "burn over large areas of the body" scored the same as an "upset stomach." Hadom, *Oregon Priority-Setting Exercise*, *supra* note 15, at 16. Michael Astrue, then-general counsel of the Department of Health and Human Services, was startled that treatments for ectopic pregnancies and appendicitis were ranked below some dental caps and splints for temporomandibular joint disorder. Michael J. Astrue, *Pseudoscience and the Law: The Case of the Oregon Medicaid Rationing Experiment*, 9 *ISSUES L. & MED.* 375, 379 (1994); see also Hadom, *Setting Health Care Priorities*, *supra* note 15, at 2219 (suggesting that the results were the "inevitable consequence" of cost-effectiveness analysis). Oregon's rankings were sharply criticized. Daniels, *supra* note 24, at 2235 (1991) (citing William B. Schwartz & Henry J. Aaron, *The Achilles Heel of Health Care Rationing*, *N.Y. TIMES*, July 9, 1990, at A17). After scrapping the initial list, the Oregon Health Services Commission explained that "a ranking based on benefit or cost-benefit ratio did not comprehensively reflect public values." OREGON HEALTH SERVS. COMM'N, *supra* note 12, at 12.

Unwillingness to accept the implications of cost-effectiveness analysis, especially for the prioritization of noncritical care over life-extending care, may also partially explain the adverse reaction to this list. Hadom, *Setting Health Care Priorities*, *supra* note 15, at 2219 (discussing the "Rule of Rescue"). Oregon's revised methodology is discussed *infra* at text accompanying notes 49-54.

35. E.g., BEAUCHAMP & CHILDRESS, *supra* note 6, at 247 (stating that the problems were not fatal but suggesting caution); Robert M. Kaplan, *A Quality-of-Life Approach to Health Resource Allocation*,

potential to improve on existing practices in a wide variety of contexts, a substantial incentive exists to obtain and use the best available data.

Nonetheless, efforts to overcome the difficulties with effectiveness measures would be misplaced if ranking treatment on this basis were intrinsically unjust.

B. Discriminatory Implications

In order to calculate a treatment's medical effectiveness, analysts must estimate its probable outcome and then place a value on that outcome. Both steps could disfavor disabled patients. When outcomes are taken into account, patients with preexisting disabilities, such as diabetes, cancer, or pulmonary disease, could be disfavored because they often have more difficulty fighting unrelated illnesses (comorbidity) than patients who are otherwise healthy.³⁶ For example, diabetes reduces the probable effectiveness of some treatments for serious heart ailments.³⁷ Unchecked alcoholism, another disability, could interfere with the success of organ transplantation.³⁸ When a disability-related comorbidity causes poorer outcomes, reliance on outcomes to allocate medical care would disfavor care of the affected disabled patients.

in RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND 60, 70, 74-75 (Martin A. Strosberg et al. eds., 1992) [hereinafter RATIONING AMERICA'S MEDICAL CARE] (suggesting that bad data and time pressures, rather than methodological flaws, plagued Oregon's experiment and that sensitivity analysis near the cutoff would be useful); Eddy, *supra* note 34, at 2138-41 (suggesting that improved survey instruments could better capture public values about lifesaving); Eddy, *supra* note 33, at 2444 (suggesting that more precise categories of services would better identify ineffective care); Torrance, *supra* note 16, at 27-28 (concluding that imprecision can be ameliorated by a larger sample size and careful sensitivity analysis). The current emphasis on medical outcomes research should permit both more precise and more reliable QALY calculations. *See, e.g.,* WILLIAM J. CURRAN ET AL., HEALTH CARE LAW, FORENSIC SCIENCE, AND PUBLIC POLICY 809 (4th ed. 1990) (describing establishment of the Agency for Health Care Policy and Research to develop practice guidelines based on its research findings); Blum, *supra* note 31, at 921-22; Beck, *supra* note 1, at 31; Geoffrey Cowley, *What High Tech Can't Accomplish*, NEWSWEEK, Oct. 4, 1993, at 60, 63.

36. *See, e.g.,* David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1457-58 (1992) (noting poorer outcomes commonly associated with de facto disabilities such as severe diabetes or cancer); David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308, 310 (1994) (recognizing that patients with pulmonary disease are poor candidates for coronary bypass surgery). In another example, an HMO denied payment for a \$170,000 liver transplant requested by an e-antigen positive hepatitis-B patient due to the high rate of reinfection of e-antigen positive patients and the liver shortage. *Barnett v. Kaiser Found. Health Plan, Inc.*, Health Care Facility Mgmt. (CCH) ¶ 22,594 (N.D. Cal. 1993). The HMO's eight-member advisory board had concluded that transplantation was not an appropriate medical treatment for the patient's condition. The federal district court ruled that the HMO had not abused its discretion in considering this factor, even though transplantation might be the patient's only chance of survival. The disability rights laws were apparently not addressed.

37. OREGON HEALTH SERVS. COMM'N, *supra* note 12, at 61; Hadorn, *supra* note 36, at 1457-58.

38. The Federal Government apparently felt that this was the basis for Oregon's unfavorable treatment of alcoholic cirrhosis relative to other causes of liver failure. OREGON HEALTH SERVS. COMM'N, *supra* note 12, app. J (Prioritized Health Services List of May 1, 1991) (ranking transplantation for alcoholic cirrhosis of liver at #690, and other cirrhoses at #366). The Federal Government challenged this classification, pointing out that success does not depend upon etiology if the patient has stopped the destructive behavior. *See ADA Analyses of the Oregon Health Care Plan* (Attachment to Letter from Louis W. Sullivan to Governor Barbara Roberts (Aug. 3, 1992)), reprinted in 9 ISSUES L. & MED. 397, 409, 411-12 (1994) [hereinafter Sullivan Letter]. Oregon had not limited its unfavorable classification to active alcoholics.

In addition, seriously disabled patients could be disfavored when values are placed on treatment outcomes. For example, QALY use disfavors lifesaving care for patients who are expected to be disabled after treatment, because saving the life of a disabled person with an impaired quality of life will theoretically generate fewer quality-adjusted life years than saving the life of a person whose quality of life after treatment would be better (according to the quality of life scales used for this measurement). The Federal Government apparently suspected that the low ranking which Oregon gave to the treatment of very low birth weight, premature babies reflected this kind of calculation.³⁹

QALYs could also disadvantage permanently disabled patients who need noncritical care. Their disabilities can limit the extent of their improvement from successful therapy.⁴⁰ Consequently, their quality of life will improve less than that of otherwise healthy patients who need the same therapy. As these examples illustrate, disabled patients can be disfavored when treatment effectiveness is measured by its impact on quality of life.

The chance that disabled patients will fare unfavorably in QALY calculations is further accentuated by the risk that the scales used to measure quality of life will unfairly underestimate the quality of life of disabled persons.⁴¹ This was precisely the Federal Government's criticism of the Oregon quality of life measurements.⁴²

Yet, until the Oregon plan was submitted for Federal Government approval, no public attention had been called to the discriminatory potential of prioritization on the basis of medical effectiveness. Although the Oregon plan was vilified on other grounds (principally that only poor people would be asked to make sacrifices to help fund an expansion of health care coverage for other poor people),⁴³ virtually no public debate on disability rights had occurred. As a result, the Bush administration's rejection of the plan because of discrimination against patients with disabilities surprised most observers

39. See OREGON HEALTH SERVS. COMM'N, *supra* note 12, app. J (Prioritized Health Services List of May 1, 1991) (ranking babies under 500 grams and 23 weeks gestation at #708, rather than #22). Some economists have calculated that treatment of neonates under 1000 grams is less cost-effective than treatment of larger newborns; however, both compared favorably to dialysis for end-stage renal failure. Maynard, *supra* note 16, at 1540; Torrance, *supra* note 16, at 6 tbl. 1. The care of the smaller babies cost \$31,800 per QALY on average compared to \$4500 per QALY for the larger babies. See also Michael H. Boyle et al., *Economic Evaluation of Neonatal Intensive Care of Very Low Birth Weight Infants*, 308 NEW ENG. J. MED. 1330, 1333 tbl. 4 (calculating \$22,400 per QALY for babies 500 to 900 grams; \$3200 per QALY for babies 1000 to 1499 grams) (expressing values in 1978 Canadian dollars).

40. Orentlicher, *supra* note 36, at 312.

41. This concern is discussed *infra* at notes 200-203 and accompanying text.

42. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 410.

43. See, e.g., Alexander M. Capron, *Oregon's Disability: Principles or Politics?*, HASTINGS CTR. REP., Nov.-Dec. 1992, at 18, 19; Charles J. Dougherty, *Setting Health Care Priorities: Oregon's Next Steps*, HASTINGS CTR. REP., May-June 1991, at Supp. 1; Michael J. Garland, *Justice, Politics and Community: Expanding Access and Rationing Health Services in Oregon*, 20 L. MED. & HEALTH CARE 67, 69, 74-77 (1992); Hadorn, *Setting Health Care Priorities*, *supra* note 15, at 2224; Paul T. Menzel, *Some Ethical Costs of Rationing*, 20 L. MED. & HEALTH CARE 57, 62 (1992); W. John Thomas, *The Oregon Medicaid Proposal: Ethical Paralysis, Tragic Democracy, and the Fate of a Utilitarian Health Care Program*, 72 OR. L. REV. 47, 51-52, 127-28 (1993).

and caused some speculation that the administration had simply used the disability rights issue to derail a proposal which it found objectionable for other reasons.⁴⁴

Disability rights issues had, however, percolated beneath the surface for some time. According to one report, over twenty disability rights groups had objected to the Oregon plan.⁴⁵ In fact, the National Legal Center for the Medically Dependent & Disabled, Inc., a prominent pro-life litigation center, wrote a crucial memo on December 5, 1991, in response to an inquiry by Representative Christopher Smith (R-NJ) contending that the Oregon plan violated the disability rights laws.⁴⁶ Although the memo was written nearly one year before the government announced its objections, much of its reasoning was adopted in the government's ultimate response to the Oregon application.

C. The Oregon Experiment

Oregon wanted to expand Medicaid eligibility to include all persons below the poverty line. It hoped to keep the costs within manageable limits by restricting the range of reimbursable services.⁴⁷

Oregon's initial ranking of treatments in May, 1990, was based on a pure cost-effectiveness analysis, but problems with that list induced the Oregon Health Services Commission to abandon that list and produce another one in April, 1991, using a more intuitive, multifactorial methodology. Nonetheless, considerations of effectiveness continued to play a crucial role, and their inclusion ultimately caused the rejection of Oregon's initial request for Medicaid waivers from the Federal Government.⁴⁸

Effectiveness considerations entered the process at three junctures. First, the Commission divided all treatments into one of seventeen different categories and then ranked these categories. A sampling of the categories illustrates the methodology: "acute fatal, treatment prevents death with full recovery" (ranked #1); "maternity care" (#2); "acute fatal, treatment prevents death without full recovery" (#3); "comfort care" (#7); "acute nonfatal, treatment

44. Paul T. Menzel, *Oregon's Denial: Disabilities and Quality of Life*, HASTINGS CTR. REP., Nov.-Dec. 1992, at 21, 21, 25 n.13; Orentlicher, *supra* note 36, at 308.

45. Nancy K. Stade, Note, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV. 1985, 2004 n.101 (1993). The broadest arguments claimed that any rationing scheme at all would unlawfully discriminate "by reason of disability." Astrue, *supra* note 34, at 380; *see also* Menzel, *supra* note 44, at 25 n.13.

46. *ADA Analyses of the Oregon Health Care Plan*, reprinted in 9 ISSUES L. & MED. 397, 400 (1994) (Letter from Thomas J. Marzen, general counsel, and Daniel Avila, staff counsel, National Legal Center for the Medically Dependent & Disabled, Inc., to Representative Christopher H. Smith (Dec. 5, 1991)) [hereinafter Marzen Letter].

47. Although other states had placed some broad limits on their Medicaid coverage, Oregon wanted to make a more precise choice among treatments and conditions by considering both the effectiveness of each treatment and public priorities. Jerrold J. Hercenberg & Wendy L. Krasner, *Setting Priorities*, LEGAL TIMES, Nov. 16, 1992, at 20, 21.

48. Because Oregon's Medicaid coverage would differ from that required by federal law, Oregon requested the waiver of several Medicaid requirements. Capron, *supra* note 43, at 18-19.

causes return to previous health state" (#10); and "infertility services" (#15).⁴⁹ These rankings gave priority to treatments which produced complete cures over those which ordinarily produce only partial recovery. In this way, the Commission retained a blunt measure of effectiveness in its ranking process. The Commission also considered cost-effectiveness as one of many factors used to create and rank these categories.⁵⁰

Second, the Commission used QALYs to rank treatments within the seventeen categories.⁵¹ Third and finally, the Commissioners reviewed the resulting list and adjusted some of the rankings using their "professional judgments and their interpretation of the community values."⁵² The Commissioners imposed a "reasonableness" test upon themselves, taking into account effectiveness and cost along with other factors such as public health impact, incidence of condition, and social costs.⁵³ The result was a ranking of 709 treatments of which 587 were to be funded in the first year.⁵⁴ This ranking was submitted for Federal Government approval in August, 1991.

On August 3, 1992, the Department of Health and Human Services ("HHS") announced that Oregon had been denied a waiver because its plan violated the Americans with Disabilities Act ("ADA").⁵⁵ HHS objected to the use of quality of life considerations to measure the effectiveness of a treatment.⁵⁶ "[T]he premise 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" was, it concluded,

49. OREGON HEALTH SERVS. COMM'N, *supra* note 12, app. G-11 to G-12. Acute care was favored over chronic care, fatal conditions over nonfatal, and complete cures over partial cures. *Id.* app. G-3 to G-5. The Commission's goal in ranking these 17 categories was to use values expressed at community meetings and public hearings. *Id.* at 15, 20.

50. *Id.* at 21.

51. *Id.* at 23. Benefits were measured using Dr. Robert M. Kaplan's Quality of Well-Being ("QWB") scale. *Id.* at 6-7, 23-27, apps. C, D; *see also* Kaplan & Anderson, *supra* note 12. Using the results of a random telephone poll of 1001 Oregon households in which respondents were asked to rank 23 symptoms and 6 levels of functional impairment, the Commission assigned a value to various states of health, such as requiring a wheelchair or having severe burns. OREGON HEALTH SERVS. COMM'N, *supra* note 12, at 26, app. C-1, C-5 to C-7; *see also* Garland, *supra* note 43, at 70 (describing the survey methods); Stade, *supra* note 45, at 1989-91. The benefits associated with each treatment were then calculated by using the values for the various outcomes provided by the telephone survey and weighting those values to reflect the probability of their occurrence. OREGON HEALTH SERVS. COMM'N, *supra* note 12, app. D-3 to D-4. Expected outcomes were ascertained by polling practitioners. *Id.* at 10, app. D. Outcomes (such as death or return to former health) were estimated five years after treatment. *Id.* app. D-6. Net benefit (QWB) scores were derived by comparing the QWB score without treatment to the QWB score with treatment. *Id.* app. D-3 to D-5. The Commission multiplied the expected QWB by the duration of the benefit (thereby obtaining a measure of quality-adjusted life years or QALYs). *Id.* app. D-3, D-13. In most cases, duration was the patient's life expectancy.

52. OREGON HEALTH SERVS. COMM'N, *supra* note 12, at 28.

53. *Id.* For example, preventable or readily treated conditions were moved from relatively unfavorable positions. *Id.*

54. The legislature agreed to fund the top 587 treatments for 1991-1992 if federal approval for the experiment was granted. *See* Garland, *supra* note 43, at 70.

55. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 409. According to the attorney who was then general counsel of HHS, Oregon's application was subjected to a new, stricter standard of review. Astrue, *supra* note 34, at 378.

56. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 410. The government objected to the role of quality of life considerations in the survey and in the Commission's final adjustments to the list. *Id.*

"inconsistent with the ADA."⁵⁷ Second, HHS contended that the survey used to rank quality of life had used biased data that undervalued the quality of life of disabled persons.⁵⁸ This, too, violated the ADA. In addition, HHS specifically identified two instances in which disabilities had been impermissibly taken into account: (1) the ranking of alcoholic cirrhosis of the liver (#690) below other cirrhosises (#366) and (2) the ranking of extremely low birth weight babies (#708) below heavier babies (#22).⁵⁹

Oregon denied that it had violated the ADA,⁶⁰ but nevertheless complied with HHS's demands. Approval was not granted until Oregon had eliminated quality of life data from its formal methodology and had abandoned the separate classification of alcoholic cirrhosis and low birth weight babies.⁶¹ In addition, the newly-elected Clinton administration insisted that Oregon no longer disfavor infertility treatments.⁶² In March, 1993, the Oregon Commission approved a new list which was based first on mortality and then, as a tie-breaker, on cost considerations. It was then adjusted by the Commission to reflect community values, such as a preference for preventive services and a dislike for medically ineffective care.⁶³ The plan took effect on February 1, 1994.⁶⁴

This exchange between Oregon and the Federal Government has dramatic implications for health policy. Oregon's capitulation has cast a shadow over similar endeavors by other states.⁶⁵ In its wake, considerable confusion exists about the permissible role of effectiveness in allocating health resources. Quality of life considerations had been rejected altogether and survival rates had been permitted only after two categories which appeared to take disability into account had been deleted (alcoholic cirrhosis and premature low birth weight babies). Despite months of negotiations, Oregon remained unsure of how effectiveness could be measured and extracted a promise from the

57. *Id.*

58. *Id.* The Oregon Report notes that persons with five specific impairments (thinking clearly, trouble breathing, prescribed medication or diet, glasses, and trouble with sexual performance) did not feel their impairments were as severe as those who had not experienced the problem. The Report notes that "[t]his response has been replicated in a number of studies." OREGON HEALTH SERVS. COMM'N, *supra* note 12, app. C-11.

59. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 411-12. The government also contended that Oregon's treatment of low birth weight babies "would not be consistent with" the Child Abuse Amendments of 1984. *Id.* at 412.

60. OREGON HEALTH SERVS. COMM'N, PRIORITIZATION OF HEALTH SERVICES: A REPORT TO THE GOVERNOR AND LEGISLATURE 9 (1993).

61. On March 19, 1993, the government granted conditional approval to Oregon based on changes that Oregon had agreed to make and on the condition of further changes outlined in the government's response. *ADA Analyses of the Oregon Health Care Plan*, *supra* note 38, at 423 (Excerpt from HCFA's Special Terms and Conditions Regarding the Oregon Plan Issued March 19, 1993).

62. *Id.* at 423.

63. OREGON HEALTH SERVS. COMM'N, *supra* note 60, at 16-18.

64. See *Reform Focus: Oregon Health Plan*, CCH PULSE: THE HEALTH CARE REFORM NEWSLETTER, Feb. 21, 1994, at 10.

65. *E.g.*, Hadom, *Setting Health Care Priorities*, *supra* note 15, at 2221 (describing Colorado's exploration of prioritization before the rejection of Oregon's plan); Hercenberg & Krasner, *supra* note 47, at 23. As of 1991, at least 18 states were considering similar proposals. Robinson, *supra* note 29, at 978-79.

Federal Government to seek a definition of effectiveness that would satisfy the law.⁶⁶

Critics complained that the Federal Government had established an "almost impossible standard" for states wishing to use effectiveness criteria to make coverage decisions.⁶⁷ Some speculated that all efficiency-based rationing schemes were doomed.⁶⁸ "Indeed," wrote David Hadorn, "the 'D-word' [discrimination] threatens to replace the 'R-word' (for rationing) as the most feared epithet in the field of resource allocation."⁶⁹ Alexander Morgan Capron, another advocate of rationing, was equally dire in his assessment. "As some form of rationing is an inevitable part of all health insurance," he concluded, "the ADA roadblock to rational prioritization of services by their expected benefit should be of grave concern to us all."⁷⁰

Was the Federal Government correct? Exactly what limits do the disability rights laws place on the use of effectiveness criteria? Answering these questions requires a basic understanding of the disability rights laws.

II. FEDERAL DISABILITY RIGHTS LAW

Two federal statutes protect disabled individuals from improper discrimination in health care decision-making: The Rehabilitation Act of 1973⁷¹ and the more recent Americans with Disabilities Act of 1990 ("ADA").⁷²

A. The Basic Paradigm

Although the ADA is much more detailed than the Rehabilitation Act and the wording of the various titles of the ADA are slightly different, the basic paradigm of the two federal laws protecting disability rights can be briefly summarized. Section 504 of the Rehabilitation Act bars discrimination by any program receiving federal financial assistance or any executive agency against an "otherwise qualified" individual with a disability "by reason of her or his disability."⁷³ The ADA extends this prohibition against discrimination "on

66. See also OREGON HEALTH SERVS. COMM'N, *supra* note 60, at 15.

67. Hercenberg & Krasner, *supra* note 47, at 22; see also *A Bold Medical Plan, Derailed*, N.Y. TIMES, Aug. 6, 1992, at A22.

68. Thomas, *supra* note 43, at 139 (adopting that view and providing citations to newspaper accounts expressing it); see also Capron, *supra* note 43, at 20. Thomas asserts that all rationing is prohibited and calls the government's view "tantamount to a Rawlsian recognition of an absolute right to health care." Thomas, *supra* note 43, at 140.

69. Hadorn, *supra* note 36, at 1454.

70. Capron, *supra* note 43, at 20.

71. 29 U.S.C. § 794(a) (Supp. V 1993). Section 504 of the Rehabilitation Act, as amended, provides as follows: "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ."

72. 42 U.S.C. §§ 12101-12213 (Supp. V 1993).

73. 29 U.S.C. § 794(a) (prohibiting discrimination "on the basis of" disability); see also 45 C.F.R. § 84.4(a) (1994) (prohibiting discrimination "on the basis of handicap").

the basis of" disability to state programs and private entities that do not receive federal funding.⁷⁴

Federal law defines disabled persons as individuals who have a "physical or mental impairment which substantially limits a major life activity," "who have a record of such an impairment," or who are "regarded as having such an impairment."⁷⁵ The regulations list examples such as blindness, mental retardation, emotional illness, cancer, heart disease, and HIV infection.⁷⁶

The superficially distinct requirements that challenged conduct both disfavor a "qualified" disabled applicant and also result in discrimination "on the basis of" disability typically collapse into a single inquiry. As the U.S. Supreme Court observed in *Alexander v. Choate*, "the question of who is 'otherwise qualified' and what constitutes improper 'discrimination'. . . [are] two sides of a single coin."⁷⁷ A person who lacks legitimate qualifications has not been impermissibly discriminated against. Under both statutes, a person is "qualified" to receive services such as health care if, with reasonable modifications, she is able to meet a program's "essential" or "necessary" eligibility requirements.⁷⁸

Because disability often correlates with functional impairment and because functional impairment may affect a person's qualifications for some benefits,⁷⁹ the laws governing disability rights permit consideration of a

74. See 42 U.S.C. § 12101(a)(14); *Easley by Easley v. Snider*, 841 F. Supp. 668, 672 (E.D. Pa. 1993), *rev'd*, 36 F.3d 297 (3d Cir. 1994). The basic prohibition on disability-based discrimination is phrased somewhat differently in the various titles of the ADA which are potentially relevant to health care. See 42 U.S.C. § 12132 (barring discrimination in public services "by reason of" disability); *id.* § 12182(a) (barring discrimination in public accommodation "on the basis of disability"); *id.* § 12112(a) (barring discrimination in employment "because of the disability").

75. 42 U.S.C. § 12102(2); 29 U.S.C. § 706(8)(B) (Supp. V 1993).

76. 28 C.F.R. § 35.104 (1994). David Orentlicher notes that this definition is so broad that it is unlikely to be a serious hurdle for lawsuits over rationing. Orentlicher, *supra* note 36, at 309. Serious medical conditions that are treated unfavorably are likely to constitute legal disabilities.

77. 469 U.S. 287, 299 n.19 (1985) (discussing the Court's interpretation of § 504 in *Southeastern Community College v. Davis*, 442 U.S. 397 (1979)). The National Council on the Handicapped (which initially proposed the Americans with Disabilities Act) also felt that the two requirements were redundant and unnecessarily confusing. NATIONAL COUNCIL ON THE HANDICAPPED, TOWARD INDEPENDENCE app. A-19 to A-20 (1986).

78. Although Section 504 itself does not state when a person is "otherwise qualified" to receive services, the HHS regulations implementing the Rehabilitation Act define the term to mean "a handicapped person who meets the essential eligibility requirements for the receipt of such services." 45 C.F.R. § 84.3(k)(4) (1994) (applying to services other than employment or education). Under Title II of the ADA, which regulates government services such as the Oregon Medicaid plan, a person who is "qualified" to receive public services is someone who "meets the essential eligibility requirements" for receipt of the services "with or without reasonable modifications to rules, policies, or practices." 42 U.S.C. § 12131(2); see also *Easley*, 841 F. Supp. at 673. The Justice Department regulations implementing Title II define essential eligibility requirements to be those "necessary for the provision of the service." 28 C.F.R. § 35.130(b)(8) (1994). Title III, governing public accommodations, has no explicit qualifications requirement but achieves the same result by permitting the use of "necessary" eligibility criteria. 42 U.S.C. § 12182(b)(2)(A)(i); 28 C.F.R. § 36.301(a) (1994). Title I of the ADA, which regulates employment, also has a qualifications requirement, but it is somewhat different. See *infra* notes 106-09 and accompanying text.

79. U.S. COMM'N ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES 144 (1983) ("The goal is neither to exaggerate and stereotype nor to ignore handicapped people's functional limitations.").

person's disability if the condition legitimately affects that person's ability to meet the essential eligibility requirements.⁸⁰ This basic structure is quite different from civil rights legislation governing race because race is presumed to be irrelevant.⁸¹

While acknowledging that disabilities are sometimes relevant, Congress also recognized that their consideration would often result in the exclusion of disabled persons who could become qualified with modest modifications of policies or practices. To prevent this, Congress required that a reasonable effort be made to accommodate the needs of disabled persons before concluding that they are ineligible.⁸² By conferring on people with disabilities this right to affirmative assistance, Congress endorsed, at least in a limited way, an egalitarian approach to distributive justice which allocates extra resources for those persons with the greatest need.⁸³ As a result of the

80. See, e.g., *Davis*, 442 U.S. 397; *United States v. University Hosp.*, 729 F.2d 144, 156 (2d Cir. 1984) (holding that consideration of disability is only improper when it "is unrelated to, and thus improper to consideration of, the services in question").

81. See *Doe v. New York Univ.*, 666 F.2d 761, 776 (2d Cir. 1981); U.S. COMM'N ON CIVIL RIGHTS, *supra* note 79, at 143; NATIONAL COUNCIL ON THE HANDICAPPED, *supra* note 77, app. A-37 to A-38. The basic structure of the law governing disability rights is more like the treatment of gender, national origin, and religion. With respect to those classifications, employers are permitted to make a showing that discriminatory criteria are bona fide occupational qualifications necessary to the business. *Id.* app. A-37 to A-38. When the civil rights laws were extended to disabled persons, it was widely recognized that the presumption of irrelevancy would also be inappropriate here. See *Davis*, 442 U.S. at 405; U.S. COMM'N ON CIVIL RIGHTS, *supra* note 79, at 143-44; NATIONAL COUNCIL ON THE HANDICAPPED, *supra* note 77, app. A-37 to A-38.

82. Section 504 itself has no such requirement, but the HHS regulations implementing it expressly require reasonable accommodations by employers. See 45 C.F.R. § 84.12(a) (1994) (regulating employment); see also *Davis*, 442 U.S. at 407-13 (interpreting the education regulations); 45 C.F.R. § 84.44 (1994) (regulating accommodation in education). The ADA imposes a reasonable accommodation requirement as well. See 42 U.S.C. § 12131(2) (requiring public services to make "reasonable modifications to rules, policies and practices"); *id.* § 12182(b)(2)(A)(ii) (imposing a duty upon private entities providing public accommodations to make "reasonable modifications" to policies, practices, and procedures unless doing so would "fundamentally alter the nature of such . . . services"); *id.* §§ 12111(8)-(10), 12112(b)(5)(A), 12113(a) (imposing a duty on employers to make "reasonable accommodation[s]", including accessibility, job-restructuring, interpreters and equipment, unless doing so would impose an "undue hardship," (*i.e.*, a "significant difficulty or expense" under the circumstances)); 28 C.F.R. 35.130(b)(7) (1994) (excluding from the reasonable accommodation requirement changes that would "fundamentally alter the nature of the service"); 29 C.F.R. § 1630.9(a) (1994) (stating that it is "unlawful" for an employer "not to make reasonable accommodation").

83. As federal district court Judge Devine poignantly observed, this provision charts a course between the extremes of no assistance for overcoming disabilities (social Darwinism) and unlimited assistance. *Garrity v. Gallen*, 522 F. Supp. 171, 207 (D.N.H. 1981). Whether the reasonable accommodation obligation is viewed as "equality plus" or "equality minus" depends upon one's approach to distributive justice. If justice imposes only an obligation not to discriminate against qualified persons, then the obligation to make reasonable accommodations is an affirmative obligation that exceeds the basic demands of distributive justice. See Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 L. MED. & HEALTH CARE 331, 336 (1990) (describing the ADA as an entitlement program placed on the private sector); Peter M. Shane, *Structure, Relationship, Ideology, or, How Would We Know a "New Public Law" If We Saw It?*, 89 MICH. L. REV. 837, 862 (1991) (describing the ADA as "social welfare legislation" and not simply an "antidiscrimination" law). However, if justice requires access on the basis of need, see BEAUCHAMP & CHILDRESS, *supra* note 6, at 272-73, then the limitations placed on the law's preference for those with the greatest need could be viewed as something less than full distributive justice. Cf. Christine A. Littleton, *Reconstructing Sexual Equality*, 75 CAL. L. REV. 1279 (1987) (discussing the goal of making differences (*e.g.*, gender) "costless relative to each other").

reasonable accommodation requirement, something more than a bare right to equal access is conferred on people with disabilities. Instead, programs must make reasonable efforts to accommodate their disabilities and enable them to participate. Although reasonable accommodation is a general concept whose application will typically depend upon the facts of a particular dispute, it does not require "fundamental alteration" of, or an "undue burden" upon, the program.⁸⁴

Finally, courts require an individualized assessment of each disabled person's qualifications whenever possible.⁸⁵ Because disabilities vary in their impact on functional ability, one major objective of the civil rights laws was to replace stereotypical generalizations about classes of individuals with decisions based upon individual qualifications.⁸⁶ "Such an inquiry," observed Justice Brennan, "is essential if § 504 is to achieve its goal of protecting handicapped individuals from deprivations based on prejudice, stereotypes, or unfounded fear, while giving appropriate weight to . . . legitimate concerns . . ."⁸⁷ Nevertheless, courts tolerate broader classifications when substantially all excluded persons are unqualified or when individualization is highly impractical.⁸⁸

Although civil rights laws are sometimes defended on utilitarian terms as well, the reasonable accommodation requirement will not advance aggregate social welfare unless it is assumed that the economic and noneconomic societal benefits of accommodating disabled individuals outweigh the costs incurred. See U.S. COMM'N ON CIVIL RIGHTS, *supra* note 79, at 71-74. That assumption seems strained in the context of access to relatively ineffective health care. At any rate, reliance on cost-benefit analysis to evaluate government programs for disabled persons is controversial. *Id.* at 72-73.

84. See 29 U.S.C. § 794(a); 42 U.S.C. § 12182(b)(2)(A)(iii) (regulating public accommodations); *Davis*, 442 U.S. at 410; 28 C.F.R. § 35.130(b)(7) (1994) (regulating public services). Employers have a similar limit on their obligations. They need not make modifications which would impose an "undue burden" under the circumstances. 42 U.S.C. §§ 12111(8)-(10), 12112(b)(5)(A); see also 29 C.F.R. §§ 1630.2(p), 1630.9(a) (1994).

85. *E.g.*, *School Bd. v. Arline*, 480 U.S. 273, 287 (1987) (requiring assessment of the public health risk posed by a teacher's tuberculosis before removing her from the classroom); *Teahan v. Metro-North Commuter R.R.*, 951 F.2d 511, 515 (2d Cir. 1991) (holding that an employer must show that past alcohol abuse has some effect on current job performance to justify an employee's discharge), *cert. denied*, 113 S. Ct. 54 (1992); *Strathie v. Department of Transp.*, 716 F.2d 227, 231 n.7 (3d Cir. 1983) (holding that individual examinations for hearing aid users applying for school bus driver's licenses do not create an "undue burden"); *Crane v. Dole*, 617 F. Supp. 156 (D.D.C. 1985) (requiring an individual assessment to determine whether hearing loss interferes with job performance); *Garrity*, 522 F. Supp. at 213-18 (requiring individualization of care for institutionalized patients with mental illness); see also Karen J. Merrikin & Thomas D. Overcast, *Patient Selection for Heart Transplantation: When Is a Discriminating Choice Discrimination?*, 10 J. HEALTH POL. POL'Y & L. 7, 18 & n.51 (1985) ("Categoric exclusions of classes of handicapped individuals [from heart transplantation] might be considered overbroad whenever they exclude persons who could benefit from treatment.").

86. *E.g.*, 42 U.S.C. § 12101(a)(7); *Arline*, 480 U.S. at 287; *Davis*, 442 U.S. at 405 ("[M]ere possession of a handicap is not a permissible ground for assuming an inability to function."); 28 C.F.R. pt. 35 app. A § 35.130, at 449 (1994) (stating that individualized evaluations are necessary to avoid stereotypical assumptions).

87. *Arline*, 480 U.S. at 287.

88. The seminal case on individualization arose out of an age discrimination claim. In *Western Airlines, Inc. v. Criswell*, the Court adopted the "substantially all" and "highly impractical" tests. 472 U.S. 400, 414 (1985). No similarly definitive case has been decided in the context of disability rights. See, e.g., *Davis*, 442 U.S. at 405 (permitting exclusion of hearing impaired students from a nursing program); *Sterling Transit Co. v. Fair Employment Practice Comm'n*, 175 Cal. Rptr. 548 (Cal. Ct. App. 1981) (requiring an employer to establish a factual basis for believing that all or substantially all persons

To summarize this basic paradigm, a disabled person is qualified to receive health benefits or services if, with reasonable accommodation, she is able to meet the "essential" or "necessary" eligibility criteria. As a result, health care rationing based on the relative effectiveness of different treatments will survive challenge if, and only if, effectiveness is fairly characterized as a "necessary" or "essential" eligibility criterion (a characterization not yet considered by the courts). Unfortunately, this legal test corresponds only obliquely to the underlying ethical question: Under what circumstances should medical utility trump a more egalitarian distribution of health benefits? Nevertheless, it is by these terms that courts will measure health rationing plans. Fortunately, the terms "necessary" and "essential" are sufficiently elastic to permit judicial consideration of the important ethical issues. Furthermore, even if maximization of health outcomes qualifies as a proper eligibility requirement, courts are also likely to insist that the eligibility determinations be as individualized as possible in order to avoid unfair treatment caused by stereotypical assumptions of incapacity.

B. Essential/Necessary Eligibility Criteria

What does it mean for an eligibility criterion to be "necessary" or "essential"? Most obviously, a challenged eligibility criterion must be important to the goals and success of the program or guideline which employs it,⁸⁹ but that may not be sufficient. The United States Supreme Court suggested in *Davis* that discriminatory criteria must also be "legitimate"⁹⁰ and "reasonable."⁹¹ The Court did not, however, explain exactly how much additional scrutiny of program objectives it meant to endorse by these terms. The same ambiguity limits the conclusions that can be drawn from other federal court decisions commenting on the propriety of "reasonable" eligibility requirements.⁹²

with any back condition would be unable to perform the duties of a truck driver). *Compare* *McCrea v. Cunningham*, 277 N.W.2d 52 (Neb. 1979) (upholding visual standard for firefighters) *with* *Connecticut Inst. for the Blind v. Connecticut Comm'n on Human Rights & Opportunities*, 405 A.2d 618, 621 (Conn. 1978) (requiring an employer to show that "no member of the class excluded is physically capable of performing the tasks required by the job") (quoting *Evening Sentinel v. National Org. for Women*, 357 A.2d 498, 501 (Conn. 1975)); *see also* *BARBARA LINDEMANN SCHLIE & PAUL GROSSMAN, EMPLOYMENT DISCRIMINATION LAW 282-83* (2d ed. 1983); *U.S. COMM'N ON CIVIL RIGHTS, supra* note 79, at 100-01, 118-22, 129-34 (advocating individualization as the only effective means of dealing with overgeneralization about disabled persons, but acknowledging that the law varies with the particular exclusion and context).

89. According to the legislative history of the ADA, a "necessary" eligibility requirement is one whose prohibition would cause a "substantial interference with the operation" of the program. H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 4, at 58 (1990), *reprinted in* 1990 U.S.C.C.A.N. 512, 547. The Department of Justice refused to be more specific in its regulations, explaining that the concept of essential eligibility requirements applied in too many contexts for the agency to be more specific in its regulations. 28 C.F.R. pt. 35 app. A § 35.130 at 451 (1994).

90. 442 U.S. at 406 (interpreting § 504); *accord* *Arline*, 480 U.S. at 287 (giving weight to "such legitimate concerns" as public safety).

91. *Davis*, 442 U.S. at 414.

92. *E.g.*, *Rothschild v. Grottenthaler*, 907 F.2d 286, 290-91 (2d Cir. 1990); *Doe v. New York Univ.*, 666 F.2d 761, 775 (2d Cir. 1981).

Nevertheless, Congress apparently intended to provide at least some scrutiny of a defendant's objectives. According to the House Committee on Commerce and Energy, "the prejudice or stereotypical views of other individuals cannot be used as the basis for claiming a substantial interference with the operation of a public accommodation."⁹³ Consistent with that view, courts have regularly ruled that the beliefs of co-employees or customers may not be used as an excuse for discrimination.⁹⁴ To hold otherwise would "give effect to the prejudice of others."⁹⁵ As a result, these justifications are insufficient even if essential to the viability of the business.

Courts have not yet indicated whether they will extend their scrutiny of purported justifications to those which are not so patently based on biased attitudes. While several courts have rejected challenges to health benefit programs in the past, none of the reported opinions has sanctioned the use of either success rates or quality of life considerations.⁹⁶ When the issue is joined, as it was in Oregon, the statutory terms "essential" and "necessary" seem sufficiently elastic to permit courts to consider whether medical utility is a permissible basis for disfavoring disabled patients. In effect, courts would be deciding whether the objective of maximizing health outcomes is an "essential" program objective within the meaning of the equal opportunity laws.

Courts and administrative agencies are especially likely to use this elasticity to scrutinize the legitimacy of quality of life considerations. HHS did exactly this in responding to the Oregon waiver request, as did a federal trial court in the recent case of *Baby K*.⁹⁷ In scrutinizing proffered justifications for discriminatory classifications, judges will have to rely on the few hints provided by the legislative history and the case law, supplemented by

93. H.R. REP. NO. 485, *supra* note 89, at 58, *reprinted* in 1990 U.S.C.C.A.N. at 547.

94. *E.g.*, *Chalk v. United States Dist. Ct.*, 840 F.2d 701, 711 (9th Cir. 1988) (rejecting a defense based on the irrational fears of students and parents as insufficient to justify exclusion of teachers with AIDS); *Fernandez v. Wynn Oil Co.*, 653 F.2d 1273, 1276-77 (9th Cir. 1981) (rejecting a defense based upon a customer preference for males); *Diaz v. Pan Am. World Airways, Inc.*, 442 F.2d 385, 389 (5th Cir.) (rejecting a defense based on a customer preference for female flight attendants), *cert. denied*, 404 U.S. 950 (1971); *Cain v. Hyatt*, 734 F. Supp. 671, 681 (E.D. Pa. 1990) (rejecting a defense based on customer and co-worker preferences regarding AIDS); *see also* 28 C.F.R. pt. 36, app. B § 36.301 at 602 (1994).

95. *Palmore v. Sidoti*, 466 U.S. 429, 433 (1984) (overturning a child custody order which removed a child from her mother because she had subsequently married an African-American); *accord* *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 448 (1985) (holding that protecting facility residents from angry neighbors did not provide a rational basis for denying a zoning permit to a home for the mentally disabled).

96. *E.g.*, *Traynor v. Turnage*, 485 U.S. 535 (1988); *Alexander v. Choate*, 469 U.S. 287 (1985); *Bernard B. v. Blue Cross & Blue Shield*, 679 F.2d 7 (2d Cir. 1982); *Doe v. Colautti*, 592 F.2d 704 (3d Cir. 1979); *Duquette v. Dupuis*, 582 F. Supp. 1365 (D.N.H. 1984); *Doe v. Devine*, 545 F. Supp. 576 (D.D.C. 1982), *aff'd*, 703 F.2d 1319 (D.C. Cir. 1983). Their grounds for decision vary and are often difficult to elucidate. Insurance underwriting and cost appear to be one defense. Several opinions also appear to disfavor claims alleging discriminatory preferences for one disability over another. The EEOC cites some of these same cases for the proposition that restrictions on broad categories of treatment (such as mental health) do not constitute "disparate treatment" and therefore are not prohibited.

97. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994) (mem.).

consideration of the ethical implications and analogies to other contexts. These ingredients are the subject of Parts III and IV, which address the use of success rates and quality of life measurements, respectively.

C. *The Exemption for Insurance Underwriting*

While the legal status of rationing based on effectiveness is still uncertain, underwriting exclusions based on anticipated cost have express congressional sanction. In the ADA, Congress authorized benefits plans to engage in "the legitimate classification of risk."⁹⁸ As a result, plans remain free to consider how various disabilities influence a person's risk of death or illness.⁹⁹ This exclusion permits risk-bearing health plans (but not necessarily practicing physicians) to consider the anticipated *cost* of treating various disabilities.¹⁰⁰ However, the statutory exemption for underwriting practices does not appear to sanction the use of QALYs or other measures of a given treatment's *effectiveness*. Unlike restrictions based on underwriting risks, eligibility restrictions based on effectiveness are not based on the risk of subscriber illness and its predicted cost. They are based, instead, on predicted outcomes. Patients whose care is relatively ineffective are not necessarily any more costly or financially risky than other patients. Their care does not present the kind of cross-subsidization problems that standard underwriting practices are

98. The ADA permits "underwriting risks, classifying risks, or administering such risks." 42 U.S.C. § 12201(c)(2); *see also* 29 U.S.C. §§ 791(g), 794(d) (Supp. V 1993) (applying ADA standards to determinations of employment discrimination per the 1992 Amendment); *Bernard B.*, 528 F. Supp. at 132-33 (holding that an insurance company did not discriminate under § 504 in choosing to exclude mental health benefits from a minimum coverage plan), *aff'd*, 679 F.2d 7 (2d Cir. 1982).

The restrictions must not be a subterfuge and, unless the plan is self-insured, must comport with state law. The exemption applies to any "organization covered" by the ADA which has a "bona fide benefit plan." This very likely includes publicly-funded health plans which use underwriting calculations to predict risks and shape coverage. The language in the ADA providing this exemption is commonly referred to as "Section 501" of the ADA. 42 U.S.C. § 12201(c).

The exception for *self-insured* benefit plans includes no explicit requirement that the terms of the benefit plan be actuarially based. 42 U.S.C. § 12201(c)(3). As a result, it arguably permits discrimination whether or not based on actuarial risk. DISTRICT OF COLUMBIA BAR TASK FORCE, *supra* note 9, at 54. But the legislative history suggests a contrary intent. *Id.* The EEOC has placed the same restrictions on self-insured plans as on other plans. It uses the prohibition against subterfuge to accomplish this. EEOC, INTERIM GUIDANCE, *supra* note 8, at 140,026.

99. H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 3, at 70-71 (1990) [hereinafter H.R. REP. NO. 458(II), *reprinted in* 1990 U.S.C.C.A.N. 445, 493-94; H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 2, at 136-38 (1990) [hereinafter H.R. REP. NO. 485(II), *reprinted in* 1990 U.S.C.C.A.N. 303, 419-21. According to the legislative history, a plan based on defensible underwriting assumptions may refuse to insure, limit the amount, extent, or kind of coverage, deny coverage for preexisting conditions, or charge different premiums for the same coverage based on disability.

100. The Federal Government's correspondence with Oregon conceded that costs could be considered. Sullivan Letter, *supra* note 38, *reprinted in* 9 ISSUES L. & MED. at 411. Nevertheless, the exemption probably will not insulate the use of cost in settings which do not involve risk assessment, such as the design and application of clinical practice guidelines by nonunderwriting entities. In those circumstances, discriminatory criteria will have to be shown to be necessary or essential. *See Orentlicher, supra* note 36, at 311. Risk-bearing physicians (*e.g.*, those paid by capitation) might have a more plausible claim to the underwriting exemption, depending upon the circumstances.

meant to solve.¹⁰¹ As a result, only the cost portion of cost-effectiveness analysis has clear statutory blessing, and even then only when it is part of an underwriting process.

D. Dealing with the Multiplicity of Governing Legal Texts

The preceding Parts have outlined the basic paradigm of the disability rights laws, but the structure of the anti-discrimination statutes themselves is actually considerably more complex. Within the ADA, for example, separate titles govern public services such as Oregon's Medicaid plan, employment (including employer-sponsored health benefits plans), and public accommodations such as hospitals and physicians' offices. In addition, federal agencies and federally-funded programs are subject to the Rehabilitation Act and its regulations. Each of these statutes has its own relevant language describing prohibited discrimination, thereby creating the possibility of diverse legal standards for each activity. Fortunately, only the provisions governing employer-sponsored health benefits present a serious prospect of different requirements and, even then, courts are likely to sidestep the textual differences. Although the title governing public accommodations also appears to deviate from the basic paradigm, this appearance is misleading.

Public accommodations provided by private entities are regulated by Title III of the ADA.¹⁰² This title, which governs the practices of health insurers, hospitals, and physicians, does not explicitly require that disabled persons be "qualified" in order to receive statutory protection from discrimination. As a result, it creates the misleading impression that all persons who need health services must be given equal access to them without regard to disability. Unfortunately, the trial court in *Baby K* was fooled by this difference in text.¹⁰³

In fact, Title III expressly permits the use of discriminatory eligibility criteria if "necessary for the provision of the . . . services . . . being offered."¹⁰⁴ Discriminatory eligibility criteria are, therefore, permitted as long as (and only if) they are "necessary." This is the same test set forth in the ADA regulations to determine whether eligibility criteria employed by government programs, such as Oregon's, are "essential."¹⁰⁵

The provisions in the ADA dealing with employer-provided health benefits, on the other hand, deviate from this basic pattern. Although the ADA permits employers to insist that applicants be qualified to perform their jobs, it does not expressly authorize the imposition of separate eligibility requirements for

101. *But see* Orentlicher, *supra* note 36, at 310 (suggesting that inefficient use might constitute cross-subsidization, but also noting the differences and calling the legal status "uncertain").

102. 42 U.S.C. §§ 12181-12189.

103. *In re Baby K*, 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir), *cert. denied*, 115 S. Ct. (1994) (mem.).

104. 42 U.S.C. § 12182(b)(2)(A)(i); *see also* 28 C.F.R. § 35.130(b)(8) (1994).

105. 28 C.F.R. § 35.130(b)(8) (1994).

employee fringe benefits.¹⁰⁶ As a result, some doubt remains about the propriety of imposing any eligibility requirements (other than underwriting criteria) which have the effect of discriminating against disabled employees.

On the one hand, the idea of qualifications has less intuitive meaning when applied to benefits such as sick leave, vacation, and health insurance than it has when applied to the hiring decision. On the other hand, there is no reason to believe that Congress intended to preclude the use of bona fide measures of effectiveness to decide which treatments would be eligible for reimbursement. Indeed, Congress probably never considered the issue. Neither is there any reason to believe that Congress intended to impose more stringent restrictions on employers than it imposed on other providers of health insurance and health care, or that it meant to provide more protection to disabled employees than it provided to other disabled consumers of health services.

As a result, it is easy to understand why the EEOC has stretched the exemption for underwriting practices to permit employers to defend exclusionary restrictions on the grounds that they are "necessary . . . to prevent the occurrence of an unacceptable change either in the coverage of the health insurance plan, or in the premiums charged for the health insurance plan."¹⁰⁷ Under this interpretation of the ADA, QALYs could potentially be defended as necessary to prevent either greatly increased premiums or unacceptable reductions in coverage.¹⁰⁸ In effect, this interpretation allows employer-sponsored plans the defense that restrictions on relatively ineffective care are essential to prevent a fundamental alteration of the program and a substitution of less desirable mechanisms for controlling costs. This closely resembles the inquiry which would be undertaken to determine the necessity of discriminatory eligibility criteria in nonemployment contexts. Courts, like the EEOC, are likely to find a way to permit the use of essential eligibility criteria for employee fringe benefits. They could accomplish this either by interpreting expansively the exemption for underwriting practices, or by concluding that discrimination based on legitimate eligibility requirements is not discrimination "by reason" of disability. As the U.S. Supreme Court acknowledged years

106. In the context of employment, a "qualified handicapped person" under § 504 is someone "who, with reasonable accommodation, can perform the essential functions of the job." 45 C.F.R. § 84.3(k)(1) (1994). The employment provisions of the ADA state that a "qualified individual with a disability" is an individual who can "perform the essential functions of the employment position" with or without reasonable accommodation. 42 U.S.C. § 12111(8). Eligibility criteria that screen out disabled persons must be "job-related . . . and . . . consistent with business necessity." *Id.* §§ 12112(b)(6), 12113(a).

107. EEOC, INTERIM GUIDANCE, *supra* note 8, at 140,027.

108. The EEOC has defined an "unacceptable" change in coverage or premiums to be one which would

1) make the health insurance plan effectively unavailable to a significant number of other employees, 2) make the health insurance plan so unattractive as to result in significant adverse selection, or 3) make the health insurance plan so unattractive that the employer cannot compete in recruiting and maintaining qualified workers due to the superiority of health insurance plans offered by other employers in the community.

Id. (footnote omitted). This definition may be more narrow in practice than a more general authorization to use criteria which are "essential" or "necessary" to the integrity of the benefits plan. However, the EEOC explicitly states that its list of justifications is not exclusive. *Id.* at 140,026.

ago, exclusions based on the absence of legitimate qualifications are not the kind of discrimination that Congress meant to prohibit.¹⁰⁹

Until the courts rule on this issue, it is possible, but unlikely, that employers will be flatly prohibited from adopting health benefits plans that discriminate on the basis of disability for nonunderwriting reasons. Courts are more likely to evaluate noncost justifications by applying the same test used in nonemployment contexts: the challenged eligibility criteria must be essential or necessary.

III. "NEUTRAL" MEASURES OF EFFECTIVENESS: SURVIVAL RATES

The Federal Government's initial rejection of the Oregon rationing plan highlighted the fiercely divisive issues raised by the use of quality of life considerations. In truth, however, the use of any measure of effectiveness, no matter how superficially "neutral" or "objective," will also raise basic questions about the choice between allocative efficiency and distributive justice in health care. Even if quality of life considerations were removed entirely from the calculus and some other measure of treatment effectiveness such as survival rates were used, rationing based on effectiveness could still disfavor patients with disabilities that are resistant to treatment or which make it more difficult to treat other diseases. This Part examines the conflict between the efficiency and egalitarian perspectives which arises when survival rates—a relatively noncontroversial measure of effectiveness—are utilized.¹¹⁰ Part IV will consider the additional issues raised when quality of life is considered.

A. *The Underlying Conflict Between Utility and Equality*

QALYs seek to maximize health outcomes by eliminating the least effective treatments. David Hadorn reasons that disabled persons who are likely to have relatively poor outcomes from a medical procedure (such as heart transplant candidates who are diabetic) may be excluded from coverage on the ground that they are not qualified to receive it.¹¹¹ He suggests that the objective

109. *Alexander v. Choate*, 469 U.S. 287, 299 n.19 (1985).

110. For example, measuring effectiveness on the basis of the *duration* of benefit raises special issues of both disability and age-based discrimination. Because this criterion, like quality of life measurements, may raise additional issues, my discussion of success rates is not intended to suggest that identical conclusions would be reached regarding the use of duration as a measure of treatment effectiveness.

111. Hadorn, *supra* note 36, at 1457. Hadorn is careful to require that any restrictions be based on sound scientific criteria. *Id.* at 1458.

Supporters of the Oregon plan also believed that Oregon had not discriminated on the basis of disability because the State had offered the same package of benefits to both disabled and nondisabled patients. Hercenberg & Krasner, *supra* note 47, at 22; Thomas, *supra* note 43, at 138 (citing a telephone interview with Paige R. Sipes-Metzler, Executive Director, Oregon Health Services Commission (Aug. 5, 1992)). From this perspective, the treatment of all patients was "even-handed" and, thus, nondiscriminatory. As should be apparent, however, plans like these are hardly even-handed. In each, the *substantive coverage terms* are themselves discriminatory. In each, disabled patients would be treated less favorably than others because of their disabilities. As the Supreme Court stated in *Alexander*, "The

application of scientifically sound outcomes data would support the exclusion of patients whose outcomes are relatively nonbeneficial or unsatisfactory.¹¹² Hadorn also apparently assumes that criteria intended to maximize outcomes would meet the legal requirement of being "essential" or "necessary" for provision of the service. Karen Merrikin and Thomas Overcast considered this issue directly in their analysis of disability-based exclusions from heart transplantation programs and reached the same conclusion.¹¹³ These views, which are shared by many, if not most commentators, reflect the assumption that society can and should consider the effectiveness of a medical treatment.¹¹⁴

Ethicist Robert Veatch and others argue, however, that not all care that is cost-ineffective is morally expendable.¹¹⁵ Formal justice requires that like cases be treated alike.¹¹⁶ From an egalitarian perspective, a strong argument can be made that effectiveness does not qualify as a morally relevant basis for treating one patient differently from another. That a patient's odds are lower because of his disability in no way reflects that patient's virtue, merit, worth, or any other similarly relevant basis for treating people differently.¹¹⁷ John Harris views QALYs as part of a philosophy "in which the good guys are the fortunate for whom long and healthy life-expectancy can be cheaply provided" and the enemies are "those unfortunates who stand between the fortunate and their survival by daring to make rival claims."¹¹⁸ From this egalitarian perspective, treating like cases alike means treating equally needy patients as

benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled." *Alexander*, 469 U.S. at 301; see also NATIONAL COUNCIL ON THE HANDICAPPED, *supra* note 77, app. A-20 to A-22 (noting that if discriminatory criteria make a person unqualified, disabled persons could be eliminated from participation); *Stade*, *supra* note 45, at 2008-09 (rejecting the defense).

112. Hadorn, *supra* note 36, at 1457.

113. Merrikin & Overcast, *supra* note 85, at 15-18. Merrikin & Overcast conclude that disabled candidates may be excluded if they are "unable to benefit" or have "[no] reasonable chance of a successful clinical outcome." *Id.* at 18.

114. E.g., BEAUCHAMP & CHILDRESS, *supra* note 6, at 294-301; LARRY R. CHURCHILL, RATIONING HEALTH CARE IN AMERICA 95, 121-25 (1987); Menzel, *supra* note 43, at 57; Orentlicher, *supra* note 36, at 311-12 (endorsing likelihood, duration, and degree of benefit); Steven A. Toms, *Outcome Predictors in the Early Withdrawal of Life Support: Issues of Justice and Allocation for the Severely Brain Injured*, 4 J. CLIN. ETHICS 206, 210 (1993).

115. E.g., ROBERT M. VEATCH, THE FOUNDATIONS OF JUSTICE 149-52 (1986); Jerry Avorn, *Benefit and Cost Analysis in Geriatric Care: Turning Age Discrimination into Health Policy*, 310 NEW ENG. J. MED. 1294 (1984); John Harris, *QALYfying the Value of Life*, 13 J. MED. ETHICS 117, 120, 122 (1987) [hereinafter Harris, *QALYfying the Value of Life*] (arguing that life expectancy is irrelevant); John Harris, *Unprincipled QALYs: A Response to Cubbon*, 17 J. MED. ETHICS 185 (1991) [hereinafter Harris, *Unprincipled QALYs*] (objecting to both life expectancy and quality of life considerations); Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15, 29 (1992); see also Brock, *supra* note 28, at 93 (describing the arguments for an equal chance or lottery to ration scarce organs).

116. See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 6, at 259; VEATCH, *supra* note 115, at 6; Daniel Wikler, *Philosophical Perspectives on Access to Health Care: An Introduction*, in 2 SECURING ACCESS TO HEALTH CARE, *supra* note 20, at 109, 114 (stating that equal access should be preferred absent morally relevant differences).

117. Harris, *QALYfying the Value of Life*, *supra* note 115, at 121.

118. Harris, *Unprincipled QALYs*, *supra* note 115, at 187.

equally qualified and giving them equal access to treatment.¹¹⁹ Indeed, in Veatch's view, it may require especially favorable treatment of persons with disabilities in order to give them "an opportunity for equality of well-being over a lifetime."¹²⁰ That a person's disability deprives her of equal odds is tragic enough, without compounding that misfortune by denying her equal access to potentially beneficial medical care.

The egalitarian view is also consistent with the "differences" principle of John Rawls. In a just society, according to Rawls, "[a]ll social values—liberty and opportunity, income and wealth, and the bases of self-respect—are to be distributed equally unless an unequal distribution of any, or all, of these values is to everyone's advantage."¹²¹ Because rationing on the basis of effectiveness will disadvantage individuals with short life expectancies or with diseases that are especially difficult to cure, the differences principle seems to imply that this unequal expenditure of resources would be unjust.

These two opposing views stake out the legal and ethical battleground on which health care allocation schemes must be judged. Hadorn's view assumes that scientifically-supported effectiveness criteria are sufficient to defend a plan. Although his endorsement of these criteria has the appearance of neutrality,¹²² in truth it endorses a very utilitarian brand of distributive justice in which allocative efficiency is more important than equal access.¹²³ This tension is illustrated in Beauchamp and Childress' classic treatise on bioethics. The text first endorses a "fair opportunity" principle requiring equal distribution of social benefits unless the differences are ones for which the affected persons are responsible. Yet, it later accepts as an "unargued premise" that it is "morally imperative" to take medical utility into account in an effort to "save as many lives as possible through the available resources."¹²⁴ The noted British health economist Alan Williams correctly notes that "[a]t the end of the day we simply have to stand up and be counted as to which set of principles we wish to have underpin the way the health care system works."¹²⁵

119. VEATCH, *supra* note 115, at 149 (arguing that justice means giving disabled patients "an equal shot at a desired outcome"); *see also* Orentlicher, *supra* note 36, at 311 (acknowledging that a reasonable argument could be made under the disability rights laws that all patients who could benefit are qualified).

120. VEATCH, *supra* note 115, at 149; *see also* Alwyn Smith, *Qualms About QALYs*, THE LANCET, May 16, 1987, at 1134, 1135 (pointing out that several nonutilitarian strategies would favor patients who have the greatest need).

121. JOHN RAWLS, A THEORY OF JUSTICE 61-62 (1971). Others have referred to it as a "maximin" principle. Kenneth J. Arrow, *Some Ordinalist-Utilitarian Notes on Rawls' Theory of Justice*, 70 J. PHIL. 245, 248 (1973).

122. *See* Hercenberg & Krasner, *supra* note 47, at 22 (referring to the Oregon practice as neutral on its face); *see also* Hadorn, *supra* note 36, at 1458 (referring to the "objective application of outcome data").

123. Failure to appreciate this underlying value choice would risk conflation of efficiency with equality. *See* Brock, *supra* note 28, at 88 (arguing that medical criteria are not value-neutral); La Puma, *supra* note 11, at 437 (viewing QALYs as part of a larger societal evolution toward a utilitarian ethic); Smith, *supra* note 120, at 1136 (arguing that QALYs couch a political issue as a technical one).

124. BEAUCHAMP & CHILDRESS, *supra* note 6, at 270-72, 296-97.

125. Alan Williams, *Response: QALYing the Value of Life*, 13 J. MED. ETHICS 117, 123 (1987).

B. The Legal and Ethical Sufficiency of Success Rates

Congress did not provide specific guidance regarding this choice between medical utility and equal access, but it did provide a structure through which courts can analyze the choice. As discussed above, eligibility criteria based on effectiveness must be examined to determine if they are genuinely "necessary" or "essential" to the program.¹²⁶ At a minimum, this means that effectiveness criteria must be shown to have demonstrable importance to the program's goal of maximizing health outcomes from limited resources. The harder question is whether this *objective* is itself "essential" or whether, like satisfaction of customer preferences, it is legally and ethically insufficient to justify discriminatory conduct.

1. Importance for Plan Objectives

Although the rationing of rarely-effective care is not the only way to ration beneficial care, none of the alternatives (such as first-come-first-served service, cost-based exclusions, higher patient co-payments, and lower annual limits on coverage) have similar promise for maximizing health care outcomes. For example, if cost alone were used to rank treatments, expensive procedures which are very successful would be disfavored and inexpensive procedures which are rarely successful would be favored. Uniform spending limits would deny coverage to persons with conditions which are expensive or lengthy to treat even if the treatments are ultimately very effective. Similarly, annual or lifetime caps would subsidize the care of persons whose treatments are less expensive but less effective. Broad categorical exclusions, like noncoverage of mental or dental health, are another common alternative that is less likely to result in facial violation of the disability laws, but would deny effective care to many, while funding comparatively ineffective care to patients whose treatments are covered. In short, none of these alternatives seek to squeeze the most health benefits possible from finite resources.¹²⁷

A prohibition on disability-based rankings would reduce the ability of a health plan to accomplish its allocative objectives. Indeed, the utility of effectiveness criteria would be destroyed if plans were forbidden to favor some disabilities while disfavoring others.¹²⁸ Making distinctions of this kind is the very purpose of using QALYs. A prohibition on comorbidity considerations would also impair the goal of maximizing health outcomes, though not as dramatically. Its impact would vary with each health plan or

126. See *supra* part II.B.

127. As a result, none of the alternatives would provide a benefit to patients "in the manner targeted" by the program. *Easley by Easley v. Snider*, 841 F. Supp. 668, 675 (E.D. Pa. 1993), *rev'd*, 36 F.3d 297 (3d Cir. 1994). Ironically, each of the alternatives (except random assignments such as lotteries) retains the potential to disfavor disabled patients in practice. That is because the care of disabled persons will often be more expensive than the norm and because broad exclusions, like that of mental health, are often closely related to a large category of disabled persons.

128. Many of the conditions whose treatment would be ranked in a system like Oregon's would constitute legal disabilities. See *supra* text accompanying notes 75-76.

practice guideline, depending upon the availability and use of data regarding disability-related comorbidity. Although a prohibition on comorbidity classifications would not have been a fatal blow for Oregon's plan, Oregon was criticized for not taking greater account of comorbidity.¹²⁹ As outcomes data improve, both health plans and practice guidelines are likely to make greater use of comorbidity data.

In short, the use of effectiveness criteria is vital to the goal of maximizing health outcomes from fixed resources. Although the practical significance of a bar on effectiveness-based classifications that disfavor persons with disabilities will depend upon the facts of the particular practice being challenged, it seems safe to assume that the negative impact will often be substantial.

It is tempting to suggest, however, that no rationing of beneficial care can be characterized as necessary or essential until additional efforts have been made to eliminate waste and to increase resources.¹³⁰ Obviously, a greater effort to husband resources is vital, but consideration of effectiveness is one way to stimulate efficiency.¹³¹ Furthermore, the reality is that the resources available for health care are finite, rationing already exists, and its continuation, in one form or another, is inevitable. While efforts to increase resources and improve efficiency are urgently needed, they will not eliminate the need to make choices about whom and what services to cover.

Rationing is already a stable component of American health care. The American health care system rations on the basis of wealth and access to health insurance.¹³² Eligibility for insurance is the principal mechanism used to decide who receives care,¹³³ but our system also rations through caps on total coverage, limited coverage of disfavored conditions such as AIDS or mental illness, and exclusion of care that is "experimental" or not medically indicated. Care is rationed in overcrowded intensive care units and undersupplied organ transplantation programs.¹³⁴ It is rationed when decisions are made about who receives a second opinion, a high-tech CT scan for head pain, or a referral to a specialist.¹³⁵ The Federal Government promotes the rationing of care when it pays hospitals a lump sum for each patient with a particular diagnosis, leaving it up to the providers to decide how aggressively

129. Capron, *supra* note 43, at 20.

130. E.g., Marcia Angell, *The Doctor as Double Agent*, 3 KENNEDY INST. ETHICS J. 279, 284 (1993); Harris, *QALYfying the Value of Life*, *supra* note 115, at 122; Arnold S. Relman, *The Trouble with Rationing*, 323 NEW ENG. J. MED. 911, 912 (1990).

131. Eddy, *supra* note 24, at 420 (noting the limits of the state's power to eliminate waste and inefficiency).

132. E.g., CHURCHILL, *supra* note 114, at 14; Eddy, *supra* note 23, at 106; Leonard M. Fleck, 4 J. CLINICAL ETHICS 362, 363 (1993) (reviewing MARTIN STROSBERG ET AL., *RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND* (1992)).

133. See, e.g., Eddy, *supra* note 33, at 2443 (noting that 40% of the poor are ineligible for Medicaid).

134. See BEAUCHAMP & CHILDRESS, *supra* note 6, at 297; Tristram Engelhardt & Michael A. Rie, *Intensive Care Units, Scarce Resources and Conflicting Principles of Justice*, 255 JAMA 1159, 1162 (1986) (proposing that ICU admissions be made on the basis of likelihood of success, quantity of success, and length of survival).

135. See Paul T. Menzel, *Double Agency and the Ethics of Rationing Health Care: A Response to Marcia Angell*, 3 KENNEDY INST. ETHICS J. 287, 289 (1993); Beck, *supra* note 1, at 30.

each patient is to be treated.¹³⁶ Americans have never been willing to pay for all the health care that is of any conceivable benefit, nor are they likely to do so in the future. Unfortunately, these existing mechanisms for deciding who receives what care are blunt and often irrational or unfair, reflecting the influence of wealth, employment, habit, cost, and power.

Current attempts to reduce wealth-based rationing are long overdue. But even the Clinton administration has conceded that its efforts to increase access and security must be followed by reconsideration of funding for the least effective care.¹³⁷ Indeed, the funding requirements of comprehensive health care for all Americans will make efforts to control costs and husband resources even more vital. While calls to simplify administration and to end fraud, waste, and price-gouging are warranted and may yield some savings (perhaps significant savings), the unending capacity to generate marginally more effective health care procedures at vastly greater expense will preclude exclusive reliance upon such simple and ethically appealing methods of cost control.¹³⁸ Given the urgent need for resources in other societal contexts such as housing, education, research and development, crime control, and environmental regulation, difficult choices about health care coverage are unlikely to be avoided in the foreseeable future.¹³⁹ Americans will rightly want to insure that they get value for their health care expenditures. While cost-savings may buy time to debate the mix of rationing methods, it will not eliminate the excruciatingly painful decisions about how much health care is enough and which health care to exclude.

In fact, the Clinton administration's Health Care Reform Task Force assumed as much. To facilitate its deliberations over suitable mechanisms for resolving disputes about coverage, the Bioethics Working Group considered three treatments which might become the subject of dispute.¹⁴⁰ One was cystic fibrosis testing for pregnant women, which costs approximately two hundred dollars and is not as accurate as amniocentesis, the test for Down's Syndrome. The second was Tachrine, a newly approved drug used to ameliorate the cognitive deficits produced by Alzheimer's Disease. Tachrine

136. Leonard M. Fleck, *DRGs: Justice and the Invisible Rationing of Health Care Resources*, 12 J. MED. & PHIL. 165, 185 (1987); Fleck, *supra* note 24, at 1609-10.

137. See Grimes, *supra* note 1, at 5C.

138. See, e.g., U.S. GOV'T ACCOUNTING OFFICE, GAO/HRD-92-120, HOSPITAL COSTS: ADOPTION OF TECHNOLOGIES DRIVES COST GROWTH 4 (1992) (noting that despite the initiation of Medicare's prospective payment system, costs grew, and the single most important factor was the rapid adoption of new technology).

139. E.g., Daniel Callahan, *Rationing Health Care: Will It Be Necessary? Can It Be Done Without Age or Disability Discrimination?*, 5 ISSUES L. & MED. 353, 362 (1989); Capron, *supra* note 43, at 20; Fleck, *supra* note 132, at 363-64; Menzel, *supra* note 135, at 288; Orentlicher, *supra* note 36, at 308; Thomas, *supra* note 43, at 115-16; Robert M. Veatch, *Justice and Outcomes Research: The Ethical Limits*, 4 J. CLINICAL ETHICS 258 (1993); Robert J. Samuelson, *Health Care: How We Got Into This Mess*, NEWSWEEK, Oct. 4, 1993, at 31, 35. *Contra* Joseph A. Califano, Jr., *Rationing Health Care: The Unnecessary Solution*, 140 U. PA. L. REV. 1525, 1526-27 (1992).

140. Nancy N. Dubler, *Working on the Clinton Administration's Health Care Reform Task Force*, 3 KENNEDY INST. ETHICS J. 421, 428-29 (1993). Ms. Dubler was co-chair of the Bioethics Working Group. Her article provides the factual basis for my summaries of the three treatments.

is expensive, has little clinical effect, and may be harmful to some users.¹⁴¹ Finally, autologous bone marrow transplantation for end-stage metastatic cancer is rarely effective and extraordinarily expensive. Yet, it is understandably requested as a treatment of last resort. The Bioethics Working Group recognized that these scenarios were representative of a much larger pool of potential conflicts, including expenditures in neonatal intensive care units and on terminal care for the elderly.¹⁴² Rationing these different medical treatments involves difficult decisions which will have to be faced in the near future. Plans which seek to maximize returns from scarce resources will need to consider the relative effectiveness of each treatment.

2. Legitimacy of Plan Objectives

Should maximizing outcomes be viewed as a legitimate justification for discriminating on the basis of disability?¹⁴³ Passages from the legislative history suggest an egalitarian interpretation of the law, but their persuasive power is limited by their ambiguity and by the failure of Congress to voice any objection to the contemporaneous use of success rates in the administration of federal health care programs. These limitations leave judges with considerable freedom to implement their own views of desirable public policy. Although a few cases seem to support the egalitarian view, they are inadequately analyzed, distinguishable, and opposed by other judicial decisions. Rather than rely on these prior cases, future opinions are likely to address the substantive issue directly. Courts will very likely resolve the issue by comparing survival rates to the only other prohibited criterion (customer or co-worker preferences) and conclude that the use of survival rates is permissible because, unlike customer preferences, the use of survival rates will not give effect to invidious stereotypes. This result is good policy as well as good law.

a. Legislative History

Significant support for an egalitarian interpretation of the ADA appears in the House Judiciary Committee report. In its discussion of employee health insurance, the Committee specifically stated that any limit on insured procedures (such as a limit on dialysis) must apply to all patients, with or without disabilities. "Persons with disabilities," according to the report, "must have equal access to the health insurance coverage that is provided by the

141. Tachrine reportedly relieves memory loss slightly for one-fifth of its users, but widespread use by the approximately four million sufferers of Alzheimer's would exceed \$500 million annually to benefit only 80,000 persons. Samuelson, *supra* note 139, at 35.

142. Dubler, *supra* note 140, at 430.

143. The terms "necessary" and "essential" are very broad and are consistent with a requirement that exclusionary eligibility criteria select beneficiaries on a morally relevant basis. See *supra* part II.B.

employer to all employees."¹⁴⁴ Thus, persons with kidney disease should not be denied coverage for treatments such as heart surgery if those treatments are offered to employees who are not disabled.¹⁴⁵ This passage raises serious questions about the propriety of any coverage limitation or practice guideline which considers disability-based comorbidity.

Other passages in the legislative history suggest that differences in treatment effectiveness would not constitute a sufficient justification for disability-based discrimination. The Judiciary Committee report states that disabled persons are entitled to an "equal opportunity to obtain the same results as others."¹⁴⁶ In addition, the report of the House Committee on Energy and Commerce, while conceding that equal opportunity does not require equal results, emphasizes that "individuals with disabilities must be afforded an equal opportunity to attain substantially the same result."¹⁴⁷

To illustrate conduct that violates the right of equal opportunity, the report of the Judiciary Committee describes the exclusion of persons using wheelchairs from an exercise class: "[A]n exercise class cannot exclude a person who uses a wheelchair because he or she cannot do all of the exercises and derive the same result from the class as persons without a disability."¹⁴⁸ If a person in a wheelchair cannot be excluded from exercise class because she will derive fewer benefits than others in the class, then perhaps a disabled patient should not be excluded from treatment simply because she is less likely to derive a benefit from it. The analogy to comorbidity classifications is especially close. Those classifications, like the discrimination in the exercise class, deny a benefit to a disabled person which is offered to other individuals who lack the disability.

As a result, the legislative history provides some credible support for the view that discrimination on the basis of criteria such as success rates ought not be considered essential or necessary, at least in the context of comorbidity. It is relatively uninformative, however, about the propriety of treating one disability more favorably than others. Even with respect to comorbidity, the dispositive power of this legislative history is reduced by the absence of any indication that Congress directly considered the difficult issues posed when health care resources are allocated.

144. H.R. REP. NO. 485(III), *supra* note 99, at 38, *reprinted in* 1990 U.S.C.C.A.N. at 461; *see also* H.R. REP. NO. 485(II), *supra* note 99, at 59, *reprinted in* 1990 U.S.C.C.A.N. at 341.

145. H.R. REP. NO. 485(III), *supra* note 99, at 38, *reprinted in* 1990 U.S.C.C.A.N. at 460-61. The EEOC statements have used more ambiguous language, requiring that all employees be provided with "equal access" to whatever health insurance the employer provides to employees without disabilities." EEOC, INTERIM GUIDANCE, *supra* note 8, at 140,023.

146. H.R. REP. NO. 485(III), *supra* note 99, at 55, *reprinted in* 1990 U.S.C.C.A.N. at 478.

147. H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 4, at 57 (1990), *reprinted in* 1990 U.S.C.C.A.N. 512, 546.

148. H.R. REP. NO. 485(III), *supra* note 99, at 55, *reprinted in* 1990 U.S.C.C.A.N. at 478. Although this illustration appears in a part of the report discussing public accommodations, the legislative history leaves no doubt that the general prohibitions contained in Title II (governing public services) were meant to incorporate the specific prohibitions of Title III (governing public accommodations). *Id.* at 51 ("Title II should be read to incorporate provisions of Titles I and III which are not inconsistent with the regulations implementing Section 504 of the Rehabilitation Act of 1973 . . .").

Consider, for example, the exercise class. It seems reasonable to suppose that Congress would want to take a fresh look at this example if the exercise class were part of a health program for people with heart disease and the costs were not paid by the participant directly, but instead were paid by a health plan. Now assume that the class were oversubscribed and the health plan limited enrollment in the class to those most likely to benefit from the class and, for that reason, excluded patients with some severe disabilities. Congress' intentions regarding the allocation of scarce health resources in this situation cannot be confidently deduced from its sentiments about an ordinary exercise class with no apparent space or resource limits at stake.

Similar ambiguity limits the conclusions which can be drawn from the Judiciary Committee's statement, described above,¹⁴⁹ that any limit on insured procedures must apply equally to all patients without regard to disability. It is unclear whether Congress meant to indicate that differential coverage could never be justified by any eligibility criteria or whether it simply assumed that no such justification ordinarily existed. The latter explanation is more plausible. The Committee staff must have assumed, for example, that no actuarial basis for the differential treatment existed. Otherwise, the language in this report would be inconsistent with Congress' explicit sanction of discrimination based on actuarial calculations. The staff may similarly have assumed that no other "necessary" or "essential" eligibility requirement could explain the discrimination. If this reading of the legislative history is correct, then it provides no guidance regarding the sufficiency of survival rates as a basis for differential treatment.¹⁵⁰

Furthermore, Congress would surely have indicated more clearly if it intended to bar altogether the long-standing clinical practice of taking comorbidity into account. The legislative history indicates no objection to the contemporaneous use of effectiveness considerations in federal health programs. For example, the Health Care Finance Administration ("HCFA") had previously approved criteria for selecting heart transplant recipients that take into account comorbidities which reduce the recipients' odds of success.¹⁵¹ HCFA concluded that selection of these recipients would "waste" scarce resources.¹⁵² Courts will correctly be reluctant to read into the legislative history an intention to prohibit these practices. Perhaps for this reason, the Bush administration's objection to Oregon's unfavorable treatment of alcoholic cirrhosis was based on the absence of a "medical underpinning"

149. See *supra* text accompanying notes 146-47.

150. In addition, this discussion occurred in the context of employment benefit discrimination. See *supra* notes 106-109 and accompanying text. Congress never explicitly authorized employers to impose any eligibility criteria upon fringe benefits except those based on underwriting experience. As a result, the shadow which this legislative history casts on the use of comorbidity classifications may extend only to employer-provided health insurance.

151. Medicare Program; Criteria for Medicare Coverage of Heart Transplants, 52 Fed. Reg. 10935, at 10,949 (1987) [hereinafter Medicare Program]; Douglas J. Besharov & Jessica D. Silver, *Rationing Access to Advanced Medical Techniques*, 8 J. LEG. MED. 507, 516 (1987).

152. Medicare Program, *supra* note 151, at 10,940.

for Oregon's action.¹⁵³ In its place, the administration suggested an approach similar to the one used by Medicare, which requires evidence of sufficient social support of the patient in order to assure assistance in alcohol rehabilitation and, thus, increased odds of success.¹⁵⁴ The government's response to Oregon also appeared to leave room for Oregon to justify its low ranking for babies born after less than twenty-three weeks gestation and weighing less than 500 grams on the basis of their low survival rates.¹⁵⁵ Obviously, the Executive Branch concluded that Congress did not mean to preclude distinctions based on success rates.¹⁵⁶

To summarize, the legislative history provides credibility to the egalitarian view, at least in the context of comorbidity classifications, but does not dictate its adoption.

b. The "Capacity to Benefit" Cases

Some federal court opinions also appear to provide support for an egalitarian interpretation of disability rights laws, but the strength of that support diminishes greatly on close reading. In its important report on disability rights, the United States Commission on Civil Rights noted several cases which appear to determine a person's qualifications for education or housing by asking whether the applicant is "capable of benefitting" from the program.¹⁵⁷ Health care is an especially appealing context for using a "capacity to benefit" test because, unlike higher education or employment, health care is not allocated on the basis of ability or just deserts.¹⁵⁸ It seems strained to argue that a patient whose disease is especially difficult to treat

153. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L & MED. at 411.

154. *Id.* at 412 (citing Medicare Program; Criteria for Medicare Coverage of Adult Liver Transplants, 56 Fed. Reg. 15,006 (1991)).

155. One legal scholar believes that HHS's objections to Oregon's treatment of babies reflects opposition to effectiveness criteria. Thomas, *supra* note 43, at 137. But the Federal Government's objections to this category in the original Oregon plan appear to have been based on suspicions about Oregon's use of quality of life measurements.

156. Arguably, the Clinton administration's approval of a revised Oregon plan which relied heavily on survival rates to rank treatment supports this position as well. See OREGON HEALTH SERVS. COMM'N, *supra* note 60, at 10-12. But the revised Oregon plan had deleted its apparent comorbidity classifications. As a result, the Federal Government's approval provides no insight into its beliefs about the use of comorbidity classifications based on survival rates.

157. U.S. COMM'N ON CIVIL RIGHTS, *supra* note 79, at 115 (quoting *Camenisch v. University of Tex.*, 616 F.2d 127, 133 (5th Cir. 1980), vacated as moot, 451 U.S. 390 (1981)) (citing inter alia *Majors v. Housing Authority*, 652 F.2d 454, 457-58 (5th Cir. 1981) (holding that a woman with a mental disability who required a dog was capable of enjoying the full benefit of public housing); *Tatro v. Texas*, 625 F.2d 557, 563-64 (5th Cir. 1980) (holding that with catheterization, a school girl would realize the principal benefit from regular classroom instruction), *rev'd in part sub nom*, *Irving Indep. Sch. Dist. v. Tatro*, 468 U.S. 883 (1984); *Camenisch*, 616 F.2d at 133 (finding that a deaf graduate student could perform well, unlike the student in *Davis* who would not realize the principal benefits of nursing school)).

158. *E.g.*, *Easley v. Snider*, 841 F. Supp. 668, 673 (E.D. Pa. 1993) (requiring a state to show that persons excluded are "incapable of experiencing the benefit" targeted by a state program of attendant care), *rev'd*, 36 F.3d 297 (3d Cir. 1994); *Besharov & Silver*, *supra* note 151, at 529 ("A good argument can be made that anyone who can benefit from a heart transplant under purely medical criteria is otherwise qualified.").

(such as advanced breast cancer) is not "qualified" for the only treatment that offers any hope of success (such as a bone marrow transplant).

However, the cases which have concluded that a person's capacity to benefit from a government program is sufficient to qualify them for participation have generally involved plaintiffs believed likely to experience the *full* benefit of the program at issue in the case.¹⁵⁹ In noting this fact, the courts have left themselves freedom to reach a different conclusion when the claimant has a lesser chance to benefit than others who participate in the program. The most important exception to this generalization is the *Baby K* case recently litigated in Virginia.¹⁶⁰

In the case of *Baby K*, the trial court denied a hospital's request to withhold ventilator care from an anencephalic baby. In concluding that nontreatment would violate the disability rights laws, the district court appeared to assume both that life is always beneficial and that a patient capable of benefitting from treatment is presumptively "qualified" to receive it.¹⁶¹ "Dismal health prospects" were not, in the court's eyes, a proper disqualifying factor. But the trial court never considered whether a discriminatory eligibility criterion might sometimes be necessary or essential to the program which uses it. In addition, the presence of "quality of life" issues in the case muddies its significance as precedent on the legitimacy of success rates. Unfortunately, the Fourth Circuit did not review the trial court's conclusions when it affirmed the decision on other grounds.¹⁶² As a result, the trial court's opinion stands alone. It is too soon to discern whether other courts will accept or reject its conclusions, but the opinion provides no real analysis to illuminate the issues raised when survival rates are used to ration health care.

Indeed, other courts have reached precisely the opposite conclusion. These courts have found that disabled patients denied potentially life-extending care were not "qualified" within the meaning of the statute.¹⁶³ The Second Circuit explained its position in this way: "In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being 'otherwise qualified' to have corrective surgery performed If congress intended section 504 to apply in this manner, it chose strange language indeed."¹⁶⁴

Neither set of cases is especially well-reasoned, and no case directly considers the issue of effectiveness criteria such as survival rates. Rather than

159. See *supra* note 157.

160. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994), *cert. denied*, 115 S. Ct. 91 (1994) (mem.).

161. *Id.* at 1027-28. The Fourth Circuit did not reach this issue on appeal. The trial court applied the "qualifications" requirement of § 504, and then erroneously assumed that the absence of a "qualifications" requirement in Title II of the ADA precluded the use of discriminatory eligibility criteria. *Id.* at 1028. In fact, this title permits the use of "necessary" eligibility criteria.

162. *In re Baby K*, 16 F.3d 590.

163. See, e.g., *Johnson by Johnson v. Thompson*, 971 F.2d 1487, 1493-94 (10th Cir. 1992) (finding that the term "otherwise qualified" cannot ordinarily be applied in the fluid context of medical care "without distorting its plain meaning"), *cert. denied*, 113 S. Ct. 1255 (1993); *United States v. University Hosp.*, 729 F.2d 144, 156 (2d Cir. 1984).

164. *University Hosp.*, 729 F.2d at 156.

rely on these cases, future opinions are likely to address the substantive issue anew. When this occurs, the sparse case law that now exists will play a very limited role. Instead, the courts should look directly to the legislative history, as discussed above, and the analogies and ethical implications, which are considered below.

c. The Analogy to Education

One argument employed to defend the allocation of resources to those most likely to benefit from them makes an analogy to the practices of educational institutions in selecting the most qualified applicants to fill a limited number of places¹⁶⁵—practices to which the federal courts have already given their imprimatur.¹⁶⁶ A similar analogy can be made to employers hiring the most qualified applicants. Although this analogy could support the prioritization of patients who can benefit the most from treatment, the argument for selection of the most “qualified” patients is less powerful in the context of health care than in the theoretically merit-based realms of education and employment. In those contexts, a substantial consensus exists about the propriety of comparing the abilities of all applicants. This consensus arises not only from society’s utilitarian interests in using the most skilled and productive workers and graduates, but also from a widely-shared perception that decisions based on “merit” are just. In addition, this merit-based paradigm must be judged against the unrestricted discretion which preceded it: a climate ideal for nepotism, cronyism, racism, and sexism.

The rich mixture of values which justify the use of selective qualifications in employment and education does not transfer completely to health care allocation. A preference for patients with positive outcomes evokes none of the sense of just deserts accompanying merit-based employment decisions. Persons whose conditions are especially resistant to cure would be denied care while others who have the good fortune of suffering from a more curable disease would receive it, even if the costs for each patient were equivalent and both had paid their insurance premiums faithfully.

Nor does a health care plan’s desire to maximize its outcomes carry the same normative weight as a school’s or an employer’s desire to preserve its reputation for high standards. Although a high quality health care system is a legitimate objective, that goal is not advanced by treating only those patients most likely to have positive outcomes. Treating these patients maximizes outcomes, but has no bearing on quality of care.

Health care allocations based on medical effectiveness simply will not serve all of the nonutilitarian values associated with selective hiring and admissions criteria. In that sense, the case for effectiveness calculations in health care is distinct and appears to be less powerful. As a result, the propriety of using

165. Merrikin & Overcast, *supra* note 85, at 15-17; *see also* Hadom, *supra* note 36, at 1457 (analogizing health care qualifications to the nursing school qualifications sanctioned in *Davis*).

166. *See, e.g., Doe v. New York Univ.*, 666 F.2d 761, 777 (2d Cir. 1981).

effectiveness measurements, such as survival rates, to determine a patient's "qualifications" must be defended directly, rather than by analogy to employment or education.

d. The Ethical Choice

The values of maximizing the number of lives and providing equal access without regard to disability each have considerable moral and emotional power. The choice between these values is difficult. To help make that choice, it is useful to assume the hypothetical decision-makers' vantage point popularized by the egalitarian philosopher John Rawls¹⁶⁷ and also used by utilitarian economists.¹⁶⁸ That vantage point places decision-makers behind a veil of ignorance where they are unaware of their own status and, thus, are able to make decisions without personal conflicts of interest. The basic idea is to create an ideal context for operation of the Golden Rule,¹⁶⁹ in which decision-makers must shape rules for others that they would have govern their own circumstances.

How would people who were unaware of their own current or future medical circumstances make decisions about the use of survival rates? Rawls believed that the position of ignorance would produce an agreement that no inequalities in vital resources would be permitted unless they worked to the benefit of the least well-off members of society.¹⁷⁰ The English philosopher John Harris has concluded that QALYs would be ruled out by this principle because they harm those with the worst life expectancies and quality of life.¹⁷¹

However, Kenneth Arrow has described the unacceptable implications of the egalitarian view. It implies that society should fund "medical procedures which serve to keep people barely alive but with little satisfaction and which are yet so expensive as to reduce the rest of the population to poverty."¹⁷²

167. RAWLS, *supra* note 121, at 12. Paul Menzel's theory of presumed consent is a close cousin. Menzel suggests that autonomy, and not just efficiency, supports selective rationing. Menzel, *supra* note 43, at 65. Unlike my approach in the text, Menzel's theory does not depend upon the veil of ignorance and appears to give veto power to subgroups whose condition gives them a different perspective on tradeoffs acceptable to others. See PAUL T. MENZEL, *STRONG MEDICINE* 16, 22-36 (1990); Menzel, *supra* note 43, at 62. Because he addressed only the disability-rights issues posed by QALYs in the context of quality of life assessments, I have reserved further discussion of his approach for Part IV.

168. See J.C. Harsanyi, *Cardinal Welfare, Individualistic Ethics and Personal Comparisons of Utility*, 63 J. POL. ECON. 309, 316 (1955); W.S. Vickrey, *Measuring Marginal Utility by Reactions to Risk*, 13 *ECONOMETRICA* 319, 329 (1945).

169. Eddy, *supra* note 18, at 787.

170. RAWLS, *supra* note 121, at 62.

171. Harris, *Unprincipled QALYs*, *supra* note 115, at 188; see also Smith, *supra* note 120, at 1135. It is assumed here that health care would constitute what Rawls calls "primary goods." RAWLS, *supra* note 121, at 62.

172. Arrow, *supra* note 121, at 251. In the context of health care, egalitarians such as Daniels and Veatch have also suggested that egalitarian obligations would cease when a preference for those with the greatest need would unduly burden the social productivity necessary to provide services to them. NORMAN DANIELS, *JUST HEALTH CARE* 84 (1985); VEATCH, *supra* note 115, at 159-60. This appears to be an application of Rawls' differences principle, in which inequality can be justified if it makes even the worst off better off. See *supra* text accompanying note 121. My textual argument for the use of effectiveness criteria is not intended to be so limited.

It is more reasonable to assume that unbiased individuals would choose to place some limit on the premiums they would be willing to pay in order to buy insurance for minimally effective treatments. Even Robert Veatch, a prominent advocate of the egalitarian view, concedes that unbiased persons would at some point conclude that insurance protection is no longer worth the price.¹⁷³ Too many resources would be dedicated to nearly hopeless care.

Assume, for example, that treatments with a two-percent chance of cure and a cost of \$400,000 are considered by plan subscribers to be unaffordable (\$20 million per life saved). Does fair treatment of disabled persons preclude the application of this threshold whenever it would exclude a treatment which is specific to a particular disability or comorbidity? To the contrary, justice for all similarly situated patients requires that the threshold be applied uniformly to all patients.

In this respect, rankings based on factors such as the likelihood of survival are quite different from quality of life measurements, which place a lesser value on the life of a disabled person. Survival rates do not depreciate the lives of disabled persons, but instead treat all patients equally on the basis of expected medical outcome. While diabetic heart patients may rank lower than nondiabetic heart patients because their odds of survival are lower, they are treated the same as other patients whose conditions are similarly resistant to cure, such as patients with very advanced cancer or AIDS. From this perspective, comorbidity classifications are not only defensible, but also essential to avoid favoritism of the diabetic heart patient vis-à-vis the terminal cancer patient. In the words of Alan Williams, "A particular improvement in health status should be regarded as of equal value, no matter who gets it."¹⁷⁴

Likewise, survival rates reflect no invidious stereotypes, unlike reliance on customer or co-worker preferences. Instead, success rates more closely resemble other noninvidious considerations which legally can be used to determine a person's eligibility, such as financial risk,¹⁷⁵ fortuitously inherited talent, or an employer's considerable discretion to design a job description.¹⁷⁶ While none of these qualifications allocate on the basis of just deserts, they are at least free of prejudice or stereotype.

Given the lack of invidious stereotypes, the fact that all persons with similar prognoses would be treated equally, and the strength of the presumption that a just society would be willing to place limits on expenditures for ineffective care, survival rates belong among the tools available to health planners, even though facial discrimination against a disabled person may sometimes result. Although some affirmative effort should be taken to ease the burdens of those

173. See VEATCH, *supra* note 115, at 156; Veatch, *supra* note 139, at 258 (concluding that rationing of marginally ineffective care is inevitable).

174. Williams, *supra* note 125, at 123; see also Brock, *supra* note 28, at 95 (describing the argument that prognosis is itself a "natural lottery" that is just if criteria are consistently applied). The words of Justice Stewart are also apropos: "Sometimes the grossest discrimination can lie in treating things that are different as though they were exactly alike . . ." *Jenness v. Fortson*, 403 U.S. 431, 442 (1971).

175. See *supra* notes 98-101 and accompanying text.

176. 42 U.S.C. § 12111(8) ("[C]onsideration shall be given to the employer's judgment as to what functions of a job are essential . . .").

in society who are the worst off (e.g., by expanding access to insurance and expanding the basic benefits package), giving them priority to receive relatively ineffective health care will often be a poor way of advancing this objective. Consequently, the law ought not require it.

e. The Likely Judicial Resolution

The legislative history provides some credible support for an egalitarian interpretation of the disability rights laws, particularly in connection with comorbidity. This interpretation is also bolstered by the weakness of the analogy to higher education commonly made by defenders of QALYs. On the other hand, the legislative history gives no indication that Congress considered the impact of the disability rights laws on the measurement of health care effectiveness. It seems likely that Congress would have signaled its intention to alter the existing clinical and regulatory practice of taking medical effectiveness into account. Given these conflicting considerations and the lack of a dispositive answer in the case law, the courts have considerable discretion to resolve this interpretive dispute as they wish.

Judicial resolution of this debate is likely to depend upon the level of scrutiny that courts are inclined to give to challenged eligibility criteria. If courts are inclined to reject only those criteria which reinforce or rely upon proscribed stereotypes, then effectiveness criteria such as survival or success rates will survive the test of legitimacy. But if courts look more closely to determine the consistency of survival rates with the statutory goal of equal opportunity, then the fate of survival rates is much less certain.

Because case-by-case judicial evaluation of program objectives would be an extraordinarily complex and value-laden task, and because the courts have received little guidance from Congress on the criteria to use in undertaking this analysis, courts are likely to avoid close scrutiny of program objectives when the criteria used appear to be free of invidious stereotypes, especially if a significant modification of previously accepted practices would result from rejection of the criteria.¹⁷⁷ This hypothesis is consistent with the inclination of most courts to reject challenges to health benefits plans. All of this augurs well for plans using reliable data about survival rates or success rates, except possibly in the context of employment, where the permissibility of non-underwriting eligibility criteria is less clear.

177. See *Easley by Easley v. Snider*, 841 F. Supp. 668, 673-74 (E.D. Pa. 1993), *rev'd*, 36 F.3d 297 (3d Cir. 1994) (permitting the state to target its goals rather than equally assist all persons capable of benefitting from the program).

3. Reasonable Accommodation

Even if survival rates are a permissible eligibility criterion, health plans employing them must make reasonable modifications to their eligibility criteria if doing so will help disabled persons qualify for treatment. In determining how much accommodation is "reasonable" in other contexts such as employment or education, courts often have considerable power to broker a compromise between utility and equity, but they have surprisingly little flexibility to do so in the context of health care rationing.

Although the kinds of modifications required by this doctrine are likely to vary with the specific circumstances of the particular benefits plan or clinical practice, some general observations are possible. First, the obligation to make reasonable accommodations is likely to require reasonable efforts to improve a disabled patient's amenability to treatment. If, for example, the current status of a patient's diabetes disqualifies him from a needed surgery, efforts should be made to improve the condition of the patient's diabetes before making a final decision about surgery. Under some circumstances, reasonable accommodation might even include the provision of social supports for those whose recovery is threatened by their absence.¹⁷⁸

Second, complete abandonment of effectiveness criteria is unlikely to be required because it would constitute a "fundamental" alteration of the program.¹⁷⁹ Even a request to drop only comorbidity-based exclusions would be inconsistent with the fundamental objectives of the challenged program.¹⁸⁰ Assuming that prioritization on the basis of effectiveness is proper, the elimination of comorbidity considerations would resemble a request that an educational institution lower its standards for the benefit of disabled

¹⁷⁸ See BEAUCHAMP & CHILDRESS, *supra* note 6, at 296 (arguing that justice may require assistance with social supports rather than using the absence of social supports as a reason for excluding a patient from transplantation); DANIELS, *supra* note 172, at 46 (showing a societal obligation to correct social conditions contributing to poor health).

¹⁷⁹ See 42 U.S.C. § 12182(b)(2)(A)(ii) (stating the ADA's standard that modifications to public accommodations which "fundamentally alter the nature of such services" are not required); *Southeastern Community College v. Davis*, 442 U.S. 397, 410 (1979) (interpreting § 504); 28 C.F.R. § 35.130(b)(7) (1994) (stating that modifications to public services which "fundamentally alter the nature of the services" are not required). Employers have a similar limit on their obligations. They need not make modifications which would impose an "undue burden" under the circumstances. See 42 U.S.C. §§ 12111(8)-(10), 12112(b)(5)(A).

¹⁸⁰ It might be suggested, however, that the elimination of these classifications would not fundamentally alter either the services offered or the quality of the ultimate product. Efficiency would be lost and coverage of previously excluded patients might generate either additional costs or alternative methods of allocating care, but these consequences are not unlike the types of accommodations routinely required in other contexts, such as accessibility improvements, interpreters, job restructuring, and the modification or acquisition of equipment. See, e.g., 42 U.S.C. § 12111(9)(B). Although these concessions are costly and may reduce the efficiency of the business, under the ADA they are obligatory unless they impose an undue burden. 42 U.S.C. § 12112(b)(5)(A); see also *Davis*, 442 U.S. at 412-13 (interpreting § 504's reasonable accommodation standard). However, this contention overlooks the ethical underpinning of effectiveness criteria. Effectiveness criteria aim to advance overall social welfare and to treat patients equally with regard to their likelihood of benefit. If that is a legitimate program objective, the elimination of disability-based classifications would undermine it and, in doing so, would unfairly favor some patients merely because their misfortune arises from disability. This alteration would be fundamental.

candidates. The Supreme Court has concluded that such a request can exceed the requirement of reasonable accommodation.¹⁸¹ It is possible, however, that a modification of this sort could be required in some factual circumstances if its impact on the overall operation of the plan would be minor.

Third, courts are unlikely to require the use of more sophisticated methods, such as a weighted lottery, to reconcile efficiency with equality. In a weighted lottery, patients who are most likely to benefit from a treatment might receive several "lottery tickets" for every one given to candidates whose treatments are much less likely to be successful.¹⁸² Equality would be better served under such a system than with complete exclusion of the patients with the worst odds, because each patient would at least have a chance of selection in the lottery. In addition, a significant amount of efficiency would still be preserved by weighting the chances of each applicant to reflect their relative odds of benefitting from treatment. Unfortunately, solutions of this type would be extremely cumbersome to implement and perhaps unworkable altogether as a method of making most insurance coverage decisions. Despite their theoretical elegance, decisions made in this manner are probably less likely to be perceived as rational or principled by the public and the persons affected by the process than straightforward coverage restrictions. As a result, courts are unlikely to require an accommodation of this sort in the foreseeable future. Adventurous health plans will have to experiment successfully with ideas of this sort before they are taken seriously.

Finally, plans could conceivably be required to offer their subscribers the option of purchasing additional coverage for some or all of the treatments not covered by the basic plan. Riders of this sort would expand patient choice by permitting disabled patients with the resources to choose a more robust benefit plan. Because these riders would expand choice without sacrificing the allocation objectives of the basic benefits plan to which they are appended, courts might be willing to require accommodation of this kind. As a practical matter, however, these riders may be too costly to provide much additional access. A disproportionate number of individuals who currently need or expect to need these additional services are likely to subscribe, thereby forcing up premiums. The high initial premiums will then drive out some of the healthier purchasers, thereby forcing the price up farther still. Exclusion of patients with preexisting conditions could minimize this effect, thereby making more robust coverage more affordable, but only by denying insurance benefits to the very disabled patients seeking to enhance their coverage for comparatively ineffective care.¹⁸³ Furthermore, even if riders covering additional care are offered, allocation decisions within each additional tier of coverage will

181. *Davis*, 442 U.S. at 410.

182. See Brock, *supra* note 28, at 97; John Broome, *Good, Fairness and QALYs*, in *PHILOSOPHY AND MEDICAL WELFARE* 57, 62 (J.M. Bell & Susan Mendres eds., 1988).

183. The failure of this accommodation returns us to the original question: whether the basic plan should be required to include the excluded conditions (*i.e.*, whether cross-subsidization should be required for disabled patients who need comparatively ineffective care)? See Ellman & Hall, *supra* note 30, at 198 (expressing some interest in cross-subsidization between plans).

continue to raise the disability-rights issue discussed in this Article (*i.e.*, whether disability rights law places limits on the use of effectiveness measurements to allocate the additional resources).

4. Individualization

It is in the individualization requirement, rather than the obligation to make reasonable accommodations, that the demands of equity most prominently restrict the use of effectiveness criteria. Individualization is necessary to minimize the exclusionary effect of otherwise defensible eligibility criteria. Through this requirement, courts may demand a measure of sacrifice from health plans before permitting the sacrifice asked of excluded patients.

In health care decision-making, the extent of individualization that is feasible will depend upon the context. The implementation of practice parameters by managed-care plans, for example, might be compatible with a substantial amount of individual assessment. Treatment of patients with breast cancer might depend upon the stage, cell type, and other factors likely to influence outcome as well as the effectiveness of the treatment being requested (*e.g.*, chemotherapy, radiation, immunotherapy, surgery, or bone marrow transplantation).¹⁸⁴ In that context, a substantial amount of individualization may be clinically feasible and therefore legally obligatory.

Traditional insurance exclusions, on the other hand, are typically more blunt. Sometimes, specific disabilities (such as AIDS or infertility) are restricted or excluded. At other times, specific treatments for a particular disability (such as bone marrow transplantation for breast cancer) may be excluded because they are deemed "experimental." If available data would permit a more precise identification of the persons with a poor prognosis, the disability rights laws may require that this data be utilized before creating disability-based exclusions.¹⁸⁵ The broad categories used in Oregon probably violated this requirement.¹⁸⁶

It is much more difficult to predict what courts will do when the best that existing data permit is relatively broad exclusions. An analogy to this dilemma arises in the employment discrimination context. Could employers exclude women from the workplace based on statistical evidence that women are, on the whole, absent more often?¹⁸⁷ Although Title VII of the Civil Rights Act of 1964¹⁸⁸ allows religion, sex, and national origin to be taken into account

184. Hadorn, *Setting Health Care Priorities*, *supra* note 15, at 2223.

185. If cost-effectiveness were the basis for prioritization, then specific outcomes data would need to be matched by similarly specific data on costs and quality of life scores before the data could be used to re-rank treatments.

186. Oregon reportedly could have used existing data to be more specific in its designation of the treatments to be ranked. Hadorn, *Setting Health Care Priorities*, *supra* note 15, at 2223. The State adopted its less precise method of specifying services in order to facilitate actuarial analysis of the final priority list.

187. The hypothetical is from MACK A. PLAYER, *EMPLOYMENT DISCRIMINATION LAW* 291 (1988); see also *Phillips v. Martin Marietta Corp.* 400 U.S. 542 (1971) (holding that a policy of excluding female, but not male, job applicants with pre-school-age children raised a question of fact precluding summary judgment for the employer).

188. 42 U.S.C. § 2000e (1988 and Supp. V 1990). L.J. 531 1994-1995

when they constitute a "bona fide occupational qualification reasonably necessary to the normal operation of that particular business,"¹⁸⁹ and the Age Discrimination in Employment Act permits age to be considered under similar circumstances,¹⁹⁰ this bona fide occupational qualification ("BFOQ") defense is narrowly construed.¹⁹¹

In *Western Airlines, Inc. v. Criswell*,¹⁹² an age discrimination case addressing the issue of generalized exclusions, the Supreme Court insisted upon individual assessments except when all or substantially all persons excluded by the age restriction would be unable to perform the job safely and efficiently. Alternatively, the Court would not require an individualized assessment if it would be "impossible or highly impractical" to determine which class members would perform unsafely or inefficiently.¹⁹³ The case involved a claim that pilots over sixty years of age presented a safety risk.

Under *Criswell*, individualization is not necessary when substantially all excluded persons are unqualified. Applying this test to rationing criteria, courts will ask how strong a predictor of outcomes the challenged criteria really are. The greater the percentage of excluded persons whose outcomes are likely to be significantly better than the cut-off, the less likely it is that a disability-based criterion will survive scrutiny.

Criswell also condoned the failure to individualize when doing so was not feasible, but it did so in a case where public safety was at risk. It is unclear whether the Supreme Court would extend this exception to cases without a public safety concern.¹⁹⁴ Maximization of health outcomes is, however, a public safety objective. As a result, courts could also excuse the failure of health plans to individualize when it would be highly impractical to do so. In the context of rationing, feasibility would depend on factors such as the availability of better predictive data, the cost of acquiring it, and the administrative difficulty of using it.¹⁹⁵ The less feasible individualization is, the more tolerable some overgeneralization should be, assuming that the exclusions are otherwise empirically based and essential to the program.

As the Office of Technology Assessment noted in its evaluation of the Oregon Plan, extremely precise categorization might be "unworkable for any program purpose."¹⁹⁶ Instead, it suggested intermediate levels of definition. Concerns of this sort may help explain why the Federal Government permitted

189. 42 U.S.C. § 2000e-2(e)(1) (1988).

190. 29 U.S.C. § 621(f)(1) (1988).

191. See *Dothard v. Rawlinson*, 433 U.S. 321, 334 (1977).

192. 472 U.S. 400 (1985).

193. *Id.* at 416-17.

194. The EEOC Regulations do not limit the "impracticality" excuse to instances where safety is at stake. See 29 C.F.R. § 1625.6(b)(3) (1994).

195. Clinicians may be in a better position than benefits plans to make refined individualized assessments of prognosis, but benefits plans have a stronger claim that their decision to use effectiveness criteria is part of a coherent plan to maximize the use of finite resources, and is based on comparative data. Some marriage of their interests may be needed. I plan to discuss this issue in a subsequent article on bedside rationing.

196. OFFICE OF TECHNOLOGY ASSESSMENT, SUMMARY: EVALUATION OF THE OREGON PLAN 8 (1992).

Oregon to use aggregate conclusions about mortality to rank broad categories of illness without any mention of the individualization requirement.

C. Conclusions About Survival Rates

Although the choice is a troubling one, the case for permitting allocation decisions based on survival rates is legally and ethically more persuasive. Survival rates do not present the same risks of invidious discrimination that would be present if quality of life or social worth were considered. Persons with equal prognoses are treated equally. Under these circumstances, reasonable, unbiased persons would very likely permit limits to be placed on funding for the least successful treatments, even if doing so were to result in disability-based classifications.

This endorsement of survival rates has four important qualifications. First, it is unclear whether courts will permit the use of any exclusionary criteria in connection with employee health benefits. Second, programs using effectiveness criteria must individualize their decision-making to the maximum extent feasible. Third, plans may need to offer riders for coverage of less successful treatments. Fourth, this entire discussion has assumed that the eligibility criteria being employed by a plan or its providers have a legitimate empirical basis. Classifications that lack a defensible empirical basis are hardly "essential" to the goal of maximizing health outcomes. Because reliance on judgment or intuition introduces a risk that unfounded stereotypes about, or prejudice against, disabled persons and their outcomes have infected the data, it may be difficult to convince courts that clinical judgment or experience, standing alone, is sufficient.

IV. QUALITY OF LIFE CONSIDERATIONS

Quality of life matters. The value to Barney Clark of Jarvik's artificial heart would be greatly overestimated if no consideration were given to the quality of Clark's extra days of life. If impact on quality of life were ignored, treatments for relatively minor conditions, such as hemorrhoids, could rank above treatments with a more dramatic impact on patient well-being, such as symptomatic relief for dementia, as long as the less serious conditions were cheaper or easier to treat. A rational system for allocating health care resources needs to consider the anticipated impact of treatment on patient quality of life.¹⁹⁷

But quality of life considerations disfavor disabled patients. Saving the life of a person who will have a residual impairment after treatment¹⁹⁸ will generate fewer QALYs than saving the life of a person who could be returned

197. *E.g.*, Brock, *supra* note 28, at 89; Maynard, *supra* note 16, at 1540; Orentlicher, *supra* note 36, at 312.

198. David Hadorn has suggested that discrimination on the basis of *future* disability is not prohibited by current law. Hadorn, *supra* note 36, at 1456-57. His argument is not trivial and cannot be adequately explored here, although I disagree with his conclusion.

to full function, because the value assigned to a year of additional life with full function is greater than that assigned to a year with a serious impairment. In some circumstances, disabled patients could also be disfavored by considering quality of life in the ranking of noncritical care. For example, their disabilities could impede their recovery from other illnesses or limit the amount of functional improvement that successful therapy makes possible.¹⁹⁹

In addition to their discriminatory consequences, quality of life measurements introduce a special risk of bias. Quality of life measurements can never have the medical or scientific objectivity of survival rates. No scientific Rosetta stone will tell us whether it is worse to be infertile, arthritic, or unconscious, or whether more good will be accomplished by a partial cure of severe arthritis than by a complete cure of nearsightedness. These are value judgments. Any scale generated to reflect these judgments must avoid biased misconceptions about the actual impact of disabilities on the lives of persons who have them.²⁰⁰ Indeed, concerns that Oregon had overestimated the impact of some disabilities on patient quality of life contributed significantly to the initial rejection of the Oregon plan.²⁰¹

Nevertheless, the problem of bias should not be overstated. Improper bias can be avoided by utilizing a study design that includes an appropriate role for disabled persons in creating the value scale.²⁰² In some circumstances,

199. For a more detailed discussion of the impact of quality of life considerations in the context of noncritical care, see *infra* part IV.B.

200. Discrepancies between the views of disabled persons and the general public have been observed in some contexts but not others. Compare OREGON HEALTH SERVS. COMM'N, *supra* note 12, at C-11 (revealing that persons who had experienced a problem sometimes rated it less severely than those who had not and acknowledging similar results in other studies); Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 12 (citing studies showing that persons without disabilities undervalue the quality of life of persons with disabilities); Michael O'Donnell, *One Man's Burden*, 291 BRIT. MED. J. 60, 60 (1985) (finding that once patients become ill, they are less likely to prefer a short healthy life to a longer one with a disability); Rosser & Kind, *supra* note 33, at 352-55 (finding that patients with current medical illness produced lower scales but psychiatric patients had higher ones); David L. Sackett & George W. Torrance, *The Utility of Different Health States as Perceived by the General Public*, 31 J. CHRONIC DIS. 697, 702-03 (1978) (finding that renal dialysis patients ranked both hospital and home dialysis more favorably than healthy respondents did); Williams, *supra* note 11, at 327 (noting that physicians overstate the impact of disability) with Donald J. Balaban et al., *Weights for Scoring the Quality of Well-Being Instrument Among Rheumatoid Arthritics: A Comparison to General Population Weights*, 24 MED. CARE 973, 979 (1986) (finding that the scores of the general population and those of patients with severe to moderate rheumatoid arthritis were in close agreement); Hadorn, *supra* note 36, at 1455 (finding no bias in Oregon); Torrance, *supra* note 16, at 16 (reviewing the literature and concluding that patients and the public produced similar scales); *id.* at 27 (describing studies by Churchill in which patient utilities correlated significantly with nephrologists' ratings of patient quality of life).

201. Marzen Letter, *supra* note 46, reprinted in 9 ISSUES L. & MED. at 400; Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 409.

202. If disabled patients rank a functional impairment differently than the general public, a difficult methodological problem arises. Whose opinions should govern? Only a thumbnail outline of an answer is possible here. Defending the Oregon plan, David Hadorn rejected reliance on the preferences of disabled persons. Relying on the insurance principle, he stated that "[t]he preferences used to determine coverage . . . should be those of the beneficiaries *prior to any need for specific treatment*. . . . The assumption that post hoc preferences of disabled persons should prevail over those of the general citizenry is, therefore, problematic." Hadorn, *supra* note 36, at 1456 (emphasis added); see Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 15; see also Eddy, *supra* note 18, at 786-87 (suggesting a representative sample of persons "at risk"). Hadorn's concern is that the answers of disabled persons will be self-serving.

suspected shortcomings in the data will have no prejudicial impact on the rankings.²⁰³ As a result, defensible data can very likely be generated. But even if the scales are valid, their use will potentially disfavor individuals with disabilities. The distributive justice dilemma caused by this discriminatory potential is the subject of this Part.

The use of quality of life considerations is especially problematic when the treatments being ranked are potentially life-saving. When life is at stake, the value of the life saved is determined by the person's anticipated quality of life. In effect, a lower value is placed on the life of a disabled patient than on the life of a patient whose health can be more fully restored. Treating the lives of disabled persons as less valuable directly challenges fundamental assumptions about the equal worth of all citizens. For this reason, the use of quality of life considerations to rank treatments is far more controversial than reliance upon success rates.²⁰⁴ Michael J. Astrue, who was general counsel of the Department of Health and Human Services at the time of Oregon's original application for Medicaid waivers, has characterized Oregon's use of quality of life considerations as "the most troubling element of the process."²⁰⁵

By contrast, no threat to the presumption of equal worth arises when QALYs are used to rank noncritical care because life is not at stake. Both critics and defenders of quality of life considerations have often overlooked

Hadorn's defense of community polling has three important weaknesses. First, it overlooks the first-hand experience of disabled individuals. If the discriminatory impact of QALYs is justified because QALYs will help to maximize health care outcomes, then the actual impact of the disability is the crucial concern, not the perceived or feared impact. Second, Hadorn's position ignores the biases that could infect the answers of nondisabled respondents. Finally, it overstates the circumstances in which biased answers from disabled respondents are likely to be a serious danger. In most circumstances, the risk is minimized because incorrect answers can harm as well as help disabled respondents. For example, a skewed answer which improves a disabled respondent's priority for critical care (by understating the impact of the disability) is likely to prejudice that person's priority for noncritical care (by understating the value of a cure for the disability) and vice versa. Offsetting effects of this kind will be present in most circumstances. Ordinarily, therefore, the views of disabled respondents should govern.

203. Biased data can be harmless or actually favor disabled patients. The error would be harmless if the affected disabilities are funded anyway or the bias was not significant enough to affect the rankings. A favorable impact could occur if, for example, an overestimate of a disabling condition's severity resulted in a higher ranking for treatments which alleviate the improperly evaluated condition.

204. Many critics condemn quality of life considerations and conclude that they impermissibly discriminate against persons with disabilities. See Letter from Timothy B. Flanagan, assistant attorney general, Office of Legal Counsel to Susan K. Zagame, acting general counsel, Department of Health and Human Services (Jan. 19, 1993), reprinted in 9 ISSUES L. & MED. 418 (1994); Stade, *supra* note 45, at 2010, 2017-20 (suggesting that quality of life considerations violate the ADA, but recommending that the statute be amended to permit their use); Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 409; James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?*, 68 NOTRE DAME L. REV. 581, 584, 615 (1993). This was also the basis of the Federal Government's objection to the Oregon rationing plan. Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 409; see also *supra* text accompanying notes 55-64. On the other hand, ethicist Paul Menzel and health economist David Hadorn, for example, support the use of quality of life rankings to prioritize health decisions. See Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 11; Hadorn, *supra* note 36, at 1455; Menzel, *supra* note 44, at 21; see also Capron, *supra* note 43, at 20 (suggesting that ranking is permitted, but exclusions based on disability are not).

205. Astrue, *supra* note 34, at 381.

the implications of this distinction between the extension of life and the relief of symptoms. This Part explores the issues raised by quality of life considerations in the two distinct contexts of critical and noncritical care.

A. Life-Extending Care

Because quality of life considerations do not treat all lives as equally valuable, they present a troubling ethical and legal issue when potentially life-saving treatments are ranked against each other.

1. The Special Problems Raised by Quality of Life

Few would disagree with the initial premise that the lives of all members of the community should be treated as having equal worth.²⁰⁶ Yet, the use of quality of life considerations to rank treatments for fatal illnesses threatens this principle. This calculation disfavors both individuals who currently have permanent functional impairments and individuals who are likely to have residual impairments after treatment because "saving their lives would produce fewer QALYs than saving the lives of healthier people."²⁰⁷ As a result, critics correctly contend that QALYs do not treat the lives of all individuals as equally valuable.²⁰⁸ Oregon's low ranking of treatment for very premature babies under 500 grams was perceived by the Federal Government and David Hadorn as reflecting this kind of calculus.²⁰⁹ Much more than survival rates, quality of life considerations seem to threaten the egalitarian values underlying the disability rights laws.

When quality of life is taken into account, the very fact that a patient is disabled will automatically put that person at a disadvantage. A low quality of life score would not only result in a lower priority as against other fatal conditions, but would also increase the risk that this patient's life-saving care would receive a lower priority than treatments for some nonfatal conditions. From the egalitarian perspective, "[e]veryone who wants to go on living—however uncomfortable their continued existence may be or however brief its expectation—possesses something of equal value."²¹⁰ "Let's call it," said another critic of quality of life considerations, "the rest of their lives."²¹¹

206. VEATCH, *supra* note 115, at 121-23; Charles J. Dougherty, *Ethical Values at Stake in Health Care Reform*, 268 JAMA 2409 (1992) (arguing that this premise is one foundation of individual moral rights); Harris, *QALYing the Value of Life*, *supra* note 115, at 118 (suggesting that the idea is at the root of both democratic theory and most conceptions of justice).

207. Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 13 (claiming that if treatments offer equal additional life, QALYs favor those that offer the best quality of life and disfavor those which offer marginal prolongation of life with severe side effects); Menzel, *supra* note 43, at 60.

208. E.g., Harris, *QALYing the Value of Life*, *supra* note 115, at 121-22; Garvey, *supra* note 204, at 584 & n.15 (citing legislative testimony on this point).

209. See Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 12.

210. O'Donnell, *supra* note 200, at 60.

211. *Id.* (quoting John Harris).

The use of quality of life assessments for life-saving care also reduces the value of life (and thus the benefits of life-saving treatment) to a simple formula that multiplies quality of life by life expectancy.²¹² John Rawles correctly observes that “[l]ife is valued for infinitely more reasons than absence of suffering.”²¹³ He reminds us that “to equate the value of life with absence of disability or distress is to undervalue existence very greatly indeed.”²¹⁴

2. Potential Justifications

At least four arguments in support of quality of life considerations are possible. One, suggested by David Hadorn, is that quality of life measurements are appropriate because they measure the expected *change* in quality of life, rather than the *point-in-time* quality of life of the patient.²¹⁵ This net change, he claims, is evaluated in the same manner for disabled patients as for everyone else. Hadorn’s analysis, however, fails to appreciate the difference between fatal and nonfatal conditions. When the condition being treated is potentially fatal, the “change” or net benefit offered by treatment is the extension of life.²¹⁶ To measure the change is, therefore, to measure the value of the life itself, a point-in-time assessment.

A second potential justification is that quality of life is measured from the patient’s perspective, not society’s. QALYs typically do not attempt to establish the *social worth* of an individual by measuring factors like future employment prospects or moral character. Instead, scales such as Oregon’s are intended to estimate value conferred *on the patient* by life-sustaining care. As a result, QALYs avoid the most objectionable kind of utility calculus.²¹⁷

212. Harris, *QALYing the Value of Life*, *supra* note 115 (arguing vigorously that quality of life measurements cannot accurately reflect the real value of life to the people whose lives receive low rankings); Rawles, *supra* note 16, at 146. This objection may also suggest more concern with the variability of people’s quality of life and the difficulty of capturing it through clinical indicia of the sort that would be used to predict survival rates. *Cf.* Avorn, *supra* note 115, at 1299 (noting patient variability in quality of life assessments).

213. Rawles, *supra* note 16, at 146; *see also* Broome, *supra* note 182, at 66; Smith, *supra* note 120, at 1135.

214. Rawles, *supra* note 16, at 146. For this reason, Rawles also objects to comparisons between treatments which are lifesaving and those which are not.

215. Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 12-13; *see also* Capron, *supra* note 43, at 20. Emery and Schneiderman make the same argument. Danielle D. Emery and Lawrence J. Schneiderman, *Cost-Effectiveness Analysis in Health Care*, HASTINGS CTR. REP., July-Aug. 1989, 8, 11 (assuming that all ill people are equally favored).

216. Hadorn’s observations are, however, valid in the context of nonfatal conditions. *See infra* text accompanying note 243.

217. *See, e.g., In re Julia Warren*, 858 S.W.2d 263, 267 (Mo. Ct. App. 1993) (Smart, J., concurring) (disapproving of social worth calculations in decisions to withhold life-sustaining care); *In re Conroy*, 486 A.2d 1209, 1232-33 (N.J. 1985) (making a similar argument); BEAUCHAMP & CHILDRESS, *supra* note 6, at 294 (distinguishing medical utility from social utility and asserting that medical utility maximizes collective patient welfare while social utility maximizes social welfare); Besharov & Silver, *supra* note 151, at 526 (discussing objections to utilitarian approaches that take into account a person’s “value to society”); Orentlicher, *supra* note 36, at 312 (suggesting that social worth criteria are inappropriate). Social worth considerations could include factors such as occupation, family status, religion or character, criminal record, intelligence and education. Besharov & Silver, *supra* note 151,

This distinction is significant, but not sufficient. While it avoids some of the most damaging objections raised against unrestricted utilitarian calculations, it does not respond to the objection that QALYs treat the lives of disabled persons as less worthy of saving.

Paul Menzel, by far the most lucid and thoughtful writer on this subject, raises a third possible defense. He suggests that reasonable persons would consent to the use of quality of life considerations because the harm to those most in need of care which results from their use in some contexts is offset by the advantage that they will confer on those individuals in other circumstances. That advantage would accrue when treatment for nonfatal conditions is ranked. Here, those most in need of care will often have more to gain from successful treatment.²¹⁸ Menzel calls this package of favorable and unfavorable consequences the "QALY bargain" and seems to presume that reasonably healthy persons would consent to it if asked in advance of illness.²¹⁹ Because he presumes their consent, he views his theory as autonomy-based.

Although Menzel's insight is extremely valuable, his theory of presumed consent has two important limitations. First, Menzel suggests that his presumed consent rationale would not apply to persons with congenital handicaps or those with illnesses that began before the patient was old enough to consent to the QALY bargain.²²⁰ He dislikes the consent approach here because patients in these circumstances have had no opportunity to take account of their prospects and make real or presumed choices about insurance.²²¹ This precludes predictions based on the experience of real persons. Because Menzel is unwilling to use a Rawlsian hypothetical standpoint to make decisions about the care provided to this group of patients, he gives a veto or opt-out power to disabled persons who cannot be presumed to have previously consented to the QALY bargain.²²² He concedes that "[i]t is not clear what disabled people themselves would say about [the QALY bargain.]"²²³ If they would accept it, Menzel's autonomy-based theory provides important support for the use of QALYs. If they would reject it, however, QALY use cannot be based on his theory of consent.

at 525. Sometimes they can masquerade as medical factors. *Id.* at 522, 527 (discussing heart transplantation criteria). The use of social worth considerations in the 1970's by hospital committees allocating kidney dialysis was very controversial. *See* 3 SECURING ACCESS TO HEALTH CARE, *supra* note 20, at 285, 306 (suggesting that capacity to contribute to society influences ICU resource allocation).

218. MENZEL, *supra* note 167, at 80-81; Menzel, *supra* note 43, at 60-61.

219. MENZEL, *supra* note 167, at 85-86; Menzel, *supra* note 43, at 61.

220. MENZEL, *supra* note 167, at 62.

221. *Id.* at 99-102. Nor do patients realistically stand to receive off-setting benefits from cost-saving measures. *Id.* But, because Menzel concludes that they are not persons, he ultimately concludes that life-saving care can be rationed using the same cost-effectiveness limits to which adults consent. *Id.* at 107. I agree with his conclusion about newborns, but on a different basis. Although real persons have no experience with preconception choices, it seems fair to extrapolate from our views about the funding of post-birth conditions which resemble congenital ones, rather than to give congenitally disabled children a uniquely favored status.

222. MENZEL, *supra* note 167, at 16, 22-36; Menzel, *supra* note 43, at 62.

223. Menzel, *supra* note 44, at 23.

The second limitation on Menzel's theory is that disabled persons could object to the bundling of life-saving and nonlife-saving care. They might plausibly suggest that QALY use is permissible to rank noncritical care but not to rank life-saving care. QALYs are proper when noncritical care is prioritized because, depending upon the circumstances, they can either favor or disfavor disabled patients.²²⁴ When life-saving care is ranked, on the other hand, quality of life considerations automatically and inevitably disfavor disabled patients. Once the two kinds of care are evaluated separately, the possible benefits conferred by QALYs in the context of noncritical care disappear as a justification for the use of QALYs to rank life-saving care. As a result, the QALY bargain requires supplementation.

The fourth and strongest reason for taking quality of life into account is that quality of life really does influence the value of life.²²⁵ Indeed, some legal and ethical commentators doubt that treatments can be rationally prioritized without considering quality of life.²²⁶ This claim of relevance directly challenges the factual accuracy of the equal worth presumption.

Both David Hadorn and Alexander Morgan Capron point out that even disabled patients would prefer not to be disabled.²²⁷ Surely, Hadorn suggests, a life-sustaining treatment that offers months of pleasurable life is preferable to one that promises months of debilitating side effects.²²⁸ Hadorn's assumption seems to make common sense. But does it mean that disabled patients would agree with the conclusion that their lives are of less value to them than those of persons with no impairments?²²⁹ As Paul Menzel observes, "For all we know, *compared to death*, your paraplegic life could be still as valuable to you as anyone else's 'better' life is to him or her."²³⁰

This is an empirical question. And it seems likely that the presumption of equal value is inaccurate, at least in extreme cases. The strongest evidence of this is provided by the decisions made daily by patients and their families to discontinue life-sustaining care. Quality of life inescapably plays a vital role in these life-and-death decisions. The substantial consensus that supports these end-of-life practices provides a plausible basis for believing both that poor

224. See *infra* part IV.B for a further discussion of noncritical care.

225. E.g., Dougherty, *supra* note 43, at Supp. 6 (finding that quality of life and prevention topped the list of values articulated in Oregon community meetings); Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 12 (revealing that Oregon surveys demonstrated the importance of quality of life to community members).

226. E.g., Menzel, *supra* note 44, at 25; Note, *The Oregon Health Care Proposal and the Americans with Disabilities Act*, 106 HARV. L. REV. 1296, 1312-13 (1993).

227. Hadorn, *supra* note 36, at 1455; Capron, *supra* note 43, at 20. For an interesting contrary view, see Edward Dolnick, *Deafness as Culture*, ATLANTIC, Sept. 1993, at 37.

228. Hadorn, *Oregon Priority-Setting Exercise*, *supra* note 15, at 13; Hadorn, *supra* note 36, at 1455.

229. Harris, *QALYfying the Value of Life*, *supra* note 115, at 118, 121 (asserting that preferring a better quality of life over a worse one does not commit one to a judgment that persons with better quality of life should be saved first).

230. Menzel, *supra* note 43, at 61 (emphasis in original); see also Harris, *QALYfying the Value of Life*, *supra* note 115, at 118, 121. One possible explanation for a contrary answer to this question lies in the nonhealth benefits of being alive, which may correspond poorly with disability.

quality of life can diminish the value of life and also that our society condones quality of life assessments, even when made by third parties.²³¹

If some life-extending care is fairly perceived as not in a patient's best interests, it seems a small additional step to conclude (contrary to the trial court's assumptions in *Baby K*) that some life-extending treatments are *barely* beneficial from the patient's perspective. Barely beneficial care is a candidate for low priority. Indeed, this assumption is already reflected in existing clinical practices such as the allocation of intensive care resources²³² and organs for transplantation.²³³

Allocations of potentially beneficial care, however, are unlike individual decisions about a patient's best interests in one important respect. When allocation decisions are made, the value of saving one patient's life is compared with the value of saving another patient's life. This comparative aspect of allocations based on the effectiveness of treatment threatens the principle of equal worth in a way that individual best interests decisions do not. This is the point at which a value choice must be made between maximizing benefits from scarce resources and presuming equal worth—a choice between utility and equality. Must genuine differences in the value of life-saving treatment to the affected individuals be ignored to protect the principle of equal worth? This is the most difficult question posed by resource allocations based on medical effectiveness.

The choice is not, of course, an all-or-nothing one. Even assuming that the egalitarian view should prevail as a general rule because it is more consistent with the spirit of the disability rights laws, exceptions for extreme cases seem justifiable. At some point, unbiased persons would agree in advance that insuring themselves for barely beneficial treatment was no longer worth the expense. At some point, the social costs of insuring low-benefit life-extending care become so great that they outweigh the harm which would be done to the principle of equal worth.

Assume, for example, that a vegetative patient, or perhaps more poignantly, an elderly and severely demented patient, who cannot recognize or interact with family or caregivers, needs dialysis, an organ transplantation, or develops a cancer that would be treated at great expense if it occurred in an otherwise

231. My conclusions in this Article about the use of quality of life considerations by health plans to prioritize critical care do not necessarily carry over to individual bedside decisions about withholding life-sustaining care. Several factors distinguish those decisions. Most importantly, they typically involve individualized decisions about a patient's best interests. When that is the issue, the value of that patient's life is not being compared to the value of other patients' lives. In addition, individualized patient decisions can take into account patient preferences, patient values, and information about the patient's nonhealth quality of life. Further, the bedside treatment decision is often a dispute over the duty to treat, not a dispute over funding or access to a pool of shared resources. Finally, the disability rights statutes do not apply to the decisions of patients or their families. As a result, the impact of the anti-discrimination laws on individual medical treatment decisions requires separate and extended discussion.

232. See Mulley, *supra* note 20, at 306 (concluding that ICU allocations are influenced by impaired functional status).

233. TASK FORCE ON ORGAN TRANSPLANTATION, ORGAN TRANSPLANTATION: ISSUES AND RECOMMENDATIONS 87 (1986) (finding that organs are allocated to those with the best odds of survival and the highest quality of life).

healthy person.²³⁴ Assume further that this patient has previously requested maximally aggressive medical care and that her odds of cure are no lower than those of a healthy person. Must her health plan cover her care? The same question could be asked about very low birth weight babies with a dismal prognosis.²³⁵ A decision to preclude quality of life assessments for these cases is effectively a decision to devote resources to these patients that could otherwise be used to expand the unmet or underserved medical needs of other patients or to keep spiraling health costs in control.²³⁶ These are the social costs of an absolute equal worth principle.

Given these costs, the presumption of equal worth should yield in extreme cases.²³⁷ These cases will typically have three characteristics. First, the patient's quality of life is so poor that the net benefit to the patient from life-extending treatment is open to question. Second, the patient's cognitive function is so severely impaired that the nonhealth benefits of being alive are unlikely to be significant, leaving health status as a reasonable barometer of quality of life. Third, the anticipated costs of life-extending care are extraordinary. Patients in a persistent vegetative state meet all three criteria. By one account, medical care cost one such patient \$700,000 for nine months of additional comatose life.²³⁸ By contrast, quadriplegic patients would not meet all three criteria; life-saving treatment for them could not be disfavored.

Ultimately, Congress should address this conflict as part of the national health care debate. Limits or exceptions to the principle of equal worth ideally ought to be the product of a public and democratic process in which the choice is made explicit. Regrettably, exceptions seem necessary. Resources are finite and quality of life is relevant. Nevertheless, several factors suggest that movement in this direction should be cautious. The first is the absence of sufficient political, medical, or public discussion of this conflict between equity and utility and the resulting absence of public consensus about concrete cases. Another is the difficulty of detecting bias in the quality of life estimates made on behalf of these patients. Adult patients with Alzheimer's disease or children born with severe birth defects cannot tell us about their quality of life.²³⁹ Finally, better information is needed regarding the cost

234. For an actual example, see *supra* text accompanying note 5.

235. Oregon had concluded that these babies should receive a low priority and Florida is considering a similar proposal. See *Florida Legislator Outlines State's Next Reform Steps*, *supra* note 29, at 7.

236. I am indebted to Haavi Morreim for reminding me of this consideration.

237. For an alternative proposal, see E. Haavi Morreim, *Utilitarianism, Exotic Care, and Coerced Altruism: The ADA Meets Its Maker*, 25 SETON HALL L. REV. (forthcoming 1995) (manuscript at 36-37, on file with the *Indiana Law Journal*) (proposing that standards similar to those contained in the federal Child Care Abuse Amendments be adopted).

238. Menzel, *supra* note 43, at 59 (reporting the costs for Helen Wanglie). Some commentators propose a three-month cap on treatment. See Veatch & Spicer, *supra* note 115, at 30.

239. As a result, the scales generated by healthy individuals cannot be tested for bias by comparison with the views of persons who have these disabilities. Only indirect tests are possible. For example, the scores given to these conditions can be checked for consistency with patient-based scores given for less catastrophic conditions or for similar, but temporary, conditions. As an additional safeguard, the scores given by healthy respondents for these catastrophic conditions could be adjusted by a factor which reflects the extent of bias detected in the scoring of other conditions. And scoring could be intuitively tested by taking into account the best available medical information about life with these catastrophic

savings to be obtained by denying care in extreme cases. It is possible that most of the cases involving unwise resource use can be resolved on another basis which does not infringe the principle of equal worth, such as patient preferences, underwriting cost, or survival rates. Oregon's exclusion of very premature, low birth weight babies, for example, may be defensible on the basis of survival rates, regardless of quality of life. If so, the efficiency advantages of taking quality of life into account could be less than expected.

3. Judicial Resolution

Until Congress addresses this conflict between equality and social welfare, courts will have to interpret the existing statutes. Under these circumstances, the legal requirement that discriminatory eligibility criteria be essential is sufficiently elastic to permit courts to reject quality of life considerations if they wish to do so, much as they have rejected discrimination based on customer preferences. The differences between survival rates and quality of life considerations are sufficient to permit courts to sanction one while prohibiting the other. First, assigning a lower value to the life of a disabled person is inconsistent with the presumption of equal worth. Second, the use of quality of life measurements is arguably less essential than the use of success rates. If the use of survival rates were unlawful, the use of all other measures of effectiveness would be unlawful as well. If quality of life considerations were prohibited because of their unique attributes, on the other hand, health planners would remain free to take into account both survival rates and costs when ranking life-saving care.

Given the fundamental nature of the principle of equal worth, the absence of either legislative history or public consensus for an exception to the principle in this context, the danger of undetected bias, and the incompleteness of utility calculations which evaluate life-saving care purely on the basis of health status, courts will reasonably be reluctant to permit unrestricted use of quality of life considerations to rank life-saving care.²⁴⁰ This general rule would preclude the use methodologies, such as those used in the 1991 Oregon plan, which disfavor all life-saving treatments that leave patients with residual disabilities. Instead, health planners would have to rely on survival rates and underwriting considerations.²⁴¹

conditions and about the patient's awareness. Finally, courts and planners could consider any social consensus that has developed regarding the desirability of receiving treatment under these circumstances. None of these methods of controlling for bias is foolproof. Accordingly, courts may perceive the danger of error as yet another reason to be reluctant about allowing quality of life considerations to influence the allocation of life-saving care in the absence of either a public consensus or legislative guidance.

240. However, quality of life could still be used to compare treatments for a single disease. See Menzel, *supra* note 44, at 23. *But see* Sullivan Letter, *supra* note 38, reprinted in 9 ISSUES L. & MED. at 411-12 (objecting to Oregon's preference for prevention over treatment).

241. In this manner, life-saving treatments can also be ranked against each other and against noncritical care. Noncritical care could potentially outrank life-saving care even if quality of life considerations are not used. For example, an ineffective and expensive treatment for a fatal illness could be ranked lower than an effective and cheap treatment for a terrible (but nonfatal) disability. Making this comparison, of course, would require either an explicit or implicit assignment of some value to the

Against the framework of this general rule precluding unchecked devaluation of the lives of disabled persons, however, courts could then consider exceptions (such as the one outlined above) which attempt to identify those cases in which the goal of maximizing health care outcomes with finite resources outweighs the principle of equal worth. Most likely, courts will await more specific guidance from Congress. But the time has come to discuss the limits of the principle of equal worth.

B. *Nonfatal Conditions*

On the surface, the use of quality of life to rank the treatments for *nonfatal* conditions such as arthritis, infertility, and dental disease appears to raise precisely the same issues posed by the ranking of fatal conditions. Perhaps for this reason, the Federal Government did not differentiate between fatal and nonfatal conditions when it objected to quality of life considerations in the Oregon plan.

The similarity is only superficial. The legal and ethical issues are surprisingly different when treatments for *nonfatal* conditions, such as infertility and mental illness, are ranked on the basis of effectiveness. First, no value is placed on a person's life. Second, the use of quality of life considerations can benefit some disabled patients when noncritical care is ranked, whereas it uniformly disfavors them when life-extending care is ranked.²⁴² Third, QALY measurements here are less likely to omit important information because life is not at stake. As a result, quality of life considerations are more legitimate in connection with noncritical care. These differences have not yet been explored in the legal literature and do not appear to have been recognized in the debate over the Oregon plan.

saving of a human life. Understandably, some debate might accompany the determination of that value. And, some would object to the very enterprise on the ground that life-saving care should always receive priority over noncritical care. See, e.g., Harris, *QALYing the Value of Life*, *supra* note 115, at 120; Rawles, *supra* note 16, at 146-47; cf. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, FOREGOING LIFE-SUSTAINING TREATMENT 100 (1983) (asserting that cost containment should not begin with consideration of life-sustaining treatments); Menzel, *supra* note 43, at 66 n.20 (suggesting that comparisons between critical and noncritical care are more difficult, but not indicating why); Orentlicher, *supra* note 36, at 312 (claiming that calculations tend to undervalue the preservation of life); see also, Daniels, *supra* note 33, at 28 (suggesting that humans do not simply aggregate the benefits of noncritical care, such as toothcapping, when comparing them to the benefits of life-saving care, such as an appendectomy). This contention could be based either on a perception of greater need or on a belief in the sanctity of life. But as long as the same value is assigned to all lives, no equal worth or disability rights issues are raised. For that reason, I will not address this interesting and important issue in this Article.

242. This also reduces the danger of prejudice from biased overestimates of the impact of a disability on the patient's quality of life. Such errors will often elevate, rather than reduce, the priority given to people with disabilities. See *infra* parts IV.B.2-3.

1. The Equal Value of Life

When nonfatal treatments are ranked, a value need not be placed upon the worth of the patient's life because avoidance of death is not one of the benefits attributed to the treatment. As a result, comparative values are not placed on the lives of different classes of patients and, consequently, no harm is done to the principle that all lives have equal worth. In the context of noncritical care, QALYs instead help measure the value of improvements in quality of life. It is in this context that Hadorn's thesis about quality of life assessments is correct: they measure the *net change* in the quality of life offered by a treatment rather than the point-in-time quality of life of the patient.

Critics of quality of life considerations have typically ignored this distinction between critical care and noncritical care. Instead, they have simply assumed that quality of life is an inappropriate consideration.²⁴³ Yet, these critics invariably base their objection on the tendency of QALYs to devalue the lives of disabled persons. This defect of quality of life measurements does not arise when the treatment being evaluated is not life-extending.

2. Impact on Disabled Persons

In many cases, quality of life considerations will favor both currently disabled patients and patients with the greatest risk of becoming disabled. Because patients who face severe disability have the most to gain from successful treatments, they will often profit from a system which ranks treatments by their impact on quality of life.²⁴⁴ In addition, quality of life measurements permit plans to consider whether "small" improvements in a terrible condition are more significant (as a matter of marginal utility) than "larger" changes in the condition of the person whose health is nearly perfect.²⁴⁵ Explicit consideration of the impact of disease on a patient's quality of life would also permit plans to prioritize the care of disabled persons who suffer more seriously from conditions that would be less serious in a healthier person. The cumulative effect of chronic conditions on patient

243. A notable exception is John Rawles, who seems to accept the use of QALYs when noncritical care is prioritized. See Rawles, *supra* note 16, at 146; see also Stade, *supra* note 45, at 2015 (failing to draw the distinction, yet nonetheless using a nonfatal illustration to show the value of QALYs).

244. E.g., Menzel, *supra* note 44, at 23; Orentlicher, *supra* note 36, at 312; Note, *supra* note 226, at 1310-11.

245. Others doubt the ability of QALYs to prioritize care for those with the greatest need. E.g., ROBERT M. VEATCH, *The Oregon Experiment: Needless and Real Worries*, in RATIONING AMERICA'S MEDICAL CARE, *supra* note 35, at 78, 85; Daniels, *supra* note 33, at 28; Michael Lockwood, *Quality of Life and Resource Allocation*, in PHILOSOPHY AND MEDICAL WELFARE, *supra* note 182, at 33, 45-46. Although utility calculations would, as these commentators fear, give equal weight to equivalent benefits regardless of quality of life, the calculation process could, as I suggest in the text, reflect the greater marginal value of superficially equivalent changes in health status.

well-being could also be considered.²⁴⁶ All of these advantages would be lost if quality of life could not be taken into account.

Quality of life considerations could still disfavor patients under some circumstances, however. David Orentlicher notes that "[a] permanent disability will limit the ability of treatment to improve the functional status of persons with that disability."²⁴⁷ In addition, quality of life considerations will disfavor persons whose disabilities impair their recovery from other illnesses (comorbidity) as well as those whose disabilities can be only minimally relieved by existing therapies.²⁴⁸ As a result, the net impact of quality of life considerations on disabled persons is unclear.

Still, the use of quality of life considerations for noncritical care will not stack the deck against disabled patients as it does in the context of critical care.²⁴⁹ Because rank is based on net improvement, not point-in-time quality of life, a severely disabled patient can receive priority for an effective treatment despite (and sometimes because of) the impact of that disability on his quality of life. It is no coincidence that the illustration of impermissible quality of life usage offered by the National Legal Center for the Medically Dependent and Disabled in its memo to Representative Chris Smith criticizing the Oregon Plan involved critical care.²⁵⁰ Its concern about the bias inherent in quality of life considerations applies only to life-extending care.

3. Conclusions about Noncritical Care

In the context of nonfatal conditions, the egalitarian objections to quality of life considerations are weak because the lives of disabled patients are not treated as less valuable than the lives of others. In this context, quality of life considerations will sometimes favor disabled patients. In addition, quality of life measurements here do not present the problem of incompleteness that they do in connection with life-saving care because the nonhealth benefits of being alive are not at stake. Thus, the objections to quality of life considerations are materially weaker in the context of noncritical care.

At the same time, the rationale for taking quality of life into account is powerful. If quality of life considerations were prohibited in the context of

246. The last two advantages seemed to be of special concern to the current administration. See News Conference with Donna Shalala, Secretary of Health and Human Services, FISC, March 19, 1993, available in LEXIS, News Library, Script File.

247. Orentlicher, *supra* note 36, at 312.

248. See David Gauthier, *Unequal Need: A Problem of Equity in Access to Health Care*, in 2 SECURING ACCESS TO HEALTH CARE, *supra* note 20, at 179, 190 (suggesting that quality of life considerations could disfavor the chronically ill); Robert M. Veatch, *Research on "Big Ticket" Items: Ethical Implications for Equitable Access*, 22 J.L. MED. & ETHICS 148, 150 (1994) ("[S]ome people are so debilitated that it is very inefficient to benefit them."). Fair marginal utility calculations might reduce this risk along with a fair assessment of the long-term benefits of treatment for chronic conditions.

249. Under Menzel's consent model, the willingness of disabled persons to consent to this more truncated "QALY bargain" is unclear. On one hand, the benefits of quality of life considerations may offset the disadvantages. On the other hand, consent may be given only to advantageous uses. Because my own reasoning does not rely on assumptions about actual or presumed consent, the unbundling possibility is not central to my conclusions.

250. See Marzen Letter, *supra* note 46, reprinted in 9 ISSUES L. & MED. at 400.

noncritical care, then every treatment that improved the patient's condition by any amount would have to be treated as being equally beneficial, no matter how trivial the impact on the patient's well-being.²⁵¹ Neither law nor justice requires this.

As a result, courts will and should conclude that quality of life considerations are permissible in the context of noncritical care, as long as the scales are unbiased and reasonable accommodation and individualization are provided.²⁵²

CONCLUSION

Any method of rationing potentially beneficial care will involve tragic choices. But if society cannot afford to fund every medical service that might conceivably be beneficial, then methodologies designed to maximize the good that can be done with limited resources have considerable appeal.

Unquestionably, better data and methodologies will be needed before effectiveness analysis fulfills its potential. But efforts to correct these deficiencies would be misplaced if the rankings that would result are intrinsically unjust. The Federal Government's initial rejection of the Oregon Medicaid experiment called attention to the risk that allocation schemes based on effectiveness would unfairly discriminate against patients with disabilities.

The defensibility of effectiveness measurements depends upon the criteria used to measure effectiveness. Quality of life considerations are more objectionable than other measures of success because they treat the lives of disabled persons as less valuable than the lives of others. As a result, courts are likely to conclude that any broad-based use of quality of life considerations to measure the benefits of life-saving care is illegal. But the threat that quality of life considerations pose to the principle of equal worth when life-extending care is being evaluated does not exist when noncritical care is being ranked. As a result, quality of life can properly be used to rank noncritical care as long as the quality of life scales are accurate and unbiased.

Congress should also consider authorizing the use of quality of life considerations in extreme cases involving life-sustaining care. Under some circumstances, the principle of equal worth may demand too great a sacrifice of medical utility. But movement in this direction should be cautious, proceeding slowly as the public debates these excruciatingly difficult choices.

Other measures of effectiveness, such as survival rates, that do not take into account quality of life are more clearly permissible. Even here, however, the arguments for an egalitarian interpretation of the disability rights laws are quite powerful. But because survival rates do not reflect invidious stereotypes and do not violate the principle of equal worth, courts will and should permit their use.

251. OREGON HEALTH SERVS. COMM'N, *supra* note 60, at 17 (noting the marginal improvement provided by dental services).

252. See *supra* part III.B.3.

This endorsement of survival rates has four important qualifications. First, the rankings must be based on reliable empirical data. Second, although the prospect is unlikely, the unique statutory language governing employee health benefits could possibly be construed to prohibit the use of any exclusionary eligibility criteria in that context. Third, programs using effectiveness criteria must individualize their decision-making to the maximum extent feasible in order to avoid unfair generalizations about disabled individuals. Fourth, the reasonable accommodation requirement may obligate plans to offer riders which cover less successful treatments.

While I have concluded that effectiveness criteria are sometimes proper, I do not suggest that effectiveness or cost-effectiveness methodologies should monopolize the allocation process. Other values and methods will have a place, sometimes a central place, depending upon the overall mix of values that a health plan seeks to advance and the specific context of the allocation decision. Unfortunately, none of the rationing options is pleasant. Hopefully, those among us who are optimistic about cost-savings are correct and very little of this will be necessary. But to the extent that rationing is necessary, effectiveness belongs among the criteria legally and ethically available to health planners to make these difficult choices.

