

Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care

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INTRODUCTION

Our health care system is, in many respects, a victim of its own success. The rapid development of beneficial medical technology has produced a situation in which funding all interventions that would provide some health benefit to some patient would preclude spending on any other desirable social good.¹ As a consequence, there is an urgent need to make cost-benefit trade-offs in health care.

Health care poses, however, a somewhat unique challenge for the making of cost-benefit trade-offs. In other areas of economic life, individual consumers routinely make such rationing trade-offs on their own: they regularly opt to forego beneficial purchases because of their cost.² In the health care arena, by contrast, consumers often do not have much incentive to ration. This is because consumers typically insure themselves against medical uncertainties and thus do

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1. See Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1451, 1459 (1994) (noting that most knowledgeable observers agree that we could easily spend 100% of our GNP on beneficial interventions); see also Alan Williams, *Priority Setting in Public and Private Health Care*, 7 J. HEALTH ECON. 173, 173 (1988) (stating that no country can afford to fund all potentially beneficial procedures for those who might benefit from them).

2. I use the term "rationing" more broadly than some other commentators; these commentators argue that the term applies only to cost-based denials of beneficial care by administrative bodies. See Michael D. Reagan, *Health Care Rationing: What Does It Mean?*, 319 NEW ENG. J. MED. 1149 (1988); see also Clark C. Havighurst, *Prospective Self-Denial: Can Consumers Contract Today to Accept Health Care Rationing Tomorrow?*, 140 U. PA. L. REV. 1755, 1762-64 (1992) (arguing that the term squarely applies only to government decisions that not only limit the amount of beneficial health care it provides but also limit the freedom of individuals to purchase supplemental health care in the private market). In my view, these narrow definitions of the term "rationing" obscure the manner in which cost can operate as a factor in the calculations of all decisionmakers, including ordinary consumers. Ultimately, the dispute is semantic and likely stems from the negative connotations associated with the term "rationing." *Id.* at 1755 (noting that rationing conjures up "visions of officious interference in private choices").

not pay, out-of-pocket, the full costs of the health care interventions they consume.³

Because insured individuals have little incentive to ration, rationing for these individuals must occur through restrictions on the scope of insurance. Historically, some common restrictions have included copayments and deductibles or specific treatment exclusions. At a time when the universe of possible treatments was small, these narrow restrictions worked reasonably well to contain costs. With the enormous growth in new technology, however, these restrictions have failed to contain costs.⁴ Rising health care costs have, in turn, driven many individuals into the ranks of the uninsured: these individuals (or their employers) have not been able to afford the high costs of insurance.⁵

Among those who have studied the interrelated problems of high cost and lack of access to insurance coverage, it is commonplace that addressing these problems will require new, more considered and comprehensive approaches to rationing care.⁶ Indeed, the recent explosive growth of managed care,⁷ has, in large part, been fueled by the recognition that rationing trade-offs in health care must be made. The manner in which managed care plans make trade-offs is, however, highly suspect. Managed care plans generally ration by giving

3. Of course, consumers ultimately incur the costs of health care consumption decisions made by themselves and others in the form of higher premiums.

4. Health care spending as a percentage of the GNP grew from 9.3% to 12.6% between 1980 and 1990 and from 12.6% to 13.9% between 1990 and 1993. Katharine R. Levit et al., *National Health Spending Trends, 1960-1993*, HEALTH AFFAIRS, Winter 1994, at 14, 15. Although the rate of health care cost growth in the private sector has decreased in the past few years, see Robert Pcar, *Health Costs Are Growing More Slowly, Report Says*, N.Y. TIMES, May 28, 1996, at A13, the rate of increase in Medicare and Medicaid expenditures has not slowed down. *Id.* Moreover, most health care economists predict that the rate of health care cost growth will exceed inflation for the foreseeable future. See Mike McNamee et al., *Health Care Inflation: It's Baaack*, BUS. WEEK, Mar. 17, 1997, at 28.

5. See Emily Friedman, *The Uninsured: From Dilemma to Crisis*, 265 JAMA 2491, 2493 (1991) (stating that the major reason for growing numbers of uninsured is the high cost of insurance plans). Recent figures show that more than 40 million persons lack health insurance. Elisabeth Rosenthal, *New York Study Finds Uninsured Are on the Rise*, N.Y. TIMES, Feb. 25, 1997, at A1.

Exclusion from insurance coverage is, of course, itself a crude means of rationing. However, when such rationing options as low-cost plans that provide at least minimal coverage are not available, rationing by exclusion from insurance coverage often occurs.

6. See, e.g., Henry Aaron & William B. Schwartz, *Rationing Health Care: The Choice Before Us*, 247 SCIENCE 418, 418-19 (1990); David M. Eddy, *Health System Reform: Will Controlling Costs Require Rationing Services?*, 272 JAMA 324, 326 (1994); Richard D. Lamm, *Rationing of Health Care: Inevitable and Desirable*, 140 U. PA. L. REV. 1511, 1513 (1992).

7. According to recent surveys, managed care plans that integrate health care financing and delivery (i.e., health maintenance organizations, preferred provider organizations, and the like) may account for 70% of the market share of privately insured employees. Michael Wines & Robert Pcar, *President Finds Benefits in Defeat on Health Care*, N.Y. TIMES, July 30, 1996, at A1. This percentage has grown from 63% in 1994 and 52% in 1993. *Id.*; see also Robert Pcar, *Laws Won't Let H.M.O.'s Tell Doctors What to Say*, N.Y. TIMES, Sept. 17, 1996, at A12 (stating that 60 million Americans are in H.M.O.'s and as many as 90 million are in other managed care plans).

“gatekeeper” physicians financial incentives to reduce their rates of medical testing, hospitalization, and referral.⁸ These financial incentives place physicians at some level of personal financial risk for using high cost hospital and specialty care.⁹ Yet individuals who enroll in managed care plans typically have no knowledge of these rationing incentives;¹⁰ this is because, as a general matter, managed care organizations have no legal obligation to disclose such information.¹¹ Indeed, managed care contracts often promote the misconception that *no* rationing is contemplated: these contracts frequently state that the plan will cover all “medically necessary” care,¹² a phrase which has been interpreted by courts to mean all care that yields any health benefit.¹³ As a consequence, in our current system, individuals deciding between different health plan contracts generally have little idea what they are choosing. Moreover, the spending trade-offs that are imposed on enrollees by managed care physicians may be quite different from those that the enrollees would have chosen at the time they enrolled, had they been given an explicit choice regarding trade-offs.¹⁴

The marketplace tendency to discount the possibility of explicit, contractually-based, choice in rationing has found a parallel in the academic literature. Moral philosophers and other academic commentators who have discussed the questions

8. Marsha Gold et al., *Behind the Curve: A Critical Assessment of How Little Is Known About Arrangements Between Managed Care Plans and Physicians*, 52 MED. CARE RES. & REV. 307, 314-35 (1995).

9. *Id.*

10. See Mark A. Hall, *Informed Consent to Rationing Decisions*, 71 MILBANK Q. 645, 646 (1993).

11. Milt Freudenheim, *H.M.O.'s Cope with a Backlash on Cost Cutting*, N.Y. TIMES, May 19, 1996, at A1; Hall, *supra* note 10, at 646. At best, as a consequence of legislation recently enacted in some states, enrollees may learn of the rationing incentives used by their health plans *after* they have enrolled. See Pear, *supra* note 7 (noting that some state laws stipulate that doctors may tell patients about their financial arrangements with managed care organizations); see also Deven C. McGraw, Note, *Financial Incentives to Limit Services: Should Physicians Be Required to Disclose These to Patients?*, 83 GEO. L.J. 1821, 1839-47 (1995) (arguing that managed care physicians could be required by judicially created doctrine of informed consent to disclose rationing incentives to patients). In a recent case, one court did hold, however, that administrators of health plans that are self-funded and thus governed by the Federal Employee Retirement Income Security Act rather than by state insurance contract law have a fiduciary duty to disclose rationing incentives. See *Shea v. Esenstein*, 107 F.3d 625, 628 (8th Cir. 1997).

12. Havighurst, *supra* note 2, at 1776, 1781; see also CLARK C. HAVIGHURST, *HEALTH CARE CHOICES: PRIVATE CONTRACTS AS INSTRUMENTS OF HEALTH REFORM* 15 (1995).

13. See *infra* note 28.

14. Similar problems arise with utilization review, another common managed care rationing technique. The third party utilization reviewer who denies approval for a physician's proposed treatment plan may make cost-benefit trade-offs very different than those the enrollee would have made at the time of enrollment.

It is important to emphasize that the relevant comparison must be between the trade-offs the enrollee would have made *ex ante* (i.e., at the time of enrollment) and those made by the physician/third party. If cost containment is desired, the *ex post* preferences of insured individuals cannot be used. Once an individual is insured, she has little incentive to consider costs.

of what criteria should be used to ration care,¹⁵ and of whether these criteria should be implemented through rulemaking at the administrative level or by the physician at the bedside,¹⁶ have often urged that one approach or another is the approach to which individuals would, or should, give their consent.¹⁷

In contrast, this Article takes as its point of departure the argument that individuals should be allowed to make explicit contractual choices among a variety of rationing schemes.¹⁸ Choice is desirable for the following reasons: first, moral theory does not provide a determinate answer to the question of how we should ration care; second, the most commonly prescribed alternative to moral theory—the democratic political process—does not respect the diversity of individual health and allocational preferences, and hence individual autonomy, to the same extent as does choice; and third, choice can be implemented in a manner that not only respects individual autonomy but also attends to other important moral principles, such as justice and beneficence. The Article begins by making the case for choice. It outlines a scheme for rationing based on choice and addresses the main legal and policy obstacles to the implementation of such a scheme.

Having made the threshold argument in favor of choice, the Article takes as its focus the most prominent and systematic approach to rationing individuals could choose—rationing based on principles of medical cost-effectiveness analysis. It examines the manner in which introducing choice transforms the protracted and contentious debate over cost-effectiveness: although many participants in this debate have offered detailed examinations of cost-effectiveness as a means of rationing health care (and as a means of “rationalizing” resource allocation and

15. The literature on rationing criteria primarily comprises the numerous volumes that have argued for, and attempted to specify, a “decent minimum” of “adequate” health care that all individuals should receive. This literature is discussed *infra* Part I.A.

16. The medical ethics literature has generally rejected bedside rationing as an unacceptable violation of the physician’s beneficent duty to do everything that is in the biomedical interest of her patient, irrespective of the costs to society. *See, e.g.*, Daniel P. Sulmasy, *Physicians, Cost Control, and Ethics*, 116 *ANNALS INTERNAL MED.* 920 (1992); Susan M. Wolf, *Health Care Reform and the Future of Physician Ethics*, *HASTINGS CENTER REP.*, Mar.-Apr. 1994, at 28. Proponents of bedside rationing have argued that it is necessary because even the most detailed administrative rules cannot possibly anticipate the particular circumstances of a specific patient. Mark A. Hall, *Rationing Health Care at the Bedside*, 69 *N.Y.U. L. REV.* 693, 701-03 (1994). This Article’s argument that individuals should be able to choose their rationing scheme, *see generally infra* Part I.B, encompasses not only individual choice of rationing criteria but also the choice of whether these criteria should be implemented at the administrative level, by the physician, or by some combination of administrative rules and physician assessment.

17. *See infra* Part I.A (discussing various attempts to define “adequate care” that argue in favor of a particular approach); *see also* sources cited *supra* note 16. Some commentators have, however, made thoughtful arguments that allowing choice among rationing schemes would be morally desirable. *See, e.g.*, EZEKIEL J. EMANUEL, *THE ENDS OF HUMAN LIFE* (1991); Elhauge, *supra* note 1. I discuss these proposals and distinguish them from the proposal in this Article *infra* notes 75, 112, 120, 124, and accompanying text. I also discuss (and distinguish) proposals by market-oriented theorists that stress choice. *See infra* note 82.

18. The choice of rationing scheme should include not only rationing criteria but also the mechanism (i.e., rulemaking, physician judgment, or some combination of the two) by which the criteria would be implemented. For a discussion of this issue, *see infra* notes 180-83.

regulation generally¹⁹), they have generally not considered the possibility that cost-effectiveness could be offered to individuals as one rationing option among others.²⁰ Indeed, both within and without the area of health care, cost-effectiveness analysis has typically been associated with centralized government decisionmaking and not with individual choice. Choice transforms a very controversial rationing mechanism into one that should be appealing to a large number of individuals, including many who would consider themselves opposed to utilitarian principles. Finally, the Article addresses an important limitation on choice that is particularly significant for the choice of cost-effectiveness analysis: the limitation imposed by legal and moral arguments regarding discrimination.

The Article's analysis divides into four parts. Part I makes the general argument in favor of giving individuals rationing choices and outlines a system in which individuals would make considered and reflective choices among health plans with different rationing schemes. Part II presents a proposal for cost-effectiveness as a rationing choice and discusses how choice addresses the methodological limitations of previous attempts to implement rationing based on cost-effectiveness. Part III then argues that this choice-based approach also addresses a broad set of anti-utilitarian arguments against cost-effectiveness analysis and thus makes cost-effectiveness an attractive option for both utilitarians and non-utilitarians. Finally, Part IV discusses the manner in which a choice-based framework would address prominent legal and moral arguments that the use of cost-effectiveness analysis discriminates against the elderly and the disabled.

I. CHOICE AS A RATIONING PRINCIPLE

Most discussions of health care rationing make arguments for the proposition that society is obligated by such moral principles as justice or beneficence to make rationing trade-offs in a manner that will provide all individuals with health

19. Both cost-effectiveness analysis (which typically measures benefit in non-monetary terms) and cost-benefit analysis (which typically measures benefit in monetary terms) have been widely discussed. Commentators have urged, for example, that disparate health and safety regulations be compared in terms of their cost-effectiveness (specifically, cost-per-life-saved) ratios. See STEPHEN BREYER, *BREAKING THE VICIOUS CIRCLE* 24-27 (1993). More generally, executive orders issued by President Clinton, see Exec. Order No. 12,866, 3 C.F.R. 638 (1993), reprinted in 5 U.S.C. § 601 (1988), and President Reagan, see Exec. Order No. 12,291, 3 C.F.R. 127 (1981), reprinted in 5 U.S.C. § 601 note (1988) (revoked 1993); Exec. Order No. 12,498, 3 C.F.R. 323 (1985), reprinted in 5 U.S.C. § 601 note (1988) (revoked 1993), have emphasized cost-benefit analysis as a means of assessing agency regulation. The 104th Congress's efforts at regulatory reform also emphasized cost-benefit analysis. See generally Cass R. Sunstein, *Congress, Constitutional Moments, and the Cost-Benefit State*, 48 STAN. L. REV. 247 (1996).

20. Even those commentators who have argued in favor of securing individual consent to cost-effectiveness, see, e.g., PAUL T. MENZEL, *STRONG MEDICINE: THE ETHICAL RATIONING OF HEALTH CARE* 79-96 (1990), have tended to assume that cost-effectiveness would be the only available option, not one option among others.

care that is "adequate" or meets some "decent minimum."²¹ The argument for "adequate care" is more than just a general argument for income redistribution. Indeed, it is often advanced even by those who do not believe in redistribution of income more generally.²² Those who argue that health care is "special" rely on a variety of arguments. Some argue that society must provide adequate health care services in order to secure for its citizens "normal opportunity range," and hence equality of opportunity.²³ Others emphasize that alleviating the misery caused by lack of adequate health care is an obligation of beneficence that can (and should) be enforced through collective contribution to the provision of health care.²⁴ Whether taken together or separately, these arguments suggest strongly that the principle of ensuring adequate care for all should govern health care redistribution and rationing.²⁵

21. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 356 (1994) (developing the argument for an individual right to a decent minimum of health care and noting that it holds out the "potential for compromise among libertarians, utilitarians, communitarians, and egalitarians"); see also LARRY CHURCHILL, *RATIONING HEALTH CARE IN AMERICA* (1987); NORMAN DANIELS, *JUST HEALTH CARE* (1985); Allen E. Buchanan, *The Right to a Decent Minimum of Health Care*, 13 PHIL. & PUB. AFF. 55-78 (1984); 1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *SECURING ACCESS TO HEALTH CARE: A REPORT ON THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES* 3-6, 18-47 (1983) [hereinafter, PRESIDENT'S COMM'N, *SECURING ACCESS TO HEALTH CARE*]; 2 PRESIDENT'S COMM'N, *SECURING ACCESS TO HEALTH CARE*, app. G, H, I (1983); Charles Fried, *Equality and Rights in Medical Care*, HASTINGS CENTER REP., Feb. 1976, at 29, 29-34 (arguing for an adequate care standard). While some commentators view adequate health care as a justice-based right, see, e.g., DANIELS, *supra*, others view it as an enforceable obligation of social beneficence, see, e.g., Buchanan, *supra*.

22. See generally Elhauge, *supra* note 1, at 1473-93 and sources cited therein.

23. See DANIELS, *supra* note 21, at 36-58.

24. See, e.g., Buchanan, *supra* note 21.

25. To be sure, arguments supporting redistribution of basic health care could also be used to support redistribution of other important social goods, such as basic food and shelter. Like lack of basic health care, lack of basic food and shelter causes misery and curtails equality of opportunity. The focus on redistribution of health care may result from a perception that redistributing health care undermines productive incentives to a lesser extent than other types of redistribution. See Elhauge, *supra* note 1, at 1486-95. Alternatively, the focus on health care redistribution may be a function of the particular importance accorded to health care in the United States. See generally MICHAEL WALZER, *SPHERES OF JUSTICE: A DEFENSE OF PLURALISM AND EQUALITY* 86-91 (1983).

Although the decent minimum standard embodies, by far, the majority view, it is rejected by two groups of diametrically opposed theorists. On the one hand, it is rejected by theorists who oppose redistribution generally and further deny that redistributing health care is different from redistributing income more generally. See, e.g., Richard A. Epstein, *Why Is Health Care Special?*, 40 U. KAN. L. REV. 307 (1992); Loren E. Lomasky, *Medical Progress and National Health Care*, in *MEDICINE AND MORAL PHILOSOPHY* 115 (Marshall Cohen et al. eds., 1981). On the other hand, it is rejected by strict egalitarians who argue that the adequate care "floor" should also be the ceiling on permissible purchase of health care. See, e.g., WALZER, *supra*, at 86-91 (conceding that a "decent minimum" standard would not be unjust in principle but arguing that the significance accorded medical care in the United States requires that medical services be distributed equally); Amy Gutmann, *A Principle of Equal Access*, in 2 PRESIDENT'S COMM'N, *SECURING ACCESS TO HEALTH CARE*, *supra* note 21 app. C, at 51-65. My goal in this

If adequate care could be specified for use as a rationing standard, our rationing dilemmas would be all but resolved. All individuals would receive this publicly-funded adequate care; although individuals could spend their private resources on additional beneficial care, there would be no public obligation to fund such care. Notably, a reasonably precise definition of adequate care would resolve both the macro-allocational rationing question of how much the state should spend on health care (as opposed to other social goods) and the micro-allocational rationing question of how to distribute health care resources within the population.

The challenge lies in developing a specification of adequate care as a rationing standard. In this Part, I demonstrate that moral theory yields not a single specification but, rather, a variety of diverse, often conflicting, specifications. Given this failure of moral theory, we have one of two options: we could use democratic political procedures to forge a compromise among the conflicting specifications; alternatively, we could allow choice. I argue that because choice respects the diversity of individual health and allocational preferences, and hence individual autonomy, without compromising any other significant values, it should be allowed. I conclude this Part by outlining my precise vision of rationing through choice—a system in which individuals would receive public funding that they could use to make reflective choices between insurance plans with different rationing philosophies.

A. The Failure of Adequate Care as a Rationing Standard

Close examination of even the most systematic approaches to specifying adequate care demonstrates that each of them is, at the most fundamental level, wholly indeterminate.²⁶ Thus, even if, as a metaphysical matter, there might exist

Article is not to defend the decent minimum standard in any detail but, rather, to analyze whether the standard can be used to ration care.

26. Various commentators have noted that particular approaches to defining adequate care are unworkable. *See, e.g.*, DANIELS, *supra* note 21, at 74-78; EMANUEL, *supra* note 17, at 114-45 (1991); Elhauge, *supra* note 1, at 1465-72. Some have reached the more general conclusion that all existing approaches to specifying adequate care are unworkable. EMANUEL, *supra* note 17, at 114-45; Elhauge, *supra* note 1, at 1465-72. My critique is more narrowly focused than that of these other commentators. I do not criticize the various approaches for yielding rationing standards that may have to be modified or further clarified in order to be implemented as a matter of practical policy. Although such criticisms are important, they do not necessarily doom the approaches. Any theoretical proposal is likely to need modification or clarification in order to be implemented at the policy level. Rather, I criticize each approach for being, at the most fundamental level, entirely indeterminate. Consider the following illustration of this distinction. Some commentators have criticized the list-of-services approach to adequate care, *see infra* Part I.A.1, for failing to provide a mechanism for making necessary allocational choices within the categories of medical services covered. *See, e.g.*, EMANUEL, *supra* note 17, at 116; Elhauge, *supra* note 1, at 1470-71. Although this criticism is fair, the determination of how to make allocational choices within a specified universe of preferred services is not a fundamental one. Rather, the foundational task involves choosing the list of preferred services in the first instance. The list-of-services approach provides no guidance on how to perform this foundational task. *See infra* Part I.A.1.

a single, morally superior, specification of adequate care, we do not, as a practical matter, have the means to discern what this specification is.²⁷

Systematic approaches to specifying adequate care fall into four categories: 1) list-of-services approaches; 2) criterion-based approaches; 3) hypothetical choice approaches; and 4) approaches based on the use of analytic decision tools such as cost-benefit analysis.²⁸

1. List-of-Service Approaches to Adequate Care

Lists of basic medical services have been espoused by some economists and policy analysts. Under one such list, developed by Alan Enthoven, a plan would be required to cover the services designated as basic health services in the Health Maintenance Organization (HMO) Act of 1973.²⁹ The HMO Act's list of basic health services includes physician services, inpatient and outpatient hospital services, "medically necessary" emergency health services, up to twenty mental health visits, treatment for alcohol and drug abuse, diagnostic services, home health services, and certain preventive services.³⁰

Although the list-of-services approach creates the illusion of precision, it is ultimately indeterminate: it does not yield a unique answer to what should be

27. I note this point in order to emphasize that my argument here does not dispute the possibility of a single, correct conception of adequate care. Rather, it simply stresses that, as a practical matter, existing approaches to specifying adequate care do not tell us what this conception is. I thank Ruth Chang for pressing me on this point.

28. Norman Daniels and Ezekiel Emanuel have noted the first three of these four categories. See DANIELS, *supra* note 21, at 74; EMANUEL, *supra* note 17, at 113. Some of these specifications follow from the justifications for a right to health care services discussed above. For example, Norman Daniels's equality-of-opportunity based justification for a right to adequate care, see *supra* text accompanying note 23, also helps him define what this adequate care should be. See *infra* Part I.A.2.

Less systematic specifications of adequate care also abound. These specifications tend merely to acknowledge the need to make cost-benefit trade-offs without suggesting a workable standard for making these trade-offs. See, e.g., I PRESIDENT'S COMM'N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, at 19; Allan Gibbard, *The Prospective Pareto Principle and Equity of Access to Health Care*, in 2 PRESIDENT'S COMM'N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, app. I, at 172 (arguing that the decent minimum of care is that which it would be prudent for anyone assured a decent economic minimum of income to ensure for himself). Indeed, specifications that invoke a "need"-based standard, see, e.g., CHURCHILL, *supra* note 21, at 94, do not even acknowledge the reality that trade-offs between cost and health benefit must be made; a need could, after all, plausibly be defined to include all individual desires and preferences and thus could be even more expansive in scope than health benefit. See I PRESIDENT'S COMM'N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, at 19; see also Mark A. Hall & Gerard F. Anderson, *Health Insurers' Assessment of Medical Necessity*, 140 U. PA. L. REV. 1637, 1647-57 (1992) (summarizing court holdings to the effect that the medically necessary restriction found in many insurance plans does not even exclude experimental treatments of questionable efficacy).

29. ALAN C. ENTHOVEN, HEALTH PLAN: THE ONLY PRACTICAL SOLUTION TO THE SOARING COST OF MEDICAL CARE 127-28 (1980). President Clinton's failed health care reform proposal took a similar approach by defining 18 categories of services that all plans would be required to cover. Health Security Act, H.R. 3600, 103d Cong., §§ 1101-1128 (1994).

30. ENTHOVEN, *supra* note 29, at 128.

included in adequate care. Rather, individuals with different approaches to health valuation might desire to include very different services on their respective lists. For example, while those who formulated the HMO Act chose to include mental health treatment, and to exclude dental and vision services, others might find coverage for dental and vision services much more important than coverage for mental health treatment.³¹ Enthoven himself suggests that a health plan might choose to include only some unspecified subset of the services on the HMO Act list.³² Moreover, while the list-of-services approach generates multiple lists, it provides no mechanism for evaluating these lists so as to determine whether a particular list represents a "better" conception of adequate care than another list.

2. Criterion-Based Approaches

Unlike list-of-services approaches, which attempt to use specific rules, criterion-based approaches rely on more general standards. One influential criterion-based approach is the liberal egalitarian view, developed principally by Norman Daniels. Daniels applies John Rawls's theory of social justice,³³ in particular his "fair equality of opportunity" principle,³⁴ to define adequate care as that care which protects fair equality of opportunity.³⁵ According to Daniels, protecting fair equality of opportunity means protecting or restoring "normal opportunity range."³⁶ For any given individual, normal opportunity range is informed both by the society in which she lives and by her talents and skills.³⁷

Daniels insists that his account specifies only a circumscribed set of basic services that should be available to all.³⁸ The normal opportunity range standard is, however, extremely vague. As a consequence, health care that aims to restore normal opportunity range could conceivably include all beneficial medical

31. For a similar conclusion, see, for example, DANIELS, *supra* note 21, at 76; EMANUEL, *supra* note 17, at 118-19; Elhauge, *supra* note 1, at 1470.

32. ENTHOVEN, *supra* note 29, at 128.

33. Rawls argues that individuals under a veil of ignorance as to their personal characteristics (e.g., social status, class position, natural distribution of abilities, age, or particular conception of the good) would contract to form a society constructed on the following principles of justice: the liberty principle, which guarantees the most extensive set of liberties compatible with a similar system of liberty for all; the fair opportunity principle, which requires fixed background institutions that guarantee "fair equality of opportunity"; and the "maximin" or "difference" principle, which requires that primary social goods be distributed equally unless unequal distribution redounds to the benefit of the least advantaged. JOHN RAWLS, A THEORY OF JUSTICE 302-03 (1971).

34. *Id.*

35. See generally DANIELS, *supra* note 21, at 36-58. Daniels takes a broader view of the fair equality of opportunity principle than does Rawls. While Rawls's principle focuses on opportunity in the form of jobs and careers, Daniels construes opportunity to include the "array of life plans it is reasonable for persons to choose in a given society." *Id.* at 50.

36. *Id.* at 33; see also Norman Daniels, *Health-Care Needs and Distributive Justice*, PHIL. & PUB. AFF., Winter 1981, at 146, 158-60.

37. DANIELS, *supra* note 21, at 33. Daniels also uses a Rawlsian hypothetical contractor approach to suggest that normal opportunity range may be age relative. See *infra* notes 46-48 and accompanying text.

38. DANIELS, *supra* note 21, at 79.

interventions.³⁹ Daniels addresses squarely how his framework would apply to problems of scarcity on only a few occasions. On one such occasion, he indicates that it would require health care rationing schemes to address preferentially those diseases and disabilities that “involve a *greater* curtailment of an individual’s share of the normal opportunity range.”⁴⁰ Such prioritization is not, however, the only possible corollary of Daniels’s framework. Indeed, it might be seen as inconsistent with Daniels’s framework: such prioritization could, after all, give rise to the “bottomless pit” problem of patients whose health care costs are so high, and whose disabilities are so intractable, that promoting the normal opportunity range of these patients precludes spending to promote the normal opportunity range of all other individuals.⁴¹ At a minimum, Daniels’s framework could equally support an allocation system which helped most individuals achieve the normal opportunity range at the expense of those few for whom achieving the normal opportunity range was very costly. Ultimately, Daniels himself acknowledges this problem. He notes that his normal opportunity range framework “does not tell us which opportunities to protect when scarcity prevents us from equally protecting everyone’s.”⁴²

39. See EMANUEL, *supra* note 17, at 123 (noting that, under Daniels’s approach, people would receive “most of what modern medicine has to offer”). Indeed, Daniels’s use of normal opportunity range as a rationing standard could be seen as arguing not simply for a right to health care but for a right to health itself. Arguments for a right to health are highly dubious—there are, after all, many individuals for whom no medical intervention will succeed in providing health.

40. DANIELS, *supra* note 21, at 35 (emphasis added).

41. See Daniel Wikler, *Philosophical Perspectives on Access to Health Care: An Introduction*, in 2 PRESIDENT’S COMM’N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, app. F, at 119-20; see also Kenneth J. Arrow, *Some Ordinalist-Utilitarian Notes on Rawls’s Theory of Justice*, 70 J. PHIL. 245, 251 (1973) (discussing 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”). Of course, some individuals who are needy might benefit greatly from inexpensive health care. These individuals would be more effectively isolated, however, by a standard that used “capacity to benefit” (or capacity to benefit for a given cost) than by a standard that preferentially allocated care to the neediest.

42. Norman Daniels, *Liberalism and Medical Ethics*, HASTINGS CENTER REP. Nov.-Dec. 1992, at 41, 42; see also Daniels, *supra* note 36, at 171 (noting that his framework provides “little help” with “hard case[s], the resource allocation decisions in which we must choose between services which remove serious impairments of opportunity for a few people and those which remove significant but less serious impairments from many”).

Daniels also makes a controversial assumption in drawing a clear distinction between limits placed on fair equality of opportunity by one’s own talents and skills and those imposed by ill health. Under Daniels’s theory, justice requires eliminating only those restrictions on opportunity caused by ill health. *Id.* at 160. Although one could argue that poor health differs from talents and skills because social institutions can ameliorate poor health more readily than poor talents or skills, this argument is questionable. Indeed, unlike Daniels, Rawls himself refers to health as a *natural* good, the possession of which is not influenced significantly by background social institutions. See RAWLS, *supra* note 33, at 62; see also Daniels, *supra* note 36, at 165 n.31 (acknowledging this fact).

3. Hypothetical Choice Approaches

Procedural approaches of the type used by Rawls to formulate his theory of justice⁴³—variously known as hypothetical choice, contract, or consent approaches—are a popular mechanism for analyzing distributive justice dilemmas.⁴⁴ In the health care rationing context, hypothetical choice requires that individuals formulate allocation standards without any knowledge of their current or future health state.⁴⁵ This procedural approach yields, however, a plethora of substantive allocation standards. For example, Norman Daniels uses the hypothetical choice approach to specify further the normal opportunity range standard he derives from Rawls's fair equality of opportunity principle. Daniels asserts that hypothetical contractors would choose rationing that allowed them to achieve an "age-relative" normal opportunity range at each stage of their life.⁴⁶ Achieving this "age-relative" normal opportunity range would require contractors to choose a rationing scheme that maximized their chances of reaching a normal life span over one that gave a reduced chance of reaching that life span but, for those reaching it, an increased chance of living a life longer than the normal span.⁴⁷

Having made his argument, Daniels then admits that others might reach a different conclusion regarding which of the two rationing schemes hypothetical contractors would choose.⁴⁸ Indeed, others have gone far beyond Daniels's two

43. See RAWLS, *supra* note 33.

44. Indeed, some commentators have argued that hypothetical consent to rules of distributive justice is at least as valuable as actual consent to these rules. See Eric Rakowski, *Taking and Saving Lives*, 93 COLUM. L. REV. 1063, 1113-22 (1993); see also ERIC RAKOWSKI, EQUAL JUSTICE 306 (1991) (arguing that unanimous hypothetical consent is as valuable as actual consent).

45. In this Article, I do not differentiate between hypothetical choice procedures that employ Rawls's "thick" veil of ignorance, thus suppressing knowledge not only of health status but also of all other personal characteristics, see, e.g., DANIELS, *supra* note 21, at 103; David Gauthier, *Unequal Need: A Problem of Equity in Access to Health Care*, in 2 PRESIDENT'S COMM'N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, app. H; and those that dispense with the thick veil but nonetheless suppress knowledge of current or future health status, see RAKOWSKI, *supra* note 44, at 36, 313-14 (1991); Ronald Dworkin, *Will Clinton's Plan Be Fair?*, N.Y. REV. OF BOOKS, Jan. 13, 1994, at 22. In each of these approaches, individuals make allocation choices without knowledge of their current or future health status.

46. NORMAN DANIELS, AM I MY PARENTS' KEEPER?: AN ESSAY ON JUSTICE BETWEEN THE YOUNG AND THE OLD 87-93 (1988); DANIELS, *supra* note 21, at 103-05.

47. The first outcome—maximizing one's chance of reaching a certain age—could be achieved in a scheme that permitted no one above that age to obtain high-cost interventions, even if those interventions were highly beneficial. Individuals below that age would presumably then have greater access to such interventions. The second outcome—maximizing the life span of some percentage of the population—could be achieved by rationing costly, highly beneficial interventions by some method independent of age (e.g., capacity to benefit or lottery). Some elderly individuals who received these interventions would live years beyond the normal life span; some younger individuals who did not receive the interventions would not reach the normal life span. DANIELS, *supra* note 21, at 107.

48. *Id.* at 107-08.

suggested alternatives for hypothetical choice. They have argued, for example, that hypothetical contractors would choose rationing based on utilitarian principles such as cost-effectiveness or cost-benefit analysis.⁴⁹ By contrast, non-utilitarians have argued that individuals choosing hypothetically would opt for random selection.⁵⁰ Rawls himself argues that his hypothetical contractors would employ a "maximin" principle that maximized the share of primary social goods enjoyed by the worst-off class.⁵¹ Although Rawls does not apply this maximin principle to health care,⁵² others who have done so have concluded that Rawls's own hypothetical contractors would preferentially allocate resources to the least healthy.⁵³

Some have used hypothetical choice to reach more modest allocational conclusions. Ronald Dworkin has suggested, for example, that we could presume

49. See, e.g., Gauthier, *supra* note 45, at 201-05; Gibbard, *supra* note 28, at 171-75; see also John C. Harsanyi, *Morality and the Theory of Rational Behaviour*, in *UTILITARIANISM AND BEYOND* 39 (Amartya Sen & Bernard Williams eds., 1982) (arguing that utilitarianism can be derived from the hypothetical consent approach). Donald Hubin makes the slightly weaker claim that hypothetical contractors would accept cost-benefit analysis as one mechanism for generating important information for public policy decisions. See Donald C. Hubin, *The Moral Justification of Benefit/Cost Analysis*, 10 *ECON. & PHIL.* 169, 188-91 (1994). Arguments for utilitarian principles of rationing often suffer from question-begging difficulties. These arguments state that individuals would consent ex ante to denial of interventions for which the benefit exceeded the cost, Gibbard, *supra* note 28, at 169, but do not provide a specific mechanism for making determinations regarding benefit and cost.

50. RAKOWSKI, *supra* note 44, at 317, 323. Rakowski argues that individuals would choose random selection once individuals who were very old or had a very poor prognosis had been excluded. *Id.* at 316. Rakowski's conclusion here appears to be at odds with his subsequent assertions that age should be considered as a factor in allocation, see *infra* note 128, and that individuals would consent ex ante to life maximization. See *infra* note 198.

51. See RAKOWSKI, *supra* note 44 (discussing maximin principle). Rawls's principle accepts inequalities in distribution so long as these inequalities redound to the benefit of the least well-off. Thus, despite its strongly egalitarian foundation, Rawlsian maximin logic is compatible with the conception of a decent minimum if one assumes that the inequality between the decent minimum and the health care enjoyed by wealthier members of society redounds to the benefit of the least well-off. This would be the case if, for example, encouraging greater redistribution would reduce incentives for wealth production and thus reduce the standard of living or health of the least well-off.

52. As previously discussed, see *supra* note 42, Rawls considers health to be a natural good, the distribution of which is not influenced by social institutions, and which is therefore not governed by the maximin principle.

53. Gauthier, *supra* note 45, at 194-95. Of course, under the maximin principle, this preferential allocation to the least well-off would be limited by any gain they might achieve if greater inequalities between the least healthy and others were allowed. Notably, even if one accepts the application of the maximin principle to health care, there remains a further level of indeterminacy. As Allen Buchanan has noted, the Rawlsian veil would preclude any solution to the problem of weighting health care relative to other primary goods. At best, Rawlsian hypothetical contractors would decide to establish a right to a decent minimum of health care and agree to fill in the content of the right once they were outside the veil and had more information about their particular society. But nothing in Rawls's conceptions of decisionmaking suggests that rational individuals would agree on a single assignment of weights to the primary goods. See Buchanan, *supra* note 21, at 61-62.

no one would want treatment that would provide only a few months of additional life in old age.⁵⁴ The empirical data do not, however, necessarily support this conclusion.⁵⁵

The indeterminacy of hypothetical choice is not surprising. At bottom, the conclusions one derives from hypothetical choice necessarily depend on one's antecedent allocational beliefs. Because these antecedent beliefs are diverse, the results of hypothetical choice will also be diverse.⁵⁶

4. Cost-Benefit Approaches

In the health care rationing context, cost-benefit analysis uses a variety of methods to assign a specific dollar figure to the health benefit (e.g., life saved or inorbidity avoided) that is achieved by health care interventions. Cost-benefit analysis could, therefore, readily be applied to define adequate care—interventions that provided a higher dollar benefit than their cost would be included in adequate care, while those that did not would be excluded.⁵⁷

There are several difficulties associated with using cost-benefit analysis to define adequate care. As a threshold matter, of course, using a cost-benefit approach to define adequate care will appeal principally to those of a utilitarian bent.⁵⁸ Notably, however, even for those who accept utilitarian reasoning, cost-benefit analysis does not ultimately provide a determinate definition of adequate care. Rather than yielding, for any given health benefit, a single monetary figure that corresponds to that health benefit, cost-benefit analysis yields only a wide range of monetary valuations.

54. Dworkin, *supra* note 45, at 23.

55. Ezekiel J. Emanuel & Linda L. Emanuel, *The Economics of Dying: The Illusion of Cost Savings at the End of Life*, 330 *NEW ENG. J. MED.* 540 (1994). In any event, excluding aggressive interventions at the end of life is not likely to produce savings sufficient to resolve our cost-containment problems. As a recent analysis of this question points out, savings achieved through the exclusion of aggressive treatments at the end of life will be limited by the difficulty of predicting when individuals are going to die and by the expense of palliative care. *Id.*

56. See H. TRISTRAM ENGELHARDT, *THE FOUNDATIONS OF BIOETHICS* 51 (1996) ("One only derives from a hypothetical-choice theory those choices which one has foreordained or predestined by an antecedent choice of a particular thin theory of the good, moral sense, cluster of moral intuitions, or notion of moral rationality."); see also EMANUEL, *supra* note 17, at 124-44 (discussing the indeterminacy of the hypothetical choice approach). In arguing for this strong form of indeterminacy, I differ from those who acknowledge the variable conclusions that may be reached through hypothetical choice analysis but nonetheless argue that it can be used to exclude certain choices. See, e.g., Elhauge, *supra* note 1, at 1538-41.

57. This Part's argument against imposing cost-benefit analysis on all individuals rationing contrasts with the Article's vigorous endorsement of cost-effectiveness analysis as a rationing choice. The contrast underscores the importance of choice.

58. Hubin, *supra* note 49, at 188-90. Cost-benefit analysis is, however, an imperfect reflection of utilitarian principles. Because cost-benefit analysis generally measures benefit in terms that reflect ability to pay, it tends to discount the utility of poor individuals. *Id.* at 187-88. Cost-effectiveness analysis, which measures benefit independent of earning capacity in the marketplace, see *infra* note 146 and accompanying text, is more consistent with utilitarian principles.

To arrive at dollar valuations of health benefit, cost-benefit studies generally use one of three approaches: first, the cost of illness approach, which measures the value of health by looking at medical expenditures incurred, and earnings foregone, due to illness;⁵⁹ second, the market data approach, which analyzes people's actual willingness to pay for health, as derived from their market expenditures on risk reduction (or, in employment contexts, the additional compensation they require for exposure to risky environments);⁶⁰ and third, the "contingent valuation" approach, which measures people's hypothetical willingness to pay to avoid adverse outcomes such as death or morbidity.⁶¹

The cost of illness approach is appealing because it relies on well-defined data on medical expenditures incurred, and earnings foregone due to illness.⁶² The approach is, however, vulnerable to the charge that its exclusive focus on the outcome of averting mortality or morbidity fails to capture contextual concerns many individuals may have regarding the type of mortality or morbidity averted.⁶³ For example, under the cost of illness approach, if medical costs and foregone earnings were the same, averting an instantaneous death would be just as valuable as averting a death from cancer. Yet studies have shown that the special pain and suffering associated with cancer is such that individuals are, on average, willing to pay several times as much to avert death from cancer as to avert an instantaneous death.⁶⁴ As for valuations derived from market data on risk

59. Donald Kenkel, *Cost of Illness Approach*, in VALUING HEALTH FOR POLICY: AN ECONOMIC APPROACH 42 (George Tolley et al. eds., 1994). Because this approach focuses on foregone earnings, it has also been termed the "human capital" approach. See Jerry Avorn, *Benefit and Cost in Geriatric Care: Turning Age Discrimination into Health Policy*, 310 NEW ENG. J. MED. 1294, 1296-97 (1984).

60. See W. KIP VISCUSI, FATAL TRADEOFFS 51-54, 66 (1992) (collecting studies using data from labor markets as well as other markets to measure value of life).

61. See, e.g., Donald Kenkel et al., *Contingent Valuation of Health*, in VALUING HEALTH FOR POLICY: AN ECONOMIC APPROACH, *supra* note 59, at 72-104 (describing contingent valuation approach and summarizing studies using this approach); see also George Tolley et al., *State-of-the-Art Health Values*, in VALUING HEALTH FOR POLICY: AN ECONOMIC APPROACH, *supra* note 59, at 323, 327-44 (formulating "state-of-the-art" health values that rely primarily on contingent valuation studies).

62. Kenkel, *supra* note 59, at 42.

63. It is well-established that individuals may value morbidity and mortality differently depending on whether it is caused by risks that are particularly feared or dreaded, involuntarily suffered, new, unobservable, uncontrollable, catastrophic, or a threat to future generations. See, e.g., BREYER, *supra* note 19, at 33; Donald Hornstein, *Reclaiming Environmental Law: A Normative Critique of Comparative Risk Analysis*, 92 COLUM. L. REV. 562, 614-15 (1992). For a discussion of this charge in the context of cost-effectiveness analysis, see *infra* Part III.A.2.

64. See Tolley et al., *supra* note 61, at 340-42 (relying primarily on contingent valuation to determine that individuals were willing to pay from \$1.5 million to \$9.5 million to avert a cancer death as compared to \$1 million to \$5 million to avert an unforeseen death); see also Kenkel, *supra* note 59, at 44 (noting that the cost of illness approach does not take into account "the relatively high costs in terms of pain and suffering of cancer").

The cost of illness approach has other difficulties as well. First, it does not achieve its goal of measuring willingness to pay for health. See *generally id.* at 44-48. There is, for example, no theoretical reason to believe that an individual's future earnings will be related to her willingness to pay for a reduction in mortality or morbidity risks. *Id.* at 44-45. Second, the cost-

reduction expenditures, these also reveal that, depending on the type of risk to life involved, individuals may value mortality quite differently.⁶⁵ Market data approaches are also suspect because they incorrectly assume that one can extrapolate in a linear fashion from the amount of money one pays to avoid a small risk to a value-of-life figure.⁶⁶

Problems of context and extrapolation do not necessarily, however, invalidate the possibility of developing a single set of monetary figures that correspond to different health benefits. We could, after all, simply ask individuals what they would be willing to pay to avoid specific types of morbidity and mortality. Indeed, this is precisely what contingent valuation does—it asks individuals what they would be willing to pay to avoid particular types of death (e.g., death from lung cancer) as well as particular types of morbidity (e.g., angina, nausea, vomiting).⁶⁷

Valuation estimates derived primarily from contingent valuation demonstrate, however, that individuals vary widely in their views of particular types of

of-illness approach causes the egalitarian adequate care standard to vary by level of remunerative activity in the marketplace. Under a straightforward application of the cost-of-illness approach, a higher level of foregone earnings would yield a higher level of adequate care. *See id.* at 44.

65. ELIZABETH ANDERSON, VALUE IN ETHICS AND ECONOMICS 199 (1993) (citing studies showing that workers find risk more acceptable if they see the end for which they risk their life as a worthy one and if they have some control over, and input into, the risk); *see also* VISCUSI, *supra* note 60, at 51-54 (collecting labor market studies showing that, depending on context of risk involved, implicit valuation of life figures ranged from \$600,000 to \$16.2 million); *id.* at 66 (collecting studies from outside the labor market showing valuations ranging from \$70,000 to \$4 million).

66. *See* STUART HILL, DEMOCRATIC VALUES AND TECHNOLOGICAL CHOICES 69-70 (1992); MENZEL, *supra* note 20, at 49-50; Richard Pildes & Cass Sunstein, *Reinventing the Regulatory State*, 62 U. CHI. L. REV. 78-79 (1995); *see also* Amos Tversky & Daniel Kahneman, *The Framing of Decisions and the Psychology of Choice*, 211 SCIENCE 453 (1981) (discussing extrapolation problems). Linear extrapolation does not work for two reasons. First, when the life involved is one's own, linear extrapolation is not rational from an economic standpoint. The amount of money a rational individual would pay to avoid a 1% chance of death is less than 1% of the money she would pay to avoid death. The reason is opportunity cost. When a person faces only a 1% risk of death, the opportunity cost of her spending money to avoid that risk is great. When a person faces certain death, however, there is no opportunity cost attached to spending money to avoid death. Assuming she does not have a strong desire to leave money to others, any resources the person does not spend will have zero value once she is dead. For a similar argument, *see* RICHARD A. POSNER, AGING AND OLD AGE 110 (1995). Linear extrapolation also does not work even if the life involved is not one's own. This is because many people tend to attach a large symbolic value to saving identifiable lives. People do not attach this symbolic value to the saving of "statistical" lives—lives that are saved because the risk of death is reduced (for example) from 1/100 to 1/1000. For a detailed discussion of this symbolic value, and its impact on cost-effectiveness analysis, *see infra* Part III.B.

67. Both willingness to pay (how much someone is willing to pay to avert a risk) and willingness to accept (how much compensation one would require to accept a risk) can be measured through contingent valuation. VISCUSI, *supra* note 60, at 67-74. Although willingness to accept valuations is typically larger, willingness to pay valuations is generally accepted as the more accurate approach. *Id.* Moreover, after interviewers question individuals repeatedly, willingness to accept levels appear to approach willingness to pay levels. *Id.*

morbidity and mortality. These estimates suggest that individuals would pay anywhere from \$25 to \$145 per day to avoid a headache; from \$40,000 to \$130,000 per year to avoid the morbidity associated with lung cancer;⁶⁸ and from \$10,000 to \$25,000 per year to avoid relatively mild mobility limitations.⁶⁹ These estimates also suggest that individuals would pay anywhere from \$1 million to \$5 million to avoid an unforeseen, instantaneous death.⁷⁰ Moreover, although some of these differences in valuation may result from differences in the economic status of the respondents,⁷¹ very significant differences in valuation persist even when economic status is factored out.⁷² As a consequence, contingent valuation does not yield a single set of monetary figures that can be used to ration care.⁷³

B. Using Choice to Ration Care

As we have seen, moral philosophical analysis does not yield a determinate rationing standard.⁷⁴ When moral theory fails to yield a clear answer to distributive justice dilemmas, one commonly prescribed alternative is democratic political procedures.⁷⁵ Indeed, the macro-allocational decision regarding a state

68. See Tolley et al., *supra* note 61, at 330; see also *id.* at 329-32 (noting that these estimates of willingness to pay to avoid acute and chronic morbidity depend most directly on contingent valuation).

69. *Id.* at 337. This mobility study also indicated that individuals would be willing to pay anywhere from \$5000 to \$12,000 per year to avoid certain limitations in their ability to walk and from \$53,000 to \$131,000 per year to avoid more severe physical limitations. *Id.*

70. *Id.* at 339-40.

71. See Kenkel et al., *supra* note 61, at 75; see also Avorn, *supra* note 59, at 1298.

72. For example, the study that showed large differences in individuals' valuation of mobility limitations, see *supra* note 69 and accompanying text, was based on a version of contingent valuation that factors out economic status. In this approach to contingent valuation, willingness-to-pay values are derived by multiplying a constant dollar figure by the loss in quality of life (typically measured on a scale of 0 to 1, see *infra* Part II.A.2) that individuals associate with various states of dysfunction. See Tolley et al., *supra* note 61, at 336.

73. Moreover, it is not clear that contingent valuation figures correspond to actual behavior or that individuals can assign meaningful dollar figures to various possible states of health. VISCUSI, *supra* note 60, at 72-75. Some commentators have also argued that both contingent valuation and the market data approach are suspect because they ignore apparent distinctions between what individuals are willing to pay as consumers in private market transactions and what they are willing to pay as members of society. Pildes & Sunstein, *supra* note 66, at 79-80, 82. Contingent valuation methodology could, however, certainly be used to ask about willingness to pay as a member of society.

74. Indeed, Allen Buchanan takes the indeterminacy of moral analysis to be an endorsement of his beneficence-based approach to justifying health care redistribution. He notes that, as contrasted with rights, duties of charity and beneficence are "not precisely delineated." Buchanan, *supra* note 21, at 77.

75. See, e.g., EMANUEL, *supra* note 17, at 45-46. Emanuel himself squarely rejects democratic political procedures as a mechanism for allocating health care resources. He argues that, in a liberal polity, citizens cannot fruitfully debate the issue of health care resource allocation. Fruitful debate of resource allocation requires invoking a conception of the good life, a move that the liberal state does not allow. *Id.* at 147-50. An extended discussion of whether a liberal society can achieve agreement on a substantive conception of distributive

budget for health care must be made through democratic political procedures—we must, after all, use a single national budget for all individuals.⁷⁶ At the micro-allocational level, however, we do not necessarily have to rely upon democratic political procedures—we could ration health care through ex ante choice.⁷⁷ In this Part, I argue that because choice affords greater respect to the diversity of health and allocational preferences, and hence to autonomy, than do collective political procedures, we should allow choice. The type of choice that I advocate would not, however, simply involve uncoerced decisionmaking among a variety of available options. Rather, the choice would be reflective. After discussing what this reflective choice would look like, I discuss, and attempt to resolve, various legal and policy difficulties that would arise in a choice-based system.

1. Why Choice Should Be Allowed

At the micro-allocational level, we could choose to ration through democratic political procedures or through ex ante choice. Supporters of using democratic political procedures to make micro-allocational rationing decisions argue that although there exists a variety of justifiable ethical standards for rationing care, we can use political procedures to forge “reasoned agreement” on a collective standard.⁷⁸ This argument is not unpersuasive. If choice were not available as an

justice is beyond the scope of this Article. Unlike Emanuel, however, I do not believe that democratic political procedures in a liberal state must reduce to mere interest group politics. To the contrary, I believe that democratic political procedures must and should be used to make certain determinations, such as the macro-allocational determination of a governmental health care budget. See *infra* notes 95-100 and accompanying text. Emanuel’s sweeping rejection of democratic political procedures forces him to adopt a rather awkward position with respect to this macro-allocational determination. He argues that, rather than make a considered macro-allocational determination, we should simply take as our budget the current level of health care spending. EMANUEL, *supra* note 17, at 185-86. Given the many market distortions that have led to insufficient consideration of cost-benefit trade-offs in health care, however, see, e.g., HAVIGHURST; *supra* note 12, at 100-01; Kenneth E. Thorpe, *Health Care Cost Containment: Results and Lessons from the Past 20 Years*, in *IMPROVING HEALTH POLICY AND MANAGEMENT: NINE CRITICAL RESEARCH ISSUES FOR THE 1990S* at 227 (Stephen M. Shortell & Uwe E. Reinhardt eds., 1992) (discussing the distorting effect of the tax subsidy for health insurance), the current level of health care spending is unlikely to reflect the socially optimal level.

76. In this Article, the general terms “state” or “government” refer primarily to the federal government. I assume that the federal government would need to be primarily responsible for the funding and regulation of a rationing scheme. Coordination at the federal level would be necessary in order to ensure relatively uniform implementation of the scheme.

77. By health care, I mean routine medical procedures and services. I do not include items, such as human organs, that cannot (at least under current law) be bought and sold on the market. How the supply and demand of organs should be regulated is beyond the scope of this Article.

78. See Leonard M. Fleck, *Just Health Care Rationing: A Democratic Decisionmaking Process*, 140 U. PA. L. REV. 1597, 1600-01 (1992). Similarly, Allen Buchanan argues that little can be said about the specification of the content of a decent minimum “prior to the outcome of political processes or extensive empirical research . . .” Buchanan, *supra* note 21, at 77. To

allocational option, using democratic political procedures to make all allocational decisions would be justifiable.⁷⁹ Given that choice is an option, however, we should allow choice. Allowing choice accommodates diverse individual health and allocational preferences⁸⁰ and thus respects autonomy, a value central to moral philosophy generally⁸¹ and to medical ethics in particular.⁸²

To be sure, the autonomy argument does not run in one direction only. Even a choice-based system would impose substantial limitations on autonomy. Perhaps most obviously, autonomy would be limited to the extent that all individuals would be required to contribute to a publicly-funded health care

some extent, this focus on justifiable political processes rather than comprehensive moral theory follows the work of the later Rawls. *See generally* JOHN RAWLS, *POLITICAL LIBERALISM* (1993); John Rawls, *Justice as Fairness: Political Not Metaphysical*, 14 *PHIL. & PUB. AFF.* 223 (1985).

79. Indeed, as I argue below, it is likely that, even within a choice-based system, we would need to make risk-adjustment determinations based on democratic political procedures. *See infra* Part I.B.2.b).

80. For example, both cost-benefit studies, *see supra* Part I.A.4, and cost-effectiveness studies, *see infra* Part II, clearly demonstrate that individuals view the same health states in different ways and make different trade-offs between quality and quantity of life. In addition, philosophical analysis indicates that individuals might choose a variety of rationing methods. *See supra* Part I.A.3. Finally, it is likely that individuals would choose different rationing decisionmakers. For example, while some individuals might prefer rationing through an explicit set of rules, others might prefer to delegate rationing responsibility to a physician working under modest, clearly disclosed financial incentives. Indeed, in the somewhat parallel context of advance directives, it is clear that some individuals prefer to specify their health preferences through the mechanism of a living will while others prefer to designate a proxy to make health care decisions for them at the time of treatment.

81. Respect for autonomy is often associated with deontological reasoning, which gives preeminent importance to the ideal of self-governance as an intrinsic value central to the definition of personhood. *See, e.g.*, IMMANUEL KANT, *GROUNDING FOR THE METAPHYSICS OF MORALS* 41 (James Ellington trans., 3d ed. 1993) ("Thereby is he free as . . . obeys only those laws which he gives to himself."). It has antecedents, however, in both deontological and utilitarian thought. For utilitarians, autonomy generally has instrumental value—an individual's assessment of his own welfare is more likely to be accurate than an assessment by a third party. *See, e.g.*, JOHN STUART MILL, *ON LIBERTY* 142-43 (Penguin Books 1974). It bears mention, however, that some utilitarians, including John Stuart Mill, also appear to accord non-instrumental significance to autonomy. As a consequence, Mill is, for example, categorically opposed even to the voluntary alienation of autonomy in certain contexts (as in a voluntary slavery contract). *See infra* note 111. For a summary of contemporary philosophical discussions on why autonomy has value, *see* Rakowski, *supra* note 44, at 1113-15.

82. Perhaps because of the intensely personal nature of many health care decisions, medical ethicists have given autonomy a particularly prominent role. *See, e.g.*, BEAUCHAMP & CHILDRESS, *supra* note 21, at 120-88 (enunciating principle of respect for autonomy as one of central principles of biomedical ethics); ENGELHARDT, *supra* note 56, at 102-34 (giving autonomy or "permission" preeminent ethical importance). An individual's ex ante exercise of autonomy in choosing a rationing scheme would not, however, be the traditional type of autonomy valued by medical ethicists. For medical ethicists, autonomy has traditionally meant that individuals can make treatment choices without regard to cost after they have developed particular conditions. Given the need for cost containment, however, rationing by ex ante choice is the only means by which to preserve autonomy: the only stage at which individuals can exercise autonomy in a manner consistent with cost-containment goals is ex ante.

system and would also be required to spend the public funding they received on health care (as opposed to other desired goods). This limitation on autonomy would be necessary because other moral principles, such as justice and beneficence, strongly suggest that all individuals should be required to spend *some* amount of money on such care (even if they cannot define exactly what this sum should be).⁸³ Moreover, because of the collective nature of health insurance, it is unlikely that individuals would be able to find a rationing scheme that precisely reflected their every preference.⁸⁴ Nonetheless, the limitations on individual preferences imposed by a choice-based framework that offered a variety of rationing options would be less substantial than those imposed by a single, centrally administered, rationing scheme.⁸⁵

A more fundamental autonomy-based challenge to choice is raised by the argument that citizen participation in the collective political procedures that were used to formulate rationing standards would constitute an expression of autonomy.⁸⁶ Indeed, to the extent that autonomy is less a matter of expressing one's "first-order" preferences and more a matter of using one's "second-order" capacity to reflect critically upon those first-order preferences and desires,⁸⁷ reflective political deliberation by citizens could be seen as more expressive of autonomy than non-reflective individual choice.⁸⁸ Choice need not, however, be

83. See *supra* notes 21-25. To implement this universal spending requirement, all individuals (not just the indigent) would receive public funding to purchase health care. Having a health care program that was not means-tested would also be important because the middle class would then have some stake in keeping the level of public funding adequate.

84. In addition, as discussed further below, a decision to make risk-adjustment determinations through democratic political procedures would place certain limitations on choice. See *infra* Part I.B.2.b.

85. Because my argument in favor of choice-based rationing focuses on accommodating the different ways in which individuals with diverse health and allocational preferences would make rationing trade-offs, it differs in emphasis from arguments in favor of choice made by some market-oriented theorists. Market theorists have tended to focus on how choice could be used to accommodate not different rationing *approaches* but different rationing *levels* (e.g., high premium plans with no rationing, lower premium plans with some rationing, lowest premium plans with extensive rationing). See, e.g., HAVIGHURST, *supra* note 12, at 250 (discussing plans that would incorporate cost considerations to varying extents). In contrast, my focus is on allowing choice within one general level of rationing—in particular, the level of rationing the average individual should expect to face.

86. ELIZABETH ANDERSON, VALUE IN ETHICS AND ECONOMICS 142 (1993) ("Autonomy can be realized on a collective scale through democratic institutions. Collective autonomy consists in collective self-governance by principles and valuations that everyone, or the majority, reflectively endorses.").

87. For a discussion of autonomy that focuses on the distinction between first and second order preferences, see GERALD DWORKIN, THE THEORY AND PRACTICE OF AUTONOMY 108 (1988). See also Harry Frankfurt, *Freedom of the Will and the Concept of a Person*, reprinted in THE IMPORTANCE OF WHAT WE CARE ABOUT 11 (1988) (discussing distinction between lower-order desires—desires to do certain things—and higher-order desires—desires to have or not have certain lower-order desires).

88. See ANDERSON, *supra* note 86, at 162 (arguing that choice-based systems emphasize "exit" over "voice" and thus do not differentiate between "reasoned ideals" and "unreflective wants").

non-reflective. Indeed, the choice-based system that I discuss below⁸⁹ would be grounded in reflective decisionmaking.

Health care also represents an area of resource allocation where an emphasis on individual autonomy does not compromise other significant values. As such, it differs from education, the area of spending where choice has been debated most extensively. In education, it has been argued that while allowing choice would promote individual autonomy, it would interfere with important collective social goals, such as transmitting a common culture, inculcating democratic character, and preparing children for responsible citizenship, that counsel in favor of an educational system that is directed by collective political procedures.⁹⁰ Moreover, it has been argued that because parents might want to deny their children training in argument and reasoning as well as access to various types of knowledge, respecting *parental* autonomy might compromise the future autonomy of their *children*.⁹¹

Whatever merit these two criticisms may have in the area of education,⁹² they do not apply to health care. With respect to the first criticism, although commentators have made compelling arguments that a just society has an obligation to provide some level of redistributed health care to all of its citizens, no one has made a convincing argument that the content of this care should be judged according to a single standard.⁹³ As for the second criticism, it is unlikely that parents *could* choose health plans that would seriously compromise the future autonomy of their children. As discussed further below,⁹⁴ all plans would be required to cover the very basic services most often needed by

89. See *infra* Part I.B.2.a.

90. See, e.g., AMY GUTMANN, *DEMOCRATIC EDUCATION* 68 (1987); Amy Gutmann, *Democratic Schools and Moral Education*, 1 NOTRE DAME J.L. ETHICS & PUB. POL'Y 461, 476-80 (1985).

91. See ANDERSON, *supra* note 86, at 163.

92. It is not clear, for example, why a choice-based educational system could not address these criticisms by requiring all schools to offer a specified core curriculum and allowing choice beyond that core curriculum (for example, choice as to how the curriculum is taught and how the school is run). See Suzanna Sherry, *Responsible Republicanism: Educating for Citizenship*, 62 U. CHI. L. REV. 131, 206-07 (1995).

93. See *generally supra* Part I.A. Because it would respect diverse preferences and beliefs, choice may also be more politically feasible than a single rationing scheme developed through democratic political procedures. The failure of President Clinton's health care reform proposal was, in large part, attributable to the perception that the proposal would eliminate individual health choice. See *generally* Elizabeth McCaughey, *No Exit: What the Clinton Plan Will Do for You*, NEW REPUBLIC, Feb. 7, 1994, at 21. Allowing individual choice among plans would also address to some significant extent the explosive political question of whether publicly funded insurance plans should cover such morally controversial procedures as abortion, physician-assisted suicide, and the like. Individuals who were morally opposed to such procedures would simply enroll in plans that did not fund those procedures. By contrast, President Clinton's proposal, which would have required that all plans offer a certain set of minimum benefits, *supra* note 25, became embroiled from the outset in controversy over whether this set of benefits should include abortion coverage. See, e.g., Nadine Strossen, *National Health Care: Will Big Brother's Doctor Be Watching Us?*, 4 CORNELL J.L. & PUB. POL'Y 438, 440 (1995).

94. See *infra* note 114 and accompanying text.

children—preventive services and inexpensive lifesaving services. Moreover, the best interests standard that governs medical decisionmaking for children generally would also govern the parental choice of a health plan. To the extent that parents did not act in the best interests of their child, their choice of a health plan could be overridden.

Finally, although it could be argued that the administrative costs of a choice-based system would be quite high, these administrative costs might well be offset by the efficiency gains brought about by competition among different plans. Even if efficiency gains were not realized, however, any additional costs would be justified by the increased autonomy allowed by a choice-based system.

2. A Choice-Based System for Rationing

Implementation of a choice-based scheme would begin with a democratic political determination of the government budget for health care.⁹⁵ The details of how this democratic political determination would be made are not essential for my proposal, and I will not discuss them here. One point merits a brief mention, however: informed democratic political discussion, even for the limited purpose of setting a government budget for health care, will be very difficult to achieve. As matters currently stand, the maximalist vision that we will spare no expense to save lives or cure disease⁹⁶ has tended to suppress discussion of the trade-offs between health care spending and spending on other desirable social goods.⁹⁷ Informed democratic discussion about a government health care budget would look very different from current health care spending debates. It would examine explicitly how health care spending compares with other types of spending in terms of promoting health. For example, cost-per-life-saved (or cost-per-quality-adjusted-life-year-gained⁹⁸) analysis could be used to compare the health effects of traditional health care spending (i.e., spending on the types of interventions typically covered by health insurance plans) with the often more marked health

95. Cf. Elhauge, *supra* note 1, at 1493, 1524-26 (arguing for choice within a fixed overall budget).

96. George Tolley et al., *The Use of Health Values in Policy*, in VALUING HEALTH FOR POLICY: AN ECONOMIC APPROACH, *supra* note 59, at 345, 363; see also VICTOR R. FUCHS, THE FUTURE OF HEALTH POLICY 49 (1993) ("That life is priceless need not imply that we will spare no expense to save a life or cure a disease. Yet that myth persists and gives us comfort.").

97. The most prominent recent attempt at comprehensive health care reform, the Clinton Administration's proposed Health Security Act, did not confront the need for health care rationing. Rather, the proposal created a large list of covered services and required coverage of all "medically necessary" interventions that fell within that list of covered services. Health Security Act, H.R. 3600, 103d Cong., § 1141(a)(1) (1994). Although the Clinton Administration apparently intended the limitation of coverage to "medically necessary" interventions to be a rationing principle, Dworkin, *supra* note 45, at 21, "medical necessity" has not proved to be a useful rationing standard. See *supra* note 24.

The difficulty of discussing trade-offs between health care and other desirable social goods is compounded by the fact that there is no single health care budget in need of reform. Instead, health care spending is the sum total of several quite disparate spending sectors—Medicare, Medicaid, managed care, and private, non-managed care, medicine.

98. For a discussion of quality-adjusted-life-years, see *infra* Part II.A.2.

effects of spending in other areas (e.g., public health and the environment, health and safety regulations, even housing and education).⁹⁹ This method of setting a budget for adequate care would parallel proposals that urge the use of cost-per-life-saved analysis to compare, and standardize, regulations governing disparate health and safety risks.¹⁰⁰

Once the state budget had been determined, it would be used to provide health care choices to individuals. Choice could be implemented either through vouchers or through direct government funding of health plans.¹⁰¹ Under the first approach, individuals would receive a health voucher that they would use to purchase coverage in plans administered either by private companies or by the government. If an individual wanted to purchase coverage in a plan that charged a premium greater than the level of her voucher, she could supplement the voucher with private funds.¹⁰² This voucher scheme would have the advantage of interfering least with existing market mechanisms for health care delivery. It might, however, produce a situation where the vast majority of plans catered to individuals who could afford to supplement their vouchers with private funds; those who could not afford to devote private resources to health care might be

99. See Elhauge, *supra* note 1, at 1460 (noting that improvements in housing and education are more highly correlated with improvements in health than health care itself).

100. See generally BREYER, *supra* note 19, at 24-27, 59-72 (using cost-per-life-saved analysis to analyze regulations governing inter alia space heaters, seat belts, aircraft seats, concrete and masonry construction, asbestos occupational exposure, and municipal solid waste landfills, and proposing cadre of civil servants who would standardize such regulation by, for example, setting a maximum cost-per-life-saved figure to be used in all regulation).

The budget-setting process should not, however, focus exclusively on aggregate morbidity and mortality figures; rather, it should include contextual information about morbidity or mortality. See *supra* notes 63-64 and accompanying text. For suggestions on how cost-effectiveness analysis could be expanded to include contextual information about morbidity and mortality, see *infra* Part III.A.2. For other suggestions, see Pildes & Sunstein, *supra* note 66, at 72-75 (outlining methods for supplementing information on health end states with contextual information). The budget-setting process should also confront squarely the complicated valuation issues that would arise because the diverse sectors of spending being compared would have an impact not only on health but on other, quite disparate, social goods. For example, expenditures on environmental cleanup and education would obviously have an effect not only on health but also on the overall state of the environment and the educational system itself. These disparate effects should not be aggregated into a single benefit valuation; rather, they should be examined separately. See *id.* at 64-66 (arguing that qualitatively different effects should not be aggregated). The theoretical concern underlying proposals for looking at effects in a disaggregated fashion is that such diverse social goods as (say) better health, a cleaner environment, and improved education are not commensurable—that is, they cannot be compared on a single scale. For a detailed discussion of the question of commensurability, see *infra* Part III.A.3.

101. Under either approach, the level of spending per individual would not be means tested. See *supra* note 83.

102. Some proponents of choice in education have similarly argued that parents should be given vouchers that they could use, either exclusively or in conjunction with private funds, to choose between public and private schools. U.S. DEP'T OF EDUC., CHOOSING BETTER SCHOOLS: THE FIVE REGIONAL MEETINGS ON CHOICE IN EDUCATION 8 (1990).

very restricted in their choice of plan.¹⁰³ An alternate approach would involve direct government funding of participating health plans—both public and private plans would receive funds directly from the government for each individual they enrolled.¹⁰⁴ Participating plans would be required to accept all individuals who wished to enroll in their “basic” package of services. Individuals could also use their private funds to purchase any additional coverage that they desired.

For any given geographic area or population, the government (or some government-designated entity) would be responsible for selecting the plans that would be available and for managing competition between them. The competition manager would ensure, for example, that all available plans satisfied certain criteria of financial soundness. Significantly, however, the competition manager would not require that all plans offer a particular set of services or use a particular rationing scheme. Rather, the competition manager would allow a variety of different benefit options and rationing schemes.¹⁰⁵ Indeed, to the extent that private insurance companies did not generate a sufficiently large number of rationing schemes, the competition manager would administer plans with rationing schemes not provided by private companies.¹⁰⁶ As a consequence, individuals would have access to a variety of rationing schemes; these might include, for example: schemes with different lists of covered services (and services not covered); schemes that did not specifically exclude any services but required significant deductibles and copayments at each level of expenditure;¹⁰⁷ schemes in which physicians operating under modest, clearly disclosed, financial pressures were given rationing responsibility; schemes that used random allocation or some combination of utilitarian criteria and random allocation;

103. This problem could, of course, be addressed through price caps. The government could require that, for any given individual, a plan’s “basic” package of services be available at a premium no greater than the level of that individual’s voucher. Such price caps would, however, be equivalent to simply requiring that plans be required to accept all individuals who wished to enroll in their “basic” package of services. I discuss this approach in the text, see *infra* text following note 112.

104. John Chubb and Terry Moe make a similar proposal in their argument for school choice. See JOHN E. CHUBB & TERRY M. MOE, *POLITICS, MARKETS, AND AMERICA’S SCHOOLS* 219 (1990).

105. In contrast, managed competition advocates have traditionally argued in favor of requiring relatively uniform benefits. They note that such uniformity would discourage risk selection problems and facilitate individuals’ ability to make informed choices between plans. See HAVIGHURST, *supra* note 12, at 36-37 (summarizing arguments). For similar reasons, President Clinton’s health care proposal would have required all plans to offer a fairly extensive set of uniform benefits. See *supra* notes 29, 97. I address the problems of risk selection and of informed choice between plans *infra* Part I.B.2.a-b.

106. Both federal and state competition managers might be involved in administering such plans.

107. This graduated scheme for copayments and deductibles would be necessary because a scheme that required a copayment or deductible to be paid only once (and provided all health services free of charge after the initial copayment or deductible) would not contain costs sufficiently. A graduated scheme would, of course, be vulnerable to the same criticisms as ordinary copayment and deductible schemes, namely that such schemes undermine the function of health insurance by forcing individuals to consider costs at a time when their decisionmaking capacity has been compromised by illness.

schemes that rationed according to greatest need; and benefit maximization schemes (described further in Part II below) that did not exclude any particular category of service but excluded particular interventions based on a calculation of their costs and health benefits.¹⁰⁸

a. A Model of Reflective Choice

In an area as complicated (and as important) as health care, one obvious difficulty with choice is the possibility that individuals will make foolish choices, choices that reflect insufficient critical reflection on their health care priorities and on the ends that health care promotes. Indeed, because autonomy depends not simply on the ability to act on one's preferences but, perhaps even more importantly, on the ability to shape those preferences through critical reflection,¹⁰⁹ a choice-based system that allowed ill-considered choices might be seen as *undermining* rather than promoting autonomy. The concern that individuals will choose foolishly is particularly acute in the case of rationing choices, which must be made *ex ante*: until they are faced with a particular medical situation, many individuals may find it difficult to consider their health care priorities carefully.¹¹⁰

One response to this concern would be to limit the range of allowable choices. Some narrow restrictions on choice would, for example, be appropriate as a means of *protecting* autonomy in the long term. Thus *ex ante* rationing choices that contemplated very serious and irreversible deprivations of liberty might be disallowed.¹¹¹ In addition, choices that bound individuals for excessively long

108. Many of these rationing options are, of course, generated by the approaches to specifying adequate care discussed *supra* Part I.A. The viability of these options underscores the point that the various approaches to defining adequate care are not necessarily incorrect; rather, they are simply indeterminate.

109. See *supra* note 87 and accompanying text.

110. The concern that individuals are incapable of making *ex ante* rationing choices that are adequately reflective may be responsible, at least in part, for the current reliance on *sub rosa*, physician-centered rationing. See *supra* notes 8-14 and accompanying text. For a discussion of the problem of adequate reflection in the context of making *ex ante* decisions regarding advance directives, see Allen Buchanan, *Advance Directives and the Personal Identity*, 17 PHIL. & PUB. AFF. 277 (1988). For a general discussion of problems with *ex ante* choices that bind for a long period of time, see DEREK PARFIT, REASONS AND PERSONS 326-29 (1984). See also *infra* note 112 and accompanying text (discussing limitations on the range of *ex ante* choices).

111. See, e.g., Gerald Dworkin, *Paternalism*, in MORALITY AND THE LAW 107, 118 (Richard A. Wasserstrom ed., 1971) (noting John Stuart Mill's classic rejection of voluntary slavery on the grounds that "[t]he principle of freedom cannot require that he should be free not to be free" and arguing that paternalism can be justified when it preserves "a wider range of freedom for the individual in question"). Autonomy-enhancing restrictions on certain types of voluntary contracts might be justified on non-paternalistic grounds as well. A Kantian might argue, for example, that autonomy is inherent in every human being; it is not something human beings can alienate. See Joel Feinberg, *Legal Paternalism*, in PATERNALISM 3, 13 (Rolf Sartorius ed., 1983). From a more pragmatic standpoint, it could be argued that although voluntary contracts that seriously restrict autonomy are acceptable in principle, legal mechanisms for testing voluntariness in all cases would be extremely cumbersome. The least risky course would

periods of time (say over three to five years) should probably be disallowed as destructive of autonomy in the long term: disallowing such choices would address the concern, expressed by some commentators, that allowing individuals to make choices that bind their future selves is problematic because individuals view the utility of their future selves as distinct from the utility of their current selves and therefore do not value their future selves sufficiently.¹¹² Limitations on choice would also arise from the enforcement of anti-discrimination principles. Choice should not serve as a defense to charges that insurance plans discriminate on the basis of certain suspect characteristics such as race, sex, age, or disability.¹¹³

Although the aforementioned limitations on choice would be justifiable (and, indeed, a good idea), significant limitations on choice would run the risk of overriding fundamentally divergent health preferences. Similarly, although we could of course use democratic political procedures to decide upon some very minimal set of services (e.g., vaccinations, preventive care, inexpensive lifesaving interventions) that all plans would be required to offer, significant reliance on political procedures would run the risk of overriding individual autonomy.¹¹⁴

The most promising approach would therefore focus not so much on the ultimate choice but, rather, on the process by which the choice was made. By encouraging critical reflection in the choice procedure, this approach would guard against foolish or ill-considered choices. Critical reflection would occur on two levels, the first individual and the second collective. Individual reflection would occur at the time of enrollment, as potential subscribers weighed the relative advantages and disadvantages of plans with competing philosophies of rationing. Such reflection would be fostered through various forms of governmental regulation and oversight. First, and most importantly, all plans that

therefore be to assume nonvoluntariness in every case. *See id.* at 14-16.

112. *See* Elhauge, *supra* note 1, at 1517. *See generally* POSNER, *supra* note 66, at 84-95. Some commentators use hypothetical consent analysis to arrive at somewhat similar restrictions on choice. *See, e.g.,* Elhauge, *supra* note 1, at 1540 (arguing that we can use hypothetical consent to rule out certain choices to which it could be argued that no rational individual would consent). In my view, however, the fundamental indeterminacy of hypothetical consent analysis makes this approach unworkable. *See supra* Part I.A.3.

113. To some extent, the arguments for protecting autonomy in the long term by disallowing certain choices also militate in favor of disallowing the choice of discrimination. A more forceful argument for disallowing consensual discrimination, however, is that consent does not vitiate the moral wrong of discrimination. Even if, under the principle of *volenti non fit injuria* ("To one who consents no harm is done."), no harm is done to the individual against whom the discrimination occurs, discrimination harms the class to which the individual belongs as well as society generally. *Cf.* Feinberg, *supra* note 111, at 13 (arguing that the institution of slavery harms society generally). For a discussion of how anti-discrimination principles would apply to the choice of a cost-effectiveness-based scheme, *see infra* Part IV. For general discussion of how discrimination principles apply to insurance schemes, *see, for example,* KENNETH S. ABRAHAM, *DISTRIBUTING RISK: INSURANCE, LEGAL THEORY, AND PUBLIC POLICY* 64-100 (1986); Leah Wortham, *Insurance Classification: Too Important to Be Left to the Actuaries*, 18 U. MICH. J.L. REFORM 349, 350 (1986).

114. *See supra* notes 80-82 and accompanying text.

received government funds would be required to disclose, in a thorough and readily comprehensible fashion, the precise scheme they used to ration care.¹¹⁵ Plans would be required to disclose not only their formal rationing criteria but also to give concrete illustrations of the manner in which these criteria would be applied in various medical scenarios. The government would be responsible for monitoring the content and form of the disclosure.¹¹⁶ Second, the government would assist individuals in assessing the risks and benefits of different rationing schemes. It would, for example, offer extensive informational and counseling services to individuals deciding between these schemes.¹¹⁷ Third, the government would require that established plans provide potential subscribers with data on their "medical loss ratio" (the percentage of premium dollars that went to expenditures on health care) and on their performance, particularly their performance in terms of medical outcomes. Indeed, the government itself might be involved in the collection and dissemination of such outcomes information.¹¹⁸

Governmental regulation could also foster reflection at the collective level. Plans could be required, for example, to have subscriber representatives on the governing bodies that made allocational decisions. Thus basic allocation policies could be further developed and elaborated with the assistance of subscribers to the plans. Important elaborations of allocation policies might be subject to vote by all subscribers.

Within the framework outlined here, individual choice between plans with different approaches to rationing would do more than simply reflect the diversity of existing allocation preferences. Rather, such choice would help individuals

115. As discussed in *supra* note 11 and accompanying text, health plans are generally not required to disclose information about the manner in which they ration care. There is, however, much precedent for requiring such disclosure. For example, under current law, although HMOs are not required to disclose the financial incentives they give physicians to ration care, they are required to disclose a variety of other information. 42 C.F.R. § 417.124(b) (1996) (requiring "full and fair disclosure" of participating providers, service area, benefits, and procedures to be followed in obtaining benefits). Similarly, in areas other than health care, the government routinely requires that contracting parties disclose information. *See, e.g.*, Consumer Credit Protection Act, 15 U.S.C. §§ 1601-1693 (1994) (requiring disclosure of standardized finance terms in credit transactions or offers to extend credit); Interstate Land Sales Full Disclosure Act, 15 U.S.C. §§ 1701-1720 (1994) (mandating disclosure of certain information to purchasers of land in interstate transactions).

116. In other areas of health care, the federal government routinely monitors the accuracy of claims made. For example, the government monitors the accuracy of claims made with respect to drugs and medical devices, both in labeling, *see, e.g.*, 21 U.S.C. § 352(a) (1994), and in advertising, *see* 21 U.S.C. § 352(n) (1994).

117. Organizations that provided these informational and counseling services would no doubt emerge in the private sector. A public role would, however, be important for those individuals who could not afford to pay the fees charged by private organizations.

118. *See, e.g.*, Mark V. Pauly, *The Public Policy Implications of Using Outcomes Statistics*, 58 BROOK. L. REV. 35, 46-47 (1992) (arguing that outcomes information on health providers is a public good and that legal requirement or public funding may therefore be needed to generate and disseminate such information).

think about what their allocation preferences *should be*.¹¹⁹ In contrast, current methods of rationing give individuals neither incentive nor opportunity to evaluate, and decide upon, competing uses of resources.¹²⁰

Of course, some individuals might prefer not to play an active role in determining their health care priorities *ex ante*. These individuals would also, however, be well served by the proposal offered here. Various rationing alternatives could serve as a default option: for example, one possible default could be a plan in which rationing responsibility was delegated to physicians working under modest, clearly disclosed financial incentives. Alternatively, the

119. Compare Suzanna Sherry, *Responsible Republicanism: Educating for Citizenship*, 62 U. CHI. L. REV. 131, 202 (1995) (noting that, if choice in schooling is allowed, the very act of choosing a school will be educational).

120. My argument in favor of reflection borrows to some extent from Ezekiel Emanuel. In his proposal for a system of health care rationing in which individuals would use vouchers to choose between "community healthy programs" ("CHPs") with different rationing philosophies, Emanuel stresses a version of collective reflection that he terms deliberation. See generally EMANUEL, *supra* note 17, at 179-83. Emanuel's CHP proposal differs, however, from the proposal presented here in two very important respects. First, while Emanuel's proposal focuses exclusively on collective reflection, the proposal presented here stresses reflection at both the individual and collective level. Second, Emanuel rejects the idea of a "Jeremy Bentham CHP," in which decisions about medical service provision are made through cost-benefit evaluation. He argues that, under such a CHP, there would be no need for reflection regarding health values—economists and utilitarian philosophers would simply come up with the cost-benefit ranking and announce it to the CHP's members. *Id.* at 219-20. Emanuel's characterization of a "Jeremy Bentham CHP" misses the mark in several ways. Perhaps most obviously, it ignores the fact that certain types of cost-benefit analysis, particularly advanced methods of contingent valuation, explicitly attempt to incorporate lay values. These values are elicited through lengthy interview sessions that provide information, give context, and allow individual reflection. See Tolley et al., *supra* note 59, at 290-94. Moreover, medical cost-effectiveness analysis, which is derived from cost-benefit analysis, is founded on lay valuations of health states. Sophisticated methods of medical cost-effectiveness analysis use in-depth interviews in a manner that is designed to yield reflective valuations. See *infra* note 148 and accompanying text. In addition, although cost-benefit and cost-effectiveness analyses have not typically been used as bases for collective reflection, there is no reason they could not be so used. In particular, cost-effectiveness analysis could incorporate collective reflection about the values that should be assigned to various health states. See *infra* notes 175-76 and accompanying text.

Several other difficulties with Emanuel's proposal merit mention. Emanuel appears to accept race, sex, and religion-based exclusion criteria so long as these criteria are used to perpetuate the values of the CHP and not for discriminatory reasons. EMANUEL, *supra* note 17, at 239. This acceptance is problematic. Consider the example of a race-exclusive CHP. It is quite likely that *some* member of another race would share that CHP's health care values. Exclusion of that individual would be racially discriminatory. In any event, the values of the CHP would be more directly promoted by excluding all persons who disagreed with those values, irrespective of race, religion, or sex. Under this Article's proposal, all rationing plans would be subject to non-discrimination requirements. Finally, although Emanuel's proposal does indicate that individuals who are less healthy, such as the elderly, would need to receive a larger federal subsidy than other individuals, *id.* at 187, it does not consider thoroughly the question of risk adjustment; as discussed *infra* Part II.B.2.b, however, risk adjustment should probably be part of any choice-based proposal.

plan that was chosen by the largest number of individuals could serve as the default option.

b. Risk Adjustment

Under a choice-based rationing system, if insurance plans received the same payment for each individual they enrolled, they would have no incentive to offer coverage packages that included the types of expensive services needed by high-risk individuals (or at least by high-risk individuals who did not have private resources to pay for those services). Insurance companies might, for example, refuse to provide any coverage for a variety of conditions (e.g., AIDS, certain types of cancer) that are expensive to treat.

These difficulties could be mitigated if the level of payment associated with any given individual (whether given to the individual in voucher form or given to the health plan in which the individual enrolled) were "risk adjusted"—that is, adjusted for the individual's likelihood of incurring medical expenses in the future.¹²¹ With risk adjustment, unhealthy individuals would receive larger

121. Although risk-adjustment methodology is still in the early stages of development, preliminary research suggests that the health expenditures of one large group of high-risk individuals, individuals with disabilities, are quite predictable. See Richard Kronick et al., *Making Risk Adjustment Work for Everyone*, 32 *INQUIRY* 41, 41-50 (1995). Such predictability bodes well for the development of an accurate risk-adjustment system.

There is, however, some controversy over exactly which factors should be used to predict a greater likelihood of incurring medical expenses. Disability and age are two relatively uncontroversial factors. A recent Republican proposal for Medicare choice tied risk adjustment to these factors. See RICHARD EPSTEIN, *MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE?* 178 (1997) (discussing proposal). Whether risk adjustment should invoke historically invidious classifications such as race (and, to some extent, sex) is more controversial. See *id.* at 180 (noting that bill included sex but not race as a factor in risk adjustment). Although I do not take a position on this question, one point is clear. Adjustments for race and sex are needed only to the extent that insurance companies are allowed to make actuarial classifications based on these characteristics. Thus, for example, in our current system, adjustments for race would not be needed. See Jill Gaubling, Note, *Race, Sex, and Genetic Discrimination in Insurance: What's Fair?*, 80 *CORNELL L. REV.* 1646, 1659-60 (1995) (noting that insurance companies currently do not charge differential rates based on race, even in areas such as life insurance where race has a substantial actuarial impact). The question of whether risk adjustment should include area of residence as a variable is also controversial. The data are fairly clear, however: even controlling for medical risk, it appears that more resources are required to provide health care to residents of low-income communities than to residents of middle-income communities. See Kronick et al., *supra*, at 52. Risk adjustment might, therefore, have to include an adjustment based on area of residence.

Risk adjustment should probably not include, however, disabilities caused or aggravated by such "self-inflicted" risks as smoking, excessive drinking, eating fatty foods, and the like. The central problem with such risk adjustment would be moral hazard. The moral hazard argument against risk adjustment for self-inflicted illness is that such adjustment encourages individuals to engage in risky behavior. Although the boundary between self-inflicted illness and other illness has become slightly blurred as evidence emerges that behavioral tendencies may have some genetic basis, the moral hazard argument remains a compelling one. The refusal to risk-adjust for certain disabilities might, however, conflict with laws prohibiting discrimination against the disabled. For a general discussion of how disability laws apply to health care

amounts of government funds than healthy individuals. Insurance companies would then have a financial incentive to design rationing schemes tailored towards the needs of unhealthy individuals.¹²²

Risk adjustment would also address adverse selection problems that might be exacerbated by allowing choice. As a general matter, adverse selection in health insurance occurs because individuals who know they are at risk for particular health problems are disproportionately likely to seek insurance coverage for those problems. Because these individuals do not disclose the fact that they are at risk, however, insurance plans charge them an ordinary premium, rather than a premium commensurate with their level of risk. When large numbers of these unhealthy individuals enroll and consume medical resources, insurance premiums rise, and healthy individuals who do not need the coverage exit the insurance plan. Because the plan no longer has healthy enrollees to subsidize the cost of unhealthy enrollees, premiums then rise even further.¹²³

If all plans are required to offer a standard minimum benefits package, the risk of adverse selection is mitigated.¹²⁴ Individuals with particular health problems cannot seek coverage that is particularly generous for those problems; by the same token, healthy individuals cannot exit into low-premium, low-coverage plans. Under a rationing scheme that allowed significant choice, the risk of adverse selection would, by contrast, be high. Individuals would gravitate to plans that covered the types of ills to which they would be subject. Risk adjustment could, however, reduce adverse selection problems. Individuals who knew that they had particular health problems would have an incentive to disclose these problems: by disclosing these problems, they could receive greater funding. Moreover, this additional funding would make it financially feasible for the health plans in which these unhealthy individuals enrolled to fund the services needed by these individuals without raising premiums for everyone else covered under the plan. In economic terms, because all risks would have been accurately priced, there would be no incentive for low-risk individuals to leave the plan.¹²⁵

rationing scheme, see discussion *infra* Parts IV.C.1-2.

122. Einer Elhauge has made a somewhat similar argument regarding the value of risk adjustment in a choice-based rationing scheme. See Elhauge, *supra* note 1, at 1533-34. Elhauge argues, however, that hypothetical consent analysis can help guide the making of risk-adjustment determinations. *Id.* at 1540. In contrast, I argue that because hypothetical choice is fundamentally indeterminate, all risk adjustment must be done through democratic political procedures.

123. For descriptions of adverse selection in insurance generally, see, for example, KENNETH ABRAHAM, *INSURANCE LAW AND REGULATION: CASES AND MATERIALS* 1-3 (1990); Jon D. Hanson & Kyle D. Logue, *The First-Party Insurance Externality: An Economic Justification for Enterprise Liability*, 76 *CORNELL L. REV.* 129, 138-41 (1990).

124. The failed Clinton health care proposal would, for example, have required all plans to offer a rather extensive minimum set of benefits. See *supra* notes 29, 97.

125. A relatively long enrollment period would also reduce adverse selection problems. Because individuals would know that they could not switch out of their insurance plan soon after a new medical problem arose, they would be more likely to insure themselves against a wide variety of ailments. The powerful arguments against having individuals make irrevocable choices that will bind them in the distant future, see *supra* text accompanying note 112,

Risk adjustment is not, however, a neutral or objective calculation. To the contrary, risk adjustment necessarily involves value-laden and controversial choices about how much care society should fund for any given individual. For example, deciding whether risk adjustment for a patient in the later stages of AIDS should cover the cost of expensive interventions that extend life (the expansive approach) or the cost of palliative care only (the parsimonious approach) clearly involves a determination about how much health care society owes to that patient. As a consequence, it could be argued that the problem of risk adjustment mirrors the general rationing dilemma. Indeed, because the option of choice is not available with respect to the problem of risk adjustment, risk adjustment could be seen as presenting an even more acute difficulty.

Given this state of affairs, we could choose either to dispense altogether with risk adjustment or to make risk-adjustment determinations through democratic political procedures. The choice is by no means an easy one. In the final analysis, however, some level of risk adjustment is probably necessary. Absent some level of risk adjustment, it is likely that many high-risk individuals would receive no coverage whatsoever for their ailments. This result would be problematic: although adequate care does not admit of a single specification, it seems clear that a system that excluded large numbers of individuals from coverage would be inconsistent with almost any specification of adequate care. In addition, at a practical level, any choice-based system that did not include some risk adjustment would be faced with serious adverse selection problems.

Moreover, although risk-adjustment determinations based on democratic political procedures would clearly be in tension with choice, they could be made in a manner that allowed for significant choice.¹²⁶ Allowing such choice would require that risk adjustment reflect a rough compromise between the parsimonious and expansive approaches to adequate care discussed above. A compromise would not constrain unduly the choices available to individuals who needed health care but did not have private resources. At the same time, a compromise would not force others to support, through their tax dollars, a particular individual's expansive vision of adequate care. The compromise should err, however, on the side of parsimony. Erring on the side of parsimony is preferable for at least three reasons. First, some individuals who had an expansive vision of adequate care could use their private resources to fund that vision. There would be no need to force others to subscribe to that vision. Second, liberal use of risk adjustment—for example, calculating the adjustment so that it would cover the cost of all, or even most, beneficial care that could be provided to high-risk individuals—would vitiate cost containment.¹²⁷ Finally, the

suggest, however, that the enrollment period should not be over three to five years.

126. See Elhauge, *supra* note 1, at 1534 (arguing that risk adjustment can be consistent with a choice-based scheme).

127. Such expansive use of risk-adjustment methodology would essentially turn risk adjustment into a system that prepaid for all beneficial care. See EPSTEIN, *supra* note 121, at 179-81.

considerable literature supporting rationing of health care based on age¹²⁸ suggests that parsimony may be a particularly justifiable approach for elderly individuals.¹²⁹

c. Legal Obstacles to Rationing Through Choice

Contracts between insurance plans and consumers that explicitly provided for particular types of rationing would be in tension with prevailing judicial approaches to insurance contract interpretation and malpractice liability. Indeed, these legal difficulties are a major reason that the market has not evolved naturally towards a system based on explicit rationing contracts (and has relied instead on *sub rosa* mechanisms of rationing).¹³⁰ In this Part, I discuss these prevailing norms. I aim to demonstrate that the system of rationing choices proposed here would address the concerns regarding consumer vulnerability that underlie these norms and thereby obviate the need to invoke the norms.

128. See, e.g., MENZEL, *supra* note 20, at 92-93; Fried, *supra* note 21, at 32 (suggesting that preference should be given to those illnesses that strike in the prime of life); see also RAKOWSKI, *supra* note 44, at 320-21 (arguing that justice requires preferring individuals who have the bad "brute luck" of having illnesses that strike early in life to individuals who have the good "brute luck" of avoiding those illnesses until later in life). Norman Daniels and Daniel Callahan have made particularly influential arguments that age is a relevant factor for resource allocation. Daniels uses a Rawlsian hypothetical choice approach to assert that a prudent allocator under the veil of ignorance would forego the possibility of living beyond the normal life span in order to maximize her chances of achieving that life span. See *supra* note 47 and accompanying text. Compare DANIELS, *supra* note 21, at 103-05 with POSNER, *supra* note 66, at 90 (suggesting a veil of ignorance but not reaching a conclusion as to what the allocator under the veil of ignorance would choose). While Daniels argues from a Rawlsian standpoint, Daniel Callahan reaches a similar conclusion from a communitarian standpoint. Daniel Callahan asserts that once an individual has reached her "natural life span" in her late seventies or early eighties, society's goal should be to relieve suffering rather than to pursue life-extending care. DANIEL CALLAHAN, *WHAT KIND OF LIFE: THE LIMITS OF MEDICAL PROGRESS* (1990). Callahan argues that this view is consistent with a "fitting understanding of old age and death as part of the life cycle." *Id.* at 141. Of course, neither Daniels's nor Callahan's argument is dispositive on the question of how age should be viewed. As Daniels admits, because his view on how prudential contractors would allocate scarce resources is open to dispute, the ultimate choice on how age should be viewed will turn not on considerations of justice but on democratic political considerations. *Id.* at 107-08.

129. Admittedly, a democratic political process that cannot even forge agreement on relatively minor Medicare reform, see generally EPSTEIN, *supra* note 121, at 174-81, may not be able to make controversial risk-adjustment determinations. In particular, given the political power of the elderly, it may be difficult to develop a risk-adjustment procedure that is relatively parsimonious with respect to the elderly. Risk-adjustment determinations might, however, be made by a commission that was insulated from the direct pressures of the political process. Oregon used this type of commission to formulate its prioritization scheme for Medicaid services. The task of the Oregon Health Services Commission was to elicit public values regarding health care and to use these values to determine what services should be covered by Medicaid. See generally *infra* Part II.B.1. Similarly, the task of the risk-adjustment commission would be to incorporate public values into risk-adjustment determinations.

130. HAVIGHURST, *supra* note 12, at 21-22.

In assessing insurance contracts generally, courts typically analyze contract ambiguities by applying a *contra proferentum* (against the proffering party) rule of interpretation. Moreover, with respect to health insurance contracts in particular, courts have been quite aggressive in deeming “ambiguous” clauses that exclude coverage for treatment that is experimental, harmful, or of no medical benefit (or in finding that particular treatments do not fall within the scope of these exclusionary clauses).¹³¹ If courts followed a similar approach in the much broader context of rationing—aggressively seeking out ambiguities in rationing rules and interpreting these ambiguities against the insurer—it is unlikely that cost containment by choice could be implemented. Because rationing rules would have to cover a huge variety of possible medical situations, many of which could not precisely be anticipated, it might be difficult for them to apply with perfect clarity in any given situation. Construing all ambiguities against the insurer would vitiate the cost containment that the insured sought to achieve by enrolling in a plan that rationed care.

The *contra proferentum* rule has its origin in concerns about the nonproffering party’s lack of meaningful choice or lack of information in agreeing to the bargain in question.¹³² The publicly-funded system of rationing described here would, however, give individuals a substantial number of meaningful rationing choices as well as substantial information about these choices.¹³³ Within such a system, there would be no need to apply the *contra proferentum* rule. Rather than mechanically assuming that the insured did not consent to a particular rationing

131. See generally Hall & Anderson, *supra* note 28, at 1645-57 (discussing judicial treatment of such clauses). In addition, juries have awarded large sums in damages for tort actions that accompany breach of insurance contract claims—for example, tort actions alleging bad faith in the denial of insurance benefits or intentional infliction of emotional distress through the denial of insurance benefits. In one prominent case, the insurer declined to cover high-dose chemotherapy/autologous bone marrow transplantation for the treatment of the insured’s breast cancer. The insurer argued that the treatment was excluded under a contractual exclusion for experimental treatments. The insured’s family sued for breach of contract as well as intentional infliction of emotional distress and bad faith in its breach of contract. The jury awarded the plaintiffs approximately \$89 million, including \$77 million in punitive damages, on the tort aspects of their claims. See Erick Eckholm, *\$89 Million Awarded Family Who Sued H.M.O.*, N.Y. TIMES, Dec. 30, 1993, at A1 (discussing California case of *Fox v. HealthNet*).

132. See David Charny, *Hypothetical Bargains: The Normative Structure of Contract Interpretation*, 89 MICH. L. REV. 1815, 1854-55 (1991). The party lacking choice or information may be perceived to have entered into a contract of adhesion. *Id.* (citing Friedrich Kessler, *Contracts of Adhesion*, 43 COLUM. L. REV. 629, 638-40 (1943)).

133. See *supra* notes 105-08, 115-18 and accompanying text (discussing disclosure requirements for rationing schemes, governmental provision of information with respect to different rationing schemes, and governmental monitoring of the availability of such schemes). Moreover, as discussed in *supra* text accompanying notes 112, choices that involved extreme deprivations would be disallowed. See also RESTATEMENT (SECOND) OF CONTRACTS § 208 (1979) (“If a contract or term thereof is unconscionable at the time the contract is made a court may refuse to enforce the contract.”). Two other features of the choice-based system would also make unconscionable choices unlikely: first, the fact that individuals would be given public funds to spend on health care and, second, the requirement that all plans cover a set of very basic services, such as vaccinations, preventive services, and inexpensive lifesaving interventions.

trade-off, courts would examine whether the trade-off was consistent with the overall rationing philosophy of the health plan and whether this rationing philosophy was fully disclosed to the insured before she enrolled.¹³⁴

Traditional approaches to malpractice liability, in particular the assumption that medical care should be judged according to a unitary negligence standard formulated without regard to cost, would also pose a challenge for choice-based rationing. Contrary to traditional malpractice law, rationing based on choice assumes not only that cost considerations must be incorporated into the standard of care but also that individuals should be allowed to contract for the manner in which they would prefer to have cost considered as a factor. An approach to tort liability consistent with rationing based on choice would thus look to the terms of the rationing contract: to the extent that the rationing contract provided a specific mechanism for making cost-benefit trade-offs in the case at hand, the terms of the contract would govern.¹³⁵ Such an approach would represent a significant departure from current practices—because of concerns about information asymmetry between consumers and providers and lack of real choice on the part of consumers, courts have typically been wary of attempts to alter by contract the applicability of the unitary malpractice standard.¹³⁶ Under the rationing system proposed here, however, such concern would not be warranted: consumers would have had the opportunity to make a knowledgeable and meaningful choice between plans with different approaches to rationing.¹³⁷

134. Clark Havighurst has suggested that individuals could explicitly contract to waive the *contra proferentum* rule. HAVIGHURST, *supra* note 12, at 182-83. Explicit contractual waivers would only be necessary, however, if courts continued to apply the *contra proferentum* rule.

Even if the *contra proferentum* rule were not strictly applicable (as it is not, for example, in self-funded health plans governed by ERISA that bestow discretionary authority to interpret the plan upon the plan administrator or fiduciary, *see, e.g.*, *Winters v. Costco Wholesale Corp.*, 49 F.3d 550, 554 (9th Cir.); *O'Neil v. Retirement Plan for Salaried Employees of RKO General, Inc.*, 37 F.3d 55, 61 (2d Cir. 1994)), plans with rationing criteria that were particularly vague (e.g., plans that delegated authority to physicians or utilization reviewers to make rationing decisions on a case-by-case basis) might nonetheless fare poorly in the courts. Courts might treat coverage decisions by these plans more favorably, however, if the plans had fairly elaborate internal appeal procedures that accorded sufficient consideration to patient interests. *See* HAVIGHURST, *supra* note 12, at 323. For a discussion of how such appeal procedures might operate, *see id.* at 201-02.

135. To the extent that the contract did not specify a precise mechanism for making rationing trade-offs (for example, if the rationing scheme used by a plan involved giving physicians modest financial incentives to make cost-benefit trade-offs as they saw fit), the tort claim could be governed by the testimony of physicians who practiced in similar rationing contexts. For a similar suggestion, *see* Jonathan J. Frankel, Note, *Medical Malpractice Law and Health Care Cost Containment: Lessons for Reformers from the Clash of Cultures*, 103 YALE L.J. 1297, 1326 (1994).

136. *See generally* Maxwell J. Mehlman, *Fiduciary Contracting Limitations on Bargaining Between Patients and Health Care Providers*, 51 U. PITT. L. REV. 365 (1990).

137. Of course, if the fundamental changes in the structure of health care delivery proposed here did not convince courts to alter their approaches to insurance contract interpretation and malpractice liability, legislative action would be warranted. Indeed, legislative action that ensured the enforceability of rationing contracts would probably encourage the creation of an insurance market based on such contracts.

Several specific points about a contractual approach to tort liability bear mention. First, contractual variations in the standard of care would be allowed only with respect to the standard of resource use (i.e., the menu of technological interventions available), and not with respect to the standard of medical competence (i.e., the degree of skill with which the physician performs particular procedures).¹³⁸ Second, with respect to claims involving the standard of resource use, a default presumption of health plan enterprise liability (as contrasted with individual physician liability) might be warranted; such a presumption would reflect the reality that, in any given medical situation, the level of medical resources expended would largely be governed by the consumer's contractual agreement with the health plan.¹³⁹

Thus far I have made a threshold argument in favor of a system of ex ante rationing choices. I now turn to the focus of this Article: a proposal for rationing based on the ex ante choice of cost-effectiveness. After outlining the elements of cost-effectiveness analysis, and the manner in which it could be offered as a rationing choice, I argue that although cost-effectiveness itself may be very controversial, the ex ante choice of cost-effectiveness should be a highly desirable one for many individuals, including individuals who consider themselves opposed to utilitarian principles.

II. CHOOSING COST-EFFECTIVENESS: A PROPOSAL

In the health care arena, cost-effectiveness analysis is an analytic tool that can be used to compare, and prioritize, medical interventions. In contrast to cost-benefit analysis, which measures benefit in terms of dollars—and thus, as discussed above,¹⁴⁰ can be used to determine whether the benefits of a certain intervention justify its costs—medical cost-effectiveness analysis measures benefit in units known as quality-adjusted-life-years (“QALYs”) and can be used only to compare health interventions in terms of their cost-per-QALY ratios.¹⁴¹

138. See, e.g., Frankel, *supra* note 135, at 1323; E. Haavi Morreim, *Stratified Scarcity: Redefining the Standard of Care*, 17 *LAW, MEDICINE, & HEALTH CARE* 356, 359-60 (1989); John A. Siliciano, *Wealth, Equity, and the Unitary Medical Malpractice Standard*, 77 *VA. L. REV.* 439, 476-77 (1991).

139. Of course, parties could alter this default presumption by contract if they so desired. For a comprehensive discussion of the concept of enterprise liability, see Kenneth S. Abraham & Paul C. Weiler, *Enterprise Medical Liability and the Evolution of the American Health Care System*, 108 *HARV. L. REV.* 381 (1994). Although Abraham and Weiler argue for imposing liability on hospitals rather than health plans, *see id.* at 415-20, their arguments in favor of hospital enterprise liability (for example, that hospitals are responsible for selecting health care team employees and for granting admitting privileges to physicians) apply more to claims that challenge the standard of medical competence than claims that challenge the standard of resource use. With respect to claims that challenge the standard of medical competence, imposing liability on hospitals might well be preferable to imposing liability on individual physicians. That question is, however, beyond the scope of this Article.

140. See *supra* Part I.A.4.

141. Indeed, Richard Zeckhauser and Donald Shepard, who introduced the QALY concept into the health measurement literature in the mid-1970s, specifically rejected the idea that QALYs could be converted into dollar values. See Richard Zeckhauser & Donald Shepard,

In this Part, I outline the elements of cost-per-QALY (or QALY-based) analysis¹⁴² and examine the only comprehensive attempt to date to use the methodology: Oregon's effort to use a QALY-based allocation scheme for its Medicaid recipients. I then propose an alternate approach—QALY-based rationing as an individual choice—and demonstrate how this choice-based approach addresses many of the specific methodological problems of Oregon's effort.¹⁴³

A. Elements of Cost-Effectiveness Analysis

1. Calculating Cost

Assuming that the decisionmaker is adopting a societal perspective (as contrasted with that of a single hospital or physician), the costs of a medical intervention are generally calculated by including all direct medical costs, cost of adverse side effects associated with treatment, savings due to prevention or alleviation of the disease in question, and future costs related to the treatment of disease.¹⁴⁴ Unrelated future medical expenditures—medical expenditures for diseases that occur because the intervention at issue produces longer life—are often not included in studies of medical cost-effectiveness. Many leading medical decision analysts believe, however, that adopting a societal perspective requires that all health care costs, including the costs of future unrelated disease, be included.¹⁴⁵

Where Now for Saving Lives?, LAW & CONTEMP. PROBS., Autumn 1976, at 5, 15-16; see also Milton C. Weinstein & William B. Stason, *Foundations of Cost-Effectiveness Analysis for Health and Medical Practices*, 296 NEW ENG. J. MED. 716, 717 (1977) (noting that many decisionmakers find it difficult to value human lives and quality of life in dollars).

142. I use the phrases "cost-per-QALY" and "QALY-based" interchangeably, to denote allocation methods that attempt to maximize QALYs gained for a given expenditure.

143. In Part III, *infra*, I address how a choice-based approach would address the more fundamental anti-utilitarian critique of cost-effectiveness and would thus make cost-effectiveness attractive to utilitarians and non-utilitarians alike.

144. Weinstein & Stason, *supra* note 141, at 718; see also I. Steven Udvarhelyi et al., *Cost-Effectiveness and Cost-Benefit Analyses in the Medical Literature: Are the Methods Being Used Correctly?*, 116 ANNALS INT. MED. 238, 239 (1992) (summarizing costs that should be included if the decisionmaker is adopting a societal perspective).

145. Weinstein & Stason, *supra* note 141, at 718. Whether future *non-medical* costs should be included is a more controversial question. Most decision analysis theorists argue that future non-medical costs should not be included because the constrained resource in question is health care. Other commentators have argued that, in order to conform to expected utility theory, the cost calculation must include future non-medical costs. See David Meltzer, *Accounting for Future Costs in Medical Cost-Effectiveness Analysis*, J. HEALTH ECON. (unpublished article, on file with author) (arguing that future non-medical costs should be included but noting that this is a minority view). Including future non-medical costs would cause the cost calculation (and hence the QALY-based ratio) to vary by level of marketplace activity, in violation of the egalitarian assumptions of the adequate care standard. See *id.* (noting that including future non-medical costs would disfavor the elderly and other individuals who do not engage in economic activity in the marketplace). For the purposes of this Article, I assume that QALY-based

2. Calculating the QALY Benefit

Quality-adjusted-life-years, or QALYs, are a measurement of the additional life years available to an individual, as adjusted by the quality of health (usually measured on a scale of 0 to 1) that the individual will enjoy during those years.¹⁴⁶ The QALY benefit associated with a given intervention is calculated as the difference between QALYs available with the intervention and QALYs available without the intervention. Interventions that increase life expectancy, improve quality of life, or reduce the risk of mortality thus have positive QALY benefits.

The manner in which QALY benefits are calculated can be illustrated through the use of a few examples. Consider an individual (*A*) who will die without surgery. With surgery, she will live an additional ten years in a health state of 0.7. For *A*, the surgery yields a health benefit of 7 QALYs. Consider another individual (*B*) who will live for 20 additional years whether or not she receives a hip replacement. The hip replacement will, however, improve her quality of life by a factor of 0.2 for those 20 years. For *B*, the hip replacement yields a health benefit of 4 QALYs. Finally, consider an individual (*C*) who will die unless she chooses either radiation or surgery. Radiation guarantees five additional years of life, with a quality adjustment of 0.8, and thus confers a QALY benefit of 4. Surgery is associated with a 20% risk of death; for those who do not die, however, it gives eight additional years of life in full health. Surgery thus confers a QALY benefit of 6.4 (an 80% chance of achieving an 8 QALY benefit).

Quality-adjustment ratings for health states are derived from hypothetical questions to interviewees.¹⁴⁷ The quality adjustment associated with any given health state can be measured through a number of different techniques. The simplest approach is the ratings scale approach, which asks interviewees to rate a particular state of health on a scale of 0 to 1, where being dead is valued at 0 and perfect health is valued at 1. Standard gamble (what chance of death would the interviewee risk to avoid living in a particular diminished state of health) and time trade-off (how many years of life would the interviewee give up to avoid living in that diminished health state) approaches also yield cardinal rankings for health states on a scale of 0 to 1.¹⁴⁸

analysis would not incorporate future non-medical costs.

146. Unlike valuations that measure health benefit in dollar terms, *see supra* Part I.A.4, the QALY benefit valuation does not depend on wealth or earning capacity. QALY benefit measurements thus comport with the egalitarian framework of the adequate care standard. As discussed *supra* note 145, however, certain methods of calculating cost may reflect wealth or earning capacity.

147. Quality-adjustment measurements are generally not derived from patients who have experienced the particular health state at issue, but rather from the general population of potential patients. The issue of whose quality adjustments should be used for QALY-based allocation is discussed *infra* notes 266-68 and accompanying text.

148. For a discussion of these techniques, see, for example, George W. Torrance, *Measurement of Health State Utilities for Economic Appraisal: A Review*, 5 J. HEALTH ECON. 1, 18-25 (1986). The cardinal scale for health states developed through these techniques is an interval scale, not a ratio scale. With an interval scale (for example, Fahrenheit or Celsius temperature), only scale value intervals—that is, differences between scale values—can be

These approaches to measuring quality adjustment can be used either directly or indirectly. Direct methods describe all the relevant attributes of a particular health condition (e.g., bronchitis) and ask interview subjects to assign a quality-adjustment figure to that condition. Indirect approaches are more sophisticated—they often require extensive interviews with, and education of, interview subjects.¹⁴⁹ Indirect approaches view the quality associated with any given health condition as a function of different attributes or dimensions of that health condition.¹⁵⁰ In one prominent version of the indirect approach, formulated by Robert Kaplan and his colleagues, subjects are asked to assign quality-adjustment ratings to various combinations of undesirable symptoms and limitations in such functional attributes as mobility, physical activity, and social activity. Underlying values for particular undesirable symptoms and functional limitations are then derived from these quality-adjustment ratings—the assumption is that the interviewees' quality-adjustment ratings are a function (typically an additive function) of their underlying values for undesirable symptoms and functional limitations.¹⁵¹ The health value for any given health condition can then be calculated as an additive function of the combination of the functional attributes and undesirable symptoms that it represents.¹⁵²

Finally, some methodological issues apply to the calculation of both cost and QALY benefit. Both benefits and costs should be discounted.¹⁵³ Cost-

compared. Ratios of scale values cannot. By contrast, with a ratio scale (for example, length or height), both differences between scale values *and* ratios of scale values can be compared. *Id.* at 16. Because quality adjustment is measured on an interval scale, a quality-adjusted state of 0.8 is not twice as good as a quality-adjusted state of 0.4. Rather, the difference between a state of 0.8 and 0.4 is as large as the difference between 0.4 and death. Because QALY-based analysis is concerned only with differences in health state values, and not with absolute health state values, an interval scale is sufficient for such analysis. *See id.* at 17.

149. For example, the indirect approach utilized by the British National Health Service to make some of its resource allocation decisions required interviews that lasted between one and a half to four and a half hours. MENZEL, *supra* note 20, at 82.

150. *See, e.g.*, Torrance, *supra* note 148, at 25.

151. For detailed descriptions of this approach, see Robert M. Kaplan & John P. Anderson, *A General Health Policy Model: Update and Applications*, 23 HEALTH SERV. RES. 203, 208-16 (1988); Robert M. Kaplan & James W. Bush, *Health-Related Quality of Life Measurement for Evaluation Research and Policy Analysis*, 1 HEALTH PSYCHOL. 61, 68-72 (1982); Robert M. Kaplan et al., *Health Status: Types of Validity and Index of Well-Being*, 11 HEALTH SERV. RES. 478, 485-92 (1976). The state of Oregon used Kaplan's approach to develop the list of health interventions it would cover. *See infra* notes 163-66 and accompanying text. The British National Health Service has used a similar approach in some of its resource allocation decisions. *See* MENZEL, *supra* note 20, at 82-84.

152. *See, e.g.*, Kaplan & Anderson, *supra* note 151, at 210. The assumption that the interaction between health values for different functional limitations and symptoms can be modeled by simple addition has been criticized. Some commentators have developed more sophisticated approaches for aggregating different dimensions of health values. *See* David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy* (Conference Report), HASTINGS CENTER REP., May-June 1991, at 11, 16.

153. Weinstein & Stason, *supra* note 141, at 719-20. The basic argument for discounting benefits relies on the fact that benefits are being compared with costs. Because of the time value of money, costs must be discounted. As a consequence, benefits should also be

effectiveness calculations should also include a sensitivity analysis of the most uncertain features and assumptions of the cost-per-QALY ratio, such as degree and length of QALY benefit. Sensitivity analysis requires that these uncertain features be varied one at a time over the range of possible values. If the basic conclusions do not change when a particular feature is varied, confidence in the validity of the cost-per-QALY ratios increases.¹⁵⁴

B. Applications

QALY-based analysis may be used for the narrow purpose of comparing different interventions for the same condition. For example, a health plan administrator may decide to compare different interventions for managing hypertension in terms of their cost-per-QALY ratios.¹⁵⁵ She may then determine that the health plan should cover the most cost-effective intervention—that is, the intervention with the lowest cost-per-QALY ratio.

The principal appeal of cost-per-QALY ratios, however, lies in their broad application. They provide a common metric for comparing all medical interventions, including interventions as disparate as (for example) coronary artery bypass surgery, renal transplantation, estrogen use in postmenopausal women, neonatal intensive care, dialysis, and prostatectomy.¹⁵⁶ Health policymakers and administrators could, therefore, use QALY-based analysis to design a health plan that maximized total QALYs gained by the plan's subscribers. In such a QALY maximization effort, all possible interventions would be ranked in terms of their cost-per-QALY ratios (with the lowest ratio getting the highest ranking). Determinations about which interventions the health plan would cover would then be made strictly according to that rank order.¹⁵⁷

To date, only one attempt at this type of global QALY maximization has been made—Oregon's controversial attempt to use QALY-based analysis to formulate the list of interventions it would cover under its Medicaid program. As discussed below, many aspects of Oregon's methodology have been attacked vigorously. The proposal made in this article—that QALY maximization be available to individuals as a rationing choice—addresses many of the methodological problems in Oregon's approach.

discounted. *Id.*

154. *Id.* at 720-21. Sensitivity analysis is extremely important because investigators typically need to substitute estimates for unknown variables. See Udvarhelyi et al., *supra* note 144, at 239-40 (arguing that estimates and sensitivity analysis be made explicit).

155. See, e.g., John La Puma & Edward F. Lawlor, *Quality-Adjusted Life-Years: Ethical Implications for Physicians and Policymakers*, 263 JAMA 2917, 2918 (1990) (summarizing study applying QALY-based analysis for this purpose).

156. Cost-per-QALY ratios have been developed for each of these interventions. See *id.*

157. Weinstein & Stason, *supra* note 141, at 717.

1. Oregon's Effort

The Oregon prioritization effort originated in Senate Bill 27, one of three bills that formed the Oregon Basic Health Services Act of 1989. This bill provided for an expansion of the state Medicaid program to cover all residents with incomes up to 100% of the federal poverty level.¹⁵⁸ The expansion of coverage was to be accompanied by the development of a list of health services, prioritized by "the comparative [health] benefits of each service."¹⁵⁹ After the prioritized list had been developed, and actuarial estimates of the costs of providing Medicaid coverage for each of the various services on the list formulated, the Oregon legislature was to determine how many of the services the state could afford to provide as part of its Medicaid program.¹⁶⁰

To accomplish the task of developing a prioritized list, the bill created an eleven-member Health Services Commission ("HSC"). The HSC was directed to solicit the health care values of the general public.¹⁶¹ While the HSC solicited health care values in a variety of ways,¹⁶² the list was ultimately based on the results of a statewide telephone survey. This survey of 1000 Oregonians was based, in turn, on the indirect approach to quality-of-life measurement described by Robert Kaplan and his colleagues.¹⁶³ Respondents were asked to rate thirty-one hypothetical health outcomes on a Quality of Well Being ("QWB") scale from 0 (a situation "as bad as death") to 100 (a situation that describes "good health"). Each outcome represented a different combination of twenty-three symptoms and six categories of functional impairment. The Commission assumed that the overall scores for outcomes were an additive function of underlying values for symptoms and functional impairments. Based on this assumption, the Commission used the outcome scores to calculate the average valuation for each

158. OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, EVALUATION OF THE OREGON MEDICAID PROPOSAL 3 (1992) [hereinafter OTA EVALUATION]. Approximately 120,000 Oregonians who did not qualify for Medicaid coverage prior to the legislation had incomes that fell below the federal poverty line. *Id.* The other bills that formed the Basic Services Act established a state subsidized insurance pool for high-risk individuals who could not qualify for private insurance due to pre-existing conditions and mandated that employers either provide insurance for their employees (including at least the services covered by Medicaid) or pay into a state insurance pool. *Id.* at 4; see also Charles J. Dougherty, *Setting Health Care Priorities: Oregon's Next Steps*, HASTINGS CENTER REP., May-June 1991 (Supp.), at 1, 3 (providing detailed summary of Oregon Basic Health Services Act provisions).

159. OTA EVALUATION, *supra* note 158, at 39 (quoting Senate Bill 27).

160. *Id.* at 5; see also Nancy K. Stade, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV. 1985, 1989-90 (1993).

161. OTA EVALUATION, *supra* note 158, at 7; Daniel M. Fox & Howard M. Leichter, *Rationing Care in Oregon: The New Accountability*, HEALTH AFFAIRS, Summer 1991, at 7, 20.

162. In addition to the telephone survey discussed in the text, the HSC held 11 public hearings and authorized Oregon Health Decisions ("OHD"), a citizens' advocacy group, to conduct community meetings in every county of the state. Fox & Leichter, *supra* note 161, at 20.

163. See *supra* notes 150-52 and accompanying text.

symptom and impairment category.¹⁶⁴ Thus, upon completion of the survey, the HSC had average values for how Oregonians viewed various symptoms—for example, loss of consciousness, sick or upset stomach, or coughing and wheezing—as well as various functional impairments—for example, being bedbound or unable to use transportation outside the home.¹⁶⁵ The relevant values were then added together to obtain QWB scores for a variety of health outcomes represented as combinations of symptoms and impairments.

The HSC used these QWB scores to calculate the effectiveness of approximately 1600 treatments for particular conditions.¹⁶⁶ Effectiveness was calculated as the product of the net benefit from the treatment and the estimated average duration of the benefit. Net benefit, in turn, was calculated as the difference between the average QWB with treatment and average QWB without treatment. In order to determine these average QWB figures, the Commission asked panels of physician specialists to estimate the probabilities of various types of health outcomes with and without treatment.¹⁶⁷ The Commission also asked the physician specialist panels to give information regarding duration of benefit and average age of onset of the condition—from this information, the Commission formulated estimates of average duration of benefit.¹⁶⁸ Once it had obtained effectiveness data, the HSC divided the estimated cost for each treatment by its effectiveness to yield the cost-effectiveness ratio for each treatment. It then rank ordered each condition, and the intervention necessary to treat the condition (“condition/treatment pair”), according to its cost-effectiveness ratio.¹⁶⁹

Before the Oregon legislature had the opportunity to determine how many of the treatments on the prioritized list could be provided as part of the state’s Medicaid package, the list was withdrawn, primarily in response to charges that the use of cost-effectiveness undervalued saving identifiable lives.¹⁷⁰ The HSC’s second, revised list consisted of 709 condition/treatment pairs; this list went to the legislature, which determined that it could fund the first 587 treatments on the list.¹⁷¹ The revised list was also criticized, however, albeit on narrower, more

164. Stade, *supra* note 160, at 1990.

165. Dougherty, *supra* note 158, at 13.

166. The HSC used codes from the International Statistical Classification of Diseases, Injuries, and Causes of Death, Ninth Revision (“ICD-9”) to define conditions and codes from Current Procedural Terminology (“CPT-4”) to define treatments. David M. Eddy, *Oregon’s Methods: Did Cost-Effectiveness Fail?*, 266 JAMA 2135, 2136 (1991). ICD-9 and CPT-4 codes had to be combined to limit the number of possible condition and treatment pairs to 1600. *Id.*

167. *See id.* at 2137 (giving probability summation formulas used to determine average QWB states with and without treatment).

168. *Id.*

169. *Id.* David Eddy’s discussion includes the mathematical formulae that embody this discussion.

170. For further discussion of these charges, see *infra* Part III.B.

171. Michael Specter, *Providing Health Care for the Poor: Oregon: Plan Covers All Needy But Not All Ailments*, WASH. POST, July 1, 1991, at A1, available in 1991 WL 2131523.

technical grounds.¹⁷² The choice-based model for QALY-based rationing that I propose aims to address both the narrow methodological concerns expressed in the criticism of Oregon's revised list as well as the more fundamental concerns expressed in criticism of Oregon's first list. In the next Part, I discuss how allowing choice responds to concerns about specific aspects of Oregon's methodology. In Part III, I argue that the framework of choice also addresses more fundamental criticisms of cost-effectiveness.

2. Cost-Effectiveness as an Individual Choice

Cost-effectiveness as an individual rationing choice would differ significantly from Oregon's approach. The Oregon approach was criticized, for example, for violating individual autonomy by substituting a single aggregate valuation of various health states for highly diverse individual valuations.¹⁷³ By contrast, the choice-based scheme that I propose could offer different versions of cost-effectiveness-based rationing. These versions would reflect different approaches to health state valuation. For example, individuals might value health states in some of the following ways: (1) all states other than death or very significant functional/symptomatic limitation are valued similarly; (2) states with relatively high levels of functioning and no symptoms/distress are valued highly and other states are valued less highly; and (3) all states other than full health are assigned a low value.¹⁷⁴ Under QALY-based allocation, these health state valuations would correspond to the following valuations of the trade-off between quantity and quality of life: the first valuation would give greater weight to quantity of life than quality; the second would give roughly equivalent weight to both quantity and quality; and the third would give greater weight to quality than quantity.

172. When the Bush Administration rejected Oregon's use of quality-of-life measures as a violation of the Americans with Disabilities Act, Oregon had to revise this list as well. *See infra* notes 282-85 and accompanying text.

173. *See* OTA EVALUATION, *supra* note 158, at 10 (noting that an Oregon telephone survey demonstrated considerable individual differences in health state valuation and questioning whether a single average preference could be substituted for diverse individual preferences); La Puma & Lawlor, *supra* note 155, at 2919-20 (arguing that QALYs violate individual autonomy by substituting a single community valuation of health states for variable individual valuations). *See generally* JOHN F. KILNER, WHO LIVES? WHO DIES? 154 (1990) (reviewing literature discussing inappropriateness of substituting the valuations of others for an individual's own valuations). As for the more fundamental charge that Oregon's scheme, like cost-effectiveness-based schemes generally, improperly imposed utilitarian allocation principles on individuals, this charge simply does not apply to the *ex ante* choice of cost-effectiveness. Indeed, the *ex ante* choice of cost-effectiveness might be attractive to utilitarians and non-utilitarians alike. *See generally infra* Part III.

174. These examples do not, of course, represent the only possible approaches to health state valuation; rather, they merely demonstrate the diverse ways in which individuals might value health states. For a similar categorization of health state valuations, see Elmer Abbo, *Private and Public Implications of a QALY-Based Standard of Care* (unpublished paper, on file with author).

Cost-effectiveness-based schemes that reflected these basic approaches to valuation could be developed. These basic approaches to health state valuation could then be further developed and refined by deliberation among those who joined a particular scheme.¹⁷⁵ The types of hypothetical questions that are used to solicit quality-adjustment ratings could serve as a basis for this collective deliberation.¹⁷⁶ The limitation on the number of possible valuation schemes that could be developed would be their ability to attract subscribers and the principle, developed further below,¹⁷⁷ that *ex ante* preferences—the preferences of individuals before they had experienced particular disabilities—should be the basic guiding preferences. To be sure, no matter how large the number of different approaches to end-state valuation available, no cost-effectiveness-based scheme would reflect precisely the end-state valuations of any given subscriber. Allowing individuals to choose between a variety of schemes, none of which perfectly reflected their preferences, would, however, be far less violative of autonomy than using a single scheme for all individuals.

Individuals who enrolled in cost-effectiveness-based schemes would be able to use public money (in the form of vouchers or direct government funding of health plans) to purchase interventions with cost-per-QALY ratios up to a particular ceiling (say, for example, \$30,000 per QALY gained¹⁷⁸). Although the insurance plan would be responsible for determining the level of this ceiling, it would obviously depend on the amount of public funding individuals received.¹⁷⁹

The determination of which interventions had acceptably low cost-per-QALY ratios could be made in a number of different ways: through administrative rulemaking (the approach used by Oregon), through physician judgment, or through a combination of rulemaking and physician judgment. I discuss below the advantages and disadvantages of each option. I then argue that individuals should be allowed to choose among these options.

Oregon's effort provides a clear example of the rule-based approach. Oregon formulated a prioritized list of 709 condition/treatment pairs ("CT pairs") and used this list to devise a comprehensive set of coverage rules. Specifically, the legislature determined that the first 587 CT pairs on the list could be funded and all others could not. Rules have several advantages: they do not compromise the physician's traditional role as an advocate for the patient's interests; they restrict physician discretion and thus ensure consistency across coverage determinations; and they can be implemented by physicians with relative ease. Rules can, however, be very crude. For example, because the CT pairs that Oregon prioritized were defined very broadly, they encompassed patients with very

175. See *supra* note 120 (discussing role for collective reflection in health care rationing).

176. See *supra* notes 147-52 and accompanying text (discussing questions that are used to solicit quality-adjustment ratings).

177. See *infra* notes 266-68 and accompanying text.

178. This figure is not entirely arbitrary. Some public health economists have suggested that interventions that cost less than \$30,000 per QALY gained should be considered acceptable. See Robert Fabian, *The Qaly Approach*, in VALUING HEALTH FOR POLICY, *supra* note 61, at 118, 129 (citing study published in 1982 and converting figures into 1991 dollars).

179. Individuals could also use their private resources to buy interventions with cost-effectiveness ratios higher than the publicly-funded ceiling.

different conditions, comorbidities (secondary conditions associated with the primary condition that affect the efficacy of treatment for the primary condition), and expected outcomes. The level of heterogeneity in the CT pairs was so significant that some patients who could achieve excellent outcomes with treatment would fall into CT pairs that were not ranked highly (and therefore were not covered by Medicaid) while other patients who could not achieve such outcomes would fall into CT pairs that were ranked highly (and thus were covered).¹⁸⁰ The Office of Technology Assessment's review of the Oregon plan noted that, to avoid problems of overinclusiveness and underinclusiveness entirely, "CT pairs would have to be defined so specifically as to make them unworkable for any practical program purpose."¹⁸¹

Allowing physicians to determine whether particular treatments produced acceptably low cost-per-QALY ratios for particular patients would avoid such problems. Yet giving rationing responsibility to the physician would arguably compromise the physician's role as an advocate for patient interests, would raise the possibility (if not the probability) of inconsistency and bias, and would impose a substantial administrative burden on physicians.¹⁸² Rationing determinations could, of course, also be made through a combination of rules and physician judgment. Rules could be used for discrete conditions that tended to be homogeneous in terms of clinical course or age of onset—rules would be appropriate because individuals would, on average, not differ significantly in the number of QALYs they gained from the treatments for those conditions.¹⁸³ For

180. OTA EVALUATION, *supra* note 158, at 10-11.

181. *Id.* at 11.

182. These physician determinations of cost-effectiveness would, however, be very different from the rationing decisions currently made by physicians operating under financial and non-financial incentives in managed care plans. Physicians operating in cost-effectiveness-based plans would have clear standards for their determinations of cost and QALY benefit. Moreover, their patients would have chosen these standards.

Consider, for example, a patient who had chosen a plan with a \$30,000-per-QALY-gained limit that focused on maximizing quantity of life (and thus viewed most health states as fairly similar). Now suppose that the patient had cancer that would kill her immediately if left untreated, and the question for the physician was whether the plan should cover a \$50,000 course of chemotherapy that would extend the patient's life for two years. Because the patient had chosen a plan that viewed all health states as fairly similar, the adverse symptoms associated with chemotherapy would not be viewed as diminishing quality of life significantly—say a factor of 0.1 on the 0 to 1 scale. For the patient, chemotherapy would therefore yield a QALY gain of 0.9 times 2 years, or 1.8 QALYs. At a cost of \$50,000, chemotherapy's cost-per-QALY ratio would therefore be less than \$30,000 per QALY gained, and it would be covered. In contrast, if the patient had chosen a QALY-based plan in which quality of life was viewed as very significant, chemotherapy's adverse symptoms might be seen as diminishing quality of life by a factor of 0.3, to a rating of 0.7 on the 0 to 1 scale. In that case, chemotherapy would yield a QALY gain of 0.7 times 2, or 1.4 and would go over the \$30,000-per-QALY-gained limit. On the other hand, a plan that emphasized quality of life might cover all sorts of life-improving interventions, such as hip replacements for older people, that would not be covered by the plan that emphasized quantity of life.

183. Rules might also be appropriate for situations where treatment would clearly fall within the appropriate cost-per-QALY ceiling, irrespective of the age of onset and clinical course of the condition.

conditions that were heterogeneous in terms of clinical course and age of onset, physician judgment could be used. This mixed approach would, however, have advantages and disadvantages as well: while it would avoid problems of gross overinclusiveness or underinclusiveness, it would not necessarily eliminate these problems. Moreover, it would impose some administrative burdens on the physician and would continue to place the physician in the role of rationing decisionmaker.

Because no approach to the implementation of QALY-based rationing is clearly superior, individuals should be able to choose their preferred approach. Plans might, for example, compete for subscribers on the basis of the implementation scheme they offered. In this competition, one approach might, of course, emerge as a favorite; in that event, cost-effectiveness-based plans would probably rely exclusively on that approach.

Finally, it should be emphasized that health plan administrators and physicians who made QALY-based rationing decisions would be required to rely, to the largest extent possible, on published data on the clinical outcomes (i.e., additional life expectancy, reduced risk of mortality, and quality-of-life improvement) associated with various interventions.¹⁸⁴ Since the late 1980s, the federal government and private organizations have been heavily involved in efforts to develop such outcomes/effectiveness data.¹⁸⁵ Administrators and physicians might also be assisted by the thousands of clinical "practice guidelines"—treatment protocols for managing common conditions—that have been developed on the basis of clinical effectiveness data.¹⁸⁶ Health plan rationing rules could readily be formulated from these practice guidelines. If a practice guideline were developed using effectiveness measurements that comported with the quality-of-life preferences of the health plan's enrollees, and the recommended treatment protocol fell within the appropriate cost-per-QALY

184. One of the problems with the Oregon effort was that it relied on outcomes information provided by physicians that was sometimes at odds with the published data. OTA EVALUATION, *supra* note 158, at 10.

185. The Federal Agency for Health Care Policy and Research ("AHCPR") was established in 1989 primarily to conduct research into the clinical effectiveness associated with medical treatments and to develop and disseminate clinical "practice guidelines" (standardized treatment protocols for particular conditions) based on the results of that research. See Brian S. Mittman & Albert L. Siu, *Changing Provider Behavior: Applying Research on Outcomes and Effectiveness in Health Care*, in IMPROVING HEALTH POLICY AND MANAGEMENT: NINE CRITICAL RESEARCH ISSUES FOR THE 1990S at 195, 195-99 (Stephen M. Shortell & Uwe E. Reinhardt eds., 1992); Marcel E. Salive et al., *Patient Outcomes Research Teams and the Agency for Health Care Policy and Research*, 25 HEALTH SERV. RES. 697, 698 (1990). Professional associations have also been heavily involved in the development of medical practice guidelines. The American Medical Association, for example, identified nearly 1500 practice guidelines in its 1993 directory. David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308, 313 (1994). For an introduction to the field of outcomes research, see FOUNDATION FOR HEALTH SERVICES RESEARCH, HEALTH OUTCOMES RESEARCH: A PRIMER (1993). For a discussion of how the Americans with Disabilities Act might affect these efforts to systematize medical decisionmaking, see *infra* notes 339-42 and accompanying text.

186. See sources cited *supra* note 185.

ceiling, the health plan could use the guideline directly. If not, the plan might modify the guideline so that it would better reflect its enrollees' preferences regarding trade-offs between cost and various types of health benefit.¹⁸⁷ Individual physicians making cost-per-QALY determinations might also be assisted by practice guidelines that reflected the quality-of-life and cost preferences of health plan enrollees. Some practice guidelines provide formulas for individualizing effectiveness calculations so as to incorporate a patient's particular characteristics.¹⁸⁸

III. COST-EFFECTIVENESS ANALYSIS: THE ANTI-UTILITARIAN CRITIQUE

Thus far the Article has addressed methodological objections to the use of cost-effectiveness. It has proposed a scheme for cost-effectiveness as a rationing choice that addresses these objections. Critics of cost-effectiveness have, however, launched much broader attacks on the normative foundations of such rationing. These objections to QALY-based rationing roughly divide into two categories—arguments against utilitarianism and arguments concerning discrimination. In Part IV, I address the discrimination argument. In this Part, I argue that *ex ante* choice largely addresses the anti-utilitarian critique,¹⁸⁹ not merely in the simple sense that anti-utilitarians, who often accord great

187. For an extended discussion of how practice guidelines could be used as rationing tools, see HAVIGHURST, *supra* note 12, at 222-64. Although Havighurst endorses practice guidelines as a means of defining a plan's rationing obligations, and also notes that consumers would be well served if plans used "something like a QALY as a common denominator of health benefits," *id.* at 194 n.31, he stops short of advocating the *open* use of cost-per-QALY analysis as a means of determining which guidelines might be appropriate or, more importantly, as a means of determining what interventions should be covered when there are no applicable practice guidelines (as will often be the case). Havighurst argues that disclosure in health care contracting need not be carried "to the logical extreme of quantifying values for human life and health." *Id.* This argument is at odds with Havighurst's general position that consumers should have a wide range of rationing choices. Havighurst's position is particularly untenable because, as argued further *infra* notes 219-21 and accompanying text, there are many reasons why individuals would find QALY-based rationing very appealing.

188. For example, the American College of Cardiology's practice guidelines have a formula for individualizing the calculation of such effectiveness measures as symptom relief, duration of symptom relief, and likelihood of preventing death. Orentlicher, *supra* note 185, at 313.

To be sure, there would be many situations where good outcomes data or applicable practice guidelines would not be available. Outcomes data and practice guidelines are still in the early stages of development. Where such information was not available, administrators devising rationing rules and physicians making rationing judgments rules could still formulate cost-per-QALY estimates. They would use these estimates, however, in a flexible fashion—the estimates would operate as rough guidelines, not as absolute determinants of whether a given intervention would be covered. Even such rough attempts to make rationing decisions based on the cost-effectiveness preferences of health plan enrollees would be clearly superior to the implicit rationing practices common in managed care, which allow no role for enrollee preferences. See *supra* note 14 and accompanying text.

189. Once choice is introduced, only relatively minor modifications in cost-effectiveness methodology are necessary to take care of the problems raised by the anti-utilitarian critique.

significance to choice, may have no grounds to complain if individuals choose in wrongheaded utilitarian ways, but in the more fundamental sense that common objections to utilitarian methodology simply do not apply to the ex ante choice of cost-effectiveness. In other words, I aim to show that the ex ante choice of cost-effectiveness should be attractive not only to utilitarians (an obvious enough point) but also to many individuals who might consider themselves opposed to utilitarian methodology. I also aim to show that many individuals who do not place themselves squarely in the utilitarian or non-utilitarian camps should find that, among the available ex ante decision principles for rationing health care, QALY maximization is the principle that best captures the trade-offs they would make between cost and health benefit.

As an initial matter, it is important to define carefully what I mean by the term utilitarianism; utilitarianism does not necessarily consist of a definite core principle or set of principles.¹⁹⁰ For the purposes of this Article, I focus on the version of utilitarianism represented by QALY maximization. QALY maximization embodies the following principles: an emphasis on the utility produced by particular interventions; a belief that the utilities of different persons and of different interventions can be compared; and a belief that these comparisons can occur on a single quantitative scale such that global utility for a population is maximized.¹⁹¹

Anti-utilitarian arguments against QALYs begin with several threshold assertions that apply to all schemes that aim to maximize collective benefit. Anti-utilitarians assert that the general goal of maximizing collective benefit is suspect, as it disregards the separateness of persons and typically focuses on end results rather than contextual features. Further, even if the benefits counted are defined broadly to include not simply outcomes or consequences but all relevant goods, benefit maximization erroneously assumes that these goods can be placed on, and measured with respect to, a single quantitative scale. Anti-utilitarians also assert that QALY maximization in particular is suspect—they assert that the types of trade-offs it forces between life and other health benefits are inconsistent with the widely held public belief that saving identifiable lives is a higher-order symbolic value that cannot mechanically be traded for other health benefits.

190. See JOSEPH RAZ, *THE MORALITY OF FREEDOM* 267 (1986). Raz makes this observation about the more general philosophy of consequentialism; utilitarianism represents, however, the most important example of consequentialism. *Id.* at 267-69.

191. Some utilitarians specifically reject the premise that all utilities can be compared on a single scale. See, e.g., Amartya Sen, *Plural Utility*, 81 *PROC. OF THE ARISTOTELIAN SOC'Y* 193, 197-99 (1981). As discussed further *infra* Part III.A.3, however, QALY maximization clearly embodies this premise.

A. *Objections to Benefit Maximization Generally*

1. Respecting the Separateness of Persons

Anti-utilitarians argue that maximizing benefit from scarce resources is suspect because it disregards the separateness of persons—that is to say, it views all utility as if it were experienced by a single person.¹⁹² This concern for the separateness of persons encompasses at least two important criticisms. One criticism targets the assumption that utility is morally additive. The utilitarian would argue, for example, that if lives saved is the measure of utility or benefit, scarce lifesaving resources should be directed away from the single individual (*A*) who requires a large proportion of those resources and towards other individuals (*B*, *C*, and *D*), each of whom requires only one-third the resources *A* requires. The utilitarian view assumes that the combined utility *B*, *C*, and *D* derive from having their lives saved exceeds the utility *A* derives from having her life saved. By contrast, the anti-utilitarian would argue that because there is no super-person who experiences the losses of *B*, *C*, and *D*, their losses cannot be summed and compared with the loss suffered by *A*.¹⁹³ The second criticism views life maximization as a decision to “trade” *A*’s life for the lives of *B*, *C*, and *D*, and hence as a violation of the Kantian principle that each individual is an end in herself who cannot be used solely as a means for assisting other individuals.¹⁹⁴

These criticisms are based, however, on two faulty assumptions: first, that benefit or utility maximization would be an ex post calculation; and second, that such maximization would be imposed on individuals by an external decisionmaker. By contrast, the central issue for just distribution of scarce health care resources must be what distribution scheme individuals choose ex ante.¹⁹⁵

Under ex ante conditions, problems associated with adding utility across persons would not be an issue. Consider the aforementioned example of choosing

192. See, e.g., RAWLS, *supra* note 33, at 28-29, 187-88.

193. See, e.g., Christine Korsgaard, *The Reasons We Can Share: An Attack on the Distinction Between Agent-Relative and Agent-Neutral Values*, 10 SOCIAL PHIL. AND POL. 24, 29 (1993) (noting argument that “[m]y happiness is good for me and yours is good for you, but the sum of these two values is not good for anyone”) (emphasis in original); John M. Taurek, *Should the Numbers Count?*, 6 PHIL. & PUB. AFF. 293, 308 (1977) (arguing that he does not “take seriously . . . any notion of the sum of two persons’ separate losses”); see also G.E.M. Anscombe, *Who is Wronged?*, 5 OXFORD REV. 16 (1967); Jorge A. Garcia, *The New Critique of Anti-Consequentialist Moral Theory*, 71 PHILOSOPHICAL STUDIES 1, 12-13, 20-24 (1993).

194. See KANT, *supra* note 81, at 47; ROBERT NOZICK, ANARCHY, STATE, AND UTOPIA 31 (1974).

195. Choice is desirable because a single rationing standard would override individual autonomy. See generally *supra* Part I.B.1. Moreover, because of the prevalence of, and need for, health insurance, ex post preferences cannot guide the allocation of scarce resources. See *supra* note 14; see also David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1456 (1992) (terming this requirement of ex ante consent the “insurance principle”).

among four individuals, one of whom (*A*) requires three times the lifesaving resources required by the other three (*B*, *C*, and *D*). Ex ante, these individuals would not know who among them require a small amount of lifesaving resources and who would require a large amount. Therefore, their ex ante choice of benefit maximization would not, and indeed could not, require adding utility across persons. Rather than adding utility across persons, the choice of benefit maximization would simply give each individual the maximal (and equal) likelihood of having her life saved.¹⁹⁶ Moreover, because benefit maximization would be grounded in the prior consent of the persons to whom it was applied, it could not be criticized for treating those persons solely as ends.¹⁹⁷ Ultimately, even deontological philosophers who do not believe that benefit maximization, in and of itself, has any moral valence recognize the moral force of prior consent to at least some types of benefit maximization.¹⁹⁸ For a choice-based scheme that allowed ex ante consent to benefit maximization as one option, anti-utilitarian criticisms regarding the separateness of persons would not present a problem. As

196. For a similar conclusion, see Elhauge, *supra* note 1, at 1498-99. Many non-utilitarians have used arguments *other* than ex ante choice to conclude that benefit maximization (at least in the form of life maximization) is morally desirable. Jonathan Glover argues, for example, that claims regarding the irrelevance of numbers of lives saved must rest on the "unacceptable view that saving lives consecutively is more worthwhile than saving lives simultaneously." See JONATHAN GLOVER, CAUSING DEATH AND SAVING LIVES 207-09 (1977); see also Derek Parfit, *Innumerate Ethics*, 7 PHIL. & PUB. AFF. 285, 299 (1978) (arguing that even though "[t]he urgency of moral claims does not always correspond to the badness of outcomes, . . . in the case of equal harms, numbers count"). I do not discuss here the validity of these arguments. Rather, I focus on ex ante consent because it is the foundation of a choice-based system of health care rationing.

197. The validity of the consent would, of course, depend on how well-informed the individual was about the nature of the health maximization scheme to which she was consenting. As discussed below, see *infra* notes 253-55 and accompanying text, QALY-based rationing methodology has typically failed to educate interviewees sufficiently regarding the resource allocation role their quality-adjustment assignments will have.

198. Rakowski, *supra* note 44, at 1104-55 (applying ex ante consent model to justify life maximization). Rakowski develops his analysis of ex ante consent in the context of the famous trolley problem, where a trolley driver is faced with a choice between killing four people on one track or switching to another track and killing only one person. Rakowski argues that the driver could switch the trolley if he could presume ex ante consent to this switch. Moreover, the driver could presume such consent to the extent it was clear that the switch was in the ex ante best interests of all persons on the track. *Id.* at 1126-29, 1144-45. Of course, the trolley problem differs from rationing in that the rationing dilemma involves saving, not killing, different numbers of people; nonetheless, the prior consent model applies in both situations. See *id.* at 1154-56 (applying prior consent model to question of saving different numbers of people, concluding that because individuals would consent ex ante to saving the larger number of lives, saving the larger number is an acceptable option); see also RAKOWSKI, *supra* note 44, at 305-06 (arguing that hypothetical prior consent analysis mandates that both government policy and private citizens maximize life saving).

In contrast to Rakowski, I do not rely on hypothetical consent analysis to argue that all individuals would necessarily consent ex ante to life maximization. To the contrary, I argue that hypothetical consent analysis is indeterminate. See *supra* Part I.A.3. I do contend, however, that many individuals (utilitarian, non-utilitarian, and otherwise) would give actual ex ante consent to benefit maximization.

a consequence, both utilitarians and non-utilitarians who believed in respecting the separateness of persons might find the ex ante choice of benefit maximization attractive.

The case for ex ante consent to benefit maximization becomes even stronger when one considers the difficulties associated with the most prominent rationing alternatives, rationing based on greatest need and random allocation. Rationing based on greatest need raises the "bottomless pit" problem of incurably ill individuals who consume large amounts of medical resources, with little appreciable improvement to show for the consumption.¹⁹⁹ Attempts to limit this "bottomless pit" worry—such as the assertion that "the neediest have a just claim only when something fruitful can come from the resource commitment"²⁰⁰—import a vague "capacity to benefit" threshold without providing much content for that threshold.²⁰¹ In addition, there is no reason to believe that individuals would, ex ante, necessarily find rationing based on greatest need more attractive than benefit maximization. Rather, rationing based on greatest need would be attractive primarily to individuals who were quite risk-averse.

Perhaps the most prominent rationing alternative offered by anti-utilitarians is random selection among those who would benefit from an intervention.²⁰² Advocates of random selection argue that individuals would choose this rationing alternative under ex ante conditions.²⁰³ This is by no means clear, however. From an ex ante perspective, benefit maximization, not random selection, gives each individual the maximum chance of achieving health benefit. Random selection advocates also argue that, given the constraints of scarcity, random selection preserves the principle of equal respect in the best way possible—by giving all individuals who need treatment an equal opportunity to be selected for treatment.²⁰⁴ These arguments improperly adopt an ex post perspective. From the perspective of an ex ante choice, health benefit maximization no more violates the principle of equal respect for persons than does random selection: to the contrary, because all individuals who choose benefit maximization ex ante are equally accorded a maximal chance of health benefit, benefit maximization treats all individuals with equal respect.

A variant of random selection widely accepted in the medical literature is modified random selection—modified random selection allocates treatment

199. See *supra* note 41 and accompanying text.

200. Robert M. Veatch, *What is a "Just" Health Care Delivery?*, in CONTEMPORARY ISSUES IN BIOETHICS 410, 412 (Tom L. Beauchamp & Leroy Walters eds., 2d ed. 1978).

201. See KILNER, *supra* note 173, at 120-21 (discussing difficulty of defining threshold medical benefit standard). Ironically, because the "capacity to benefit" threshold would probably include some consideration of quality of life and of life extension, it would not look very different from a QALY calculation. The attempt to engraft a utilitarian threshold onto a non-utilitarian scheme is inconsistent.

202. See *id.* at 192-96 (reviewing literature on random selection); Taurek, *supra* note 193 (arguing that random selection is appropriate). Random selection could be implemented either through a traditional lottery or through a first-come, first-served approach. KILNER, *supra* note 173, at 192.

203. See *id.* at 195 (collecting sources); see also *supra* note 50 and accompanying text.

204. BEAUCHAMP & CHILDRESS, *supra* note 21, at 382-84.

among individuals who have a reasonable likelihood of benefitting.²⁰⁵ Arguments for modified random selection also take the form of claims that likelihood of benefit as a rationing criterion should only be used where differences in likelihood of benefit are large and certain.²⁰⁶ The motivating factor behind proposals for modified random selection appears to be scientific uncertainty regarding predictions of medical benefit.²⁰⁷ Admittedly, there is often great uncertainty regarding such benefit. Rather than abandoning attempts at quantification after a certain arbitrary point, however, one could instead make the level of uncertainty explicit and factor it into one's calculations.²⁰⁸ In the final analysis, for utilitarians and non-utilitarians alike, neither greatest need nor any variant of random allocation invalidates benefit maximization as a health care rationing option.

2. The Valuation of Contextual Features

It is clear that resource allocation will fail to reflect attitudes toward health risks unless it accounts not only for aggregate levels of mortality and morbidity caused by these risks but also for contextual concerns about such risks.²⁰⁹ Methods of health benefit maximization that focus exclusively on health end states, are thus vulnerable to the criticism that they fail to reflect public values. QALY-based allocation can, however, readily be modified to incorporate contextual concerns. Consider the example of death from cancer. Conventional health benefit maximization might assume that death from cancer is the same as an instantaneous death—the outcome in both cases is, after all, the same. In contrast, QALY-based allocation can include information about the process by which a particular risk causes a particular outcome by including in the health status calculation information about the health states that precede the final outcome of death. Indeed, this is the preferred method for calculating health status.²¹⁰ Thus, in the case of death from cancer (as contrasted with instantaneous death), the quality-adjustment weights for states that preceded death would presumably be quite low. Averting death from cancer would also avert these

205. See KILNER, *supra* note 173, at 120-21 (collecting sources); Elhauge, *supra* note 1, at 1503-04; Orentlicher, *supra* note 185, at 313 (arguing that all patients who achieve a minimum threshold of benefit be treated, and that random allocation be used if all individuals above that minimum threshold cannot be treated).

Modified random selection differs from the modified version of rationing according to greatest need discussed earlier. See *supra* text accompanying note 200-01. While both approaches employ a "capacity to benefit" threshold, modified random selection chooses randomly among individuals who reach this threshold. By contrast, the modified version of rationing according to greatest need uses level of need to choose among individuals who reach the threshold.

206. Orentlicher, *supra* note 185, at 313 (summarizing argument).

207. See *id.* at 312-13.

208. See *supra* note 154 and accompanying text (describing use of sensitivity analysis to test conclusions of cost-effectiveness analysis).

209. See *supra* notes 63-64 and accompanying text.

210. Kaplan & Anderson, *supra* note 151, at 214-16.

states of diminished health and would thus yield a greater number of QALYs than averting instantaneous death.

Moreover, if this process did not account sufficiently for the psychic suffering associated with cancer (or other dreaded health risks), the quality-of-life measurement methodology could also include direct questions about the risk. Under such a scheme, individuals might be asked, "If you had a choice between preventing X instantaneous deaths and preventing one death from cancer, how large would X have to be to make you indifferent to the alternatives."²¹¹ From this information, health policy analysts could calculate a quality weight for death resulting from cancer. If instantaneous death were assigned a quality weight of zero, for example, death resulting from cancer would then have a negative quality weight. Consequently, an intervention that prevented death from cancer would be valued highly not only because it averted the states of diminished health that precede a death from cancer but also because it averted a death that was directly valued as worse than instantaneous death.²¹²

Anti-utilitarians might, however, object strongly to these proposed mechanisms for taking contextual values into account. These approaches account for contextual values not as a qualitatively separate consideration, but as another variable that can be factored into the unidimensional quality-adjustment calculus. The objections of anti-utilitarians to this method for incorporating contextual concerns would be but one manifestation of their larger concern that benefit maximization erroneously assumes that all relevant health benefits can be placed on a single quantitative scale. The next Part addresses this larger concern.

3. The Commensurability of Benefits

Benefit maximization schemes assume that all benefits can be evaluated according to a single metric—that is, according to a unitary quantitative scale. If, for example, the maximization scheme being used is cost-benefit analysis, the single metric is money. With QALY maximization, the single metric is QALYs. Many anti-utilitarians would contest this assumption vigorously, arguing that benefits can be (and often are) incommensurable. At a minimum,

211. For a similar suggestion, see Eddy, *supra* note 166, at 2140.

212. Attention to type and context of risk would not necessarily, however, be an unmitigated good. Incorporating individuals' subjective attitudes towards particular risks may mean that we are incorporating attitudes based on inaccurate factual information, or on inaccurate interpretation of factual information. See *infra* note 223 and accompanying text. Still, if maximization measures are going to reflect individual utility, this problem cannot be avoided. The problem simply makes it clear that educating the public about risk is essential. A more difficult set of questions emerges from the fact that attitudes toward risk are often influenced by attitudes towards the individuals who bear the risk. Negative attitudes towards racial minorities such as African-Americans might, for example, lead some individuals to rank death or morbidity from sickle cell anemia as relatively less important than death or morbidity from cystic fibrosis (a disease found exclusively in Caucasians). Such differential allocation based solely on race would be highly problematic. On the other hand, individuals' negative attitudes toward "self-inflicted" risks may lead them to make choices that allocate resources away from diseases caused by such risks. Such differential allocation might be justifiable. See *supra* note 121.

incommensurability means that benefits cannot be assigned values along a single metric.²¹³

An important challenge to benefit maximization follows from even a minimalist definition of incommensurability. Because incommensurable benefits cannot be ranked cardinally on a single scale, there is no algorithm that will maximize benefit or value in any given situation. This problem is highlighted by the example of QALY maximization. A foundational assumption of QALY maximization is that all health states can be assigned a cardinal ranking on a single scale. This is the case even with sophisticated quality-adjustment methodologies that measure multiple dimensions of health states (e.g., mobility, social activity, physical activity, symptoms/distress, and the like). For any given health state, these multiple measures are ultimately combined to yield a single, cardinal value.²¹⁴ Thus, for example, deafness might be assigned a value of 0.6, blindness a value of 0.7, and wheelchair dependence a value of 0.8. Such an assignment would mean that the increment in value in going from deafness to blindness was considered exactly equivalent to the increment in value from blindness to wheelchair dependence. The increment in value in going from deafness to wheelchair dependence would be exactly twice that of going from deafness to blindness. Proponents of incommensurability would argue, however, that such diverse health states as deafness, blindness, and wheelchair dependence implicate very different health values; reducing these diverse values to a unitary quantitative scale—and then comparing them according to that unitary scale—does not do them justice.

213. See Cass R. Sunstein, *Incommensurability and Valuation in Law*, 92 MICH. L. REV. 779, 796 (1994) (“*Incommensurability occurs when the relevant goods cannot be aligned along a single metric without doing violence to our considered judgments about how these goods are best characterized.*”) (emphasis in original). Although Sunstein does not appear to dispute the possibility of non-quantitative or ordinal rankings, *id.* at 797 n.61, other proponents of incommensurability argue that incommensurate goods cannot be ranked either cardinally or ordinally. See, e.g., ANDERSON, *supra* note 65, at 46. Proponents of incommensurability also differ on the relation between rational choice and incommensurability. Sunstein and Anderson argue that individuals can choose rationally between incommensurate options. See *id.* at 59-64; Sunstein, *supra*, at 808-09. Joseph Raz equates incommensurability with incomparability and argues that reason cannot guide our choice between incommensurate or incomparable options. RAZ, *supra* note 190, at 322, 334.

Incommensurability is a complex philosophical concept that has been discussed widely in the legal and philosophical literature. My discussion of the topic here will only address those aspects of incommensurability directly related to my proposal for QALY maximization. For more detailed discussions of incommensurability, and of the related questions of value pluralism (i.e., whether value should be understood as plural or unitary) and of transitivity between choices, see ANDERSON, *supra* note 65; MARTHA C. NUSSBAUM, *Plato on Commensurability and Desire*, in LOVE’S KNOWLEDGE 106-24 (1990); RAZ, *supra* note 190, at 321-45; Richard H. Pildes & Elizabeth S. Anderson, *Slinging Arrows at Democracy: Social Choice Theory, Value Pluralism, and Democratic Politics*, 90 COLUM. L. REV. 2121, 2158-66 (1990); Sunstein, *supra*.

214. See *supra* notes 149-52 and accompanying text. Of course, multi-dimensional approaches may yield more accurate cardinal values than less sophisticated approaches. Even so, proponents of incommensurability would question the propriety of any sort of unidimensional ranking.

Questions of commensurability become even more complicated when one considers that QALY maximization not only assumes that various health states are commensurable but also that improvements in health status are commensurable with extension of life.²¹⁵ For example, QALY methodology considers ten years of additional life with a 0.5 quality adjustment to be equivalent to five additional years of a fully healthy life. Individuals who value life-extension and improvement in the quality of life very differently might consider such mechanical trade-offs between these health goals inconsistent with their health values.

Nonetheless, even for those who believe in incommensurability, these concerns do not invalidate QALY maximization as an *ex ante* rationing choice. To be sure, unidimensional QALY maximization would be a fairly crude rationing principle to use *ex post*, in an actual medical situation where one knew the health values implicated by different treatment options and could assess these incommensurate values in a qualitative fashion. The luxury of *ex post* decisionmaking is not, however, available to individuals who desire to have some choice in the rationing scheme used by their health plan. In order to exercise such choice, individuals must act *ex ante*.²¹⁶ *Ex ante*, individuals cannot possibly anticipate each of the various types of medical problems they might encounter in the future. As a consequence, they cannot possibly specify the unique type of qualitative analysis that should be used to make cost-benefit trade-offs in each medical situation.²¹⁷ Rather, individuals have to choose a rationing principle (or small set of rationing principles) that can apply across a wide range of diverse medical problems, many of which cannot be anticipated.²¹⁸ QALY maximization is such a principle.

This is not to say that all individuals would choose QALY maximization as their rationing principle. Health plan enrollees who believed that plan physicians operating under financial incentives to make cost-sensitive decisions would accurately reflect enrollee rationing preferences might choose to delegate all decisional authority to these physicians. Others might opt for a rationing scheme that required significant deductibles and copayments at each level of expenditure. Still others might choose random selection, rationing based on greatest need, or rationing that excluded broad categories of medical expenditure that they did not

215. QALY maximization also assumes that health improvement and extension of life are commensurable with life itself. The next Part discusses the unique commensurability issues raised by the trade-offs QALYs forces between the saving of identifiable lives and other health benefits.

216. *See supra* note 14.

217. Moreover, even if it were theoretically possible for an individual to create a detailed qualitative framework, an insurance scheme could not be created unless a significant number of other individuals agreed with this framework.

218. Indeed, even in contexts where adherence to a small set of decision principles formulated *ex ante* is needed only as a means of guarding against inconsistency and arbitrariness in decisionmaking, commentators who otherwise support incommensurability have noted that this may be an adequate pragmatic justification. In order to guard against inconsistency and arbitrariness, law and public policy might act "as if" options were commensurable. *See* Sunstein, *supra* note 213, at 842; *see also id.* at 855 (Unitary valuation is best understood "as a means of overcoming certain institutional obstacles, and not as reflecting a fully adequate understanding of the relevant problems.").

value highly. My claim here is simply that many individuals, including many who believed in incommensurability, would find QALY maximization to be the ex ante decision principle that most accurately reflected the trade-offs they would make between cost and various types of health benefit. To be sure, for believers in incommensurability, QALY maximization would not operate as a value maximization principle—for these individuals, there would be no single health value unit that *could* be maximized. Believers in incommensurability might nonetheless find, however, that the allocation results generally produced by QALY maximization better promoted their multiple health values than the results produced by other ex ante decision principles.

For incommensurabilists and non-incommensurabilists alike, the appeal of QALY maximization would rest on several factors. First, QALY maximization would afford substantial opportunity to achieve valued goals such as life extension, improvements in quality of life, and reductions in risk of mortality.²¹⁹ Second, potential subscribers who were not familiar with medical technicalities and the benefits to be gained from different interventions could nonetheless make an informed and reflective decision in favor of QALY maximization. In order to make such a decision, subscribers would only have to know two things: 1) that maximization of quality and quantity of life were the main goals they sought to achieve from medical intervention; and 2) the manner in which they wanted to trade off quantity and quality of life. Thus, for example, women choosing an insurance plan would not have to determine whether, given their age and family history of breast cancer, a plan that covered mammograms on a yearly basis was desirable. Rather, so long as the women knew that they wanted to maximize life years and quality of life, and wanted to trade off these variables in a particular fashion, they could simply enroll in a plan with a certain cost-per-QALY ceiling. For any given woman, her physician could then determine whether a yearly mammogram fell within the woman's cost-per-QALY ceiling.²²⁰ Third, QALY-based rationing would be appealing because different types of QALY maximization schemes, which reflected different valuations of health end states, and trade-offs between quality and quantity of life, could be devised.²²¹ Finally, although a subscriber's choice of a cost-per-QALY ceiling would certainly constrain to some extent the variety of medical treatment options available to her, it would not necessarily restrict her to a single treatment option. Rather, in any given medical situation, there might be multiple interventions available that fell within the subscriber's chosen cost-per-QALY ceiling. The subscribers could use qualitative decision principles to choose among these interventions.

219. For non-incommensurabilists, QALY maximization would, of course, maximize the opportunity to achieve these goals. For incommensurabilists, no such overall maximization would be possible; nonetheless, the results of QALY maximization would be likely to further these goals.

220. Of course, for women over a certain age who would all receive significant QALY benefit from a yearly mammogram, a rule establishing coverage for such a mammogram would be appropriate. Individuals could get a sense of what types of interventions the cost-per-QALY ceiling they had chosen covered by looking at such rules.

221. See *supra* notes 174-75 and accompanying text.

Another feature of QALY-based rationing schemes that would make them appealing, if not necessarily to individuals, then at least to policymakers concerned with offering plans grounded on sound rationing principles,²²² would be that these plans would not allow common cognitive errors that lay individuals make in assessing the magnitude of health risks²²³ to influence allocation: individuals would have to assess only the quality-adjustment value associated with the health state produced by a given health risk, not the likelihood that the health risk would occur or would produce that health state.²²⁴ This is not to say that cost-effectiveness analysis would focus exclusively on the end state produced by a particular risk and ignore public concerns regarding the type of risk involved. To the contrary, QALY-based allocation can, and should, incorporate contextual concerns.²²⁵ The critical point is that lay individuals would not be called upon to make judgments about questions that were essentially technical in nature—specifically, judgments about risk levels or the likelihood that a particular health risk would produce a particular health state. Consider, for example, a health risk that is not well understood by lay individuals and is not personally controlled. (The classic example in the environmental context would be nuclear power.) It is likely that individuals would fear this risk greatly and value averting death from this risk very highly.²²⁶ Assume, however, that it could be shown (to a reasonable degree of scientific certainty) that this highly feared health risk was, in fact, linked to very few deaths. In that situation, although more resources would be devoted *per death* to that risk than to other, less highly feared risks, the allocation of resources would be limited by the fact that few

222. As discussed earlier, *see supra* note 106 and accompanying text, both federal and state governments could offer rationing schemes not provided in the private market.

223. Cognitive psychologists have long noted that public reliance on common, generally reasonable, heuristics to predict the likelihood of uncertain events can lead to faulty prediction. Individuals incorrectly assess the probability of events based on their “availability”—the ease with which prior instances of a similar event can be brought to mind—and incorrectly “anchor” their value estimates in favor of initial value estimates. *See* Amos Tversky & Daniel Kahneman, *Judgment Under Uncertainty: Heuristics and Biases*, 185 *SCIENCE* 1124, 1128-30 (1974). Individual predictions are also insensitive to such important factors as the base rate frequency of outcomes, sample size, chance, and the predictive value of limited information. *Id.* at 1124-30. One systematic consequence of public reliance on these heuristics may be the well-observed phenomenon of individuals overassessing the risk of low-probability events (e.g., nuclear power accidents, plane crashes) and underassessing the risk of high-probability events (e.g., automobile accidents). *See* VISCUSI, *supra* note 60, at 102-04 (discussing seminal study illustrating this phenomenon and noting that overassessed risks may be those that have been highly publicized, and thus are readily “available”).

224. For a similar argument, see Elhauge, *supra* note 1, at 1531.

225. *See supra* notes 63-64 and accompanying text (discussing problems with decision analytic tools that ignore contextual information about risk).

226. *See, e.g.,* Peter Huber, *Safety and the Second Best: The Hazards of Public Risk Management in the Courts*, 85 *COLUM. L. REV.* 277 (1985) (observing that individuals are much more concerned about “public” risks caused by complex technology that they cannot control than they are about “private” risks that they incur voluntarily); Pildes & Sunstein, *supra* note 66, at 57 (noting that valuation of risk depends on degree to which it is understood and borne voluntarily).

deaths were in fact caused by the risk. Other risks that were perhaps less highly feared but that in fact caused many more deaths would merit more resources.

B. Objections Specific to QALY Maximization

Thus far the Article has discussed objections to the general goal of benefit maximization, using the example of QALY maximization to illustrate these objections. It has argued that the framework of choice largely addresses these concerns, at least to the extent they can be addressed given the need for ex ante decision principles. This Part addresses anti-utilitarian objections specific to QALY maximization.

1. Saving Identifiable Lives and Hierarchical Incommensurability

An important valuation issue specific to QALY maximization arises because QALYs take into account not only length and quality of life but also life itself. As such, QALY maximization forces trade-offs between length or quality of life and life itself. For example, assuming equivalent costs, QALY maximization would value saving the life of one person for ten years over saving the life of nine persons for one year. Indeed, given equivalent costs, QALY maximization would value a hip replacement that improved one person's life by a quality-adjustment increment of 0.2 per year over the course of 20 years (total gain of 4 QALYs) more highly than saving another person's life of 0.9 quality for 4 years (total gain of 3.6 QALYs).

Critics of QALY maximization argue that these mechanical trade-offs between life and other health benefits are inconsistent with the widely held public attitude that saving identifiable lives (as contrasted with statistical lives) is a higher-order value than providing other health benefits.²²⁷ Saving identifiable lives has symbolic or expressive significance that achieving other health benefits simply does not have.²²⁸ Moreover, critics contend that QALY maximization sacrifices

227. See, e.g., David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 JAMA 2218, 2219-20 (1991). It is important to emphasize that giving priority to the saving of identifiable lives is very different from giving priority to the saving of all lives, both identifiable and statistical. Indeed, a scheme that gives priority to the saving of identifiable lives is unlikely to maximize total lives saved. See also Allan Gibbard, *The Prospective Pareto Principle and Equity of Access to Health Care*, in 2 PRESIDENT'S COMM'N, SECURING ACCESS TO HEALTH CARE, *supra* note 21, app. G, at 175-77 (noting that focus on identifiable lives will not result in life maximization because we will continue to risk statistical lives and will not be able to save all the victims).

228. Following Albert Jonsen, David Hadorn dubs this symbolic value the "Rule of Rescue" value. Hadorn, *supra* note 227, at 2219. Hadorn notes that although the Rule of Rescue is most compelling in the context of lifesaving interventions for identifiable patients, it also comes into play whenever an identified patient is in serious need of major treatment. *Id.* Health economists have variously viewed this symbolic value as altruistic concern, see Tolley et al., *supra* note 96, at 356 (criticizing the Oregon effort for not taking into account altruism as an important part of health values) or as "vicarious utility," see Eddy, *supra* note 166, at 2140. Outside the health care arena, the importance of expanding decision analytic tools to take into account

this symbolic value not simply in particular contexts but in a systematic fashion. Maximizing QALYs inevitably results in the prioritization of inexpensive but minor interventions over expensive but lifesaving ones. This result obtains because large numbers of inexpensive interventions can often be performed for the same cost as a single lifesaving intervention—numerous small QALY gains combine to exceed the large QALY gain achieved through a single lifesaving intervention. The original prioritized health services list devised by the Oregon Health Services Commission appears to support these charges. The first list generated by the Commission ranked relatively minor but inexpensive interventions over more expensive interventions that saved identifiable lives. For example, the original list gave priority to dental caps for pulp exposure over lifesaving surgery for ectopic pregnancy and to splints for temporomandibular joints over lifesaving appendectomies for appendicitis.²²⁹ As a consequence, the original list was widely criticized as a failure.²³⁰

Some commentators argue that according respect to the higher-order symbolic value of saving identifiable lives means refusing to use the QALY metric to make trade-offs between saving such lives and achieving lesser health benefits, such as increased length or quality of life.²³¹ The precise claim is not one of mere incommensurability. Saving lives is not merely a different sort of value than life-extension and life-enhancement. Rather, saving life has a unique expressive significance that is both different from, and qualitatively greater than, life-extension or life-enhancement.²³²

Claims of this type of “hierarchical” incommensurability are quite common. Liberal and libertarian thinkers have, for example, often made arguments that rights or liberties are hierarchically incommensurable with ordinary utilitarian considerations.²³³ For some of these thinkers, hierarchical incommensurability

symbolic or expressive values has been noted by a variety of commentators. See, e.g., ROBERT NOZICK, *THE NATURE OF RATIONALITY* 26-35 (1993) (discussing the symbolic utility of actions); Pildes & Sunstein, *supra* note 65, at 66-71. Whether the symbolic value attached to saving identifiable lives is rational or irrational is a question that I do not take up here. Even those who conclude that this symbolic value is irrational concede that it cannot be ignored in resource allocation. See Gibbard, *supra* note 227, at 175-77 (noting that although the feeling that identifiable lives are priceless is irrational, it expresses respect for our fellow humans and strengthens the “bonds of social fellowship”).

229. Hadorn, *supra* note 227, at 2219.

230. See *id.*

231. See John Harris, *QALYing the Value of Life*, 13 J. MED. ETHICS 117, 118, 120 (1987). See generally Hadorn, *supra* note 227, at 2218 (arguing for prioritization scheme in which the saving of identifiable lives is not traded off against other health benefits).

232. See ANDERSON, *supra* note 65, at 70 (explaining how a good can be both incommensurable with, and greater than, another good).

233. See, e.g., RONALD DWORKIN, *TAKING RIGHTS SERIOUSLY* 184-205 (1977); ROBERT NOZICK, *ANARCHY, STATE, AND UTOPIA* 28-29 (1974); RAWLS, *POLITICAL LIBERALISM*, *supra* note 78, at 289-371; JOHN RAWLS, *A THEORY OF JUSTICE* 151-52, 243-51, 541-48 (1971). Similarly, the requirement that the government possess a compelling interest when it overrides certain constitutional rights can be seen as arising from a concern that rights are higher-order values than ordinary governmental interests. Also common are assertions that certain items (e.g., life, friendship, love) are incommensurable with money because they represent a higher-order value than money. See, e.g., RAZ, *supra* note 190, at 352-53 (discussing “constitutive”

implies that rights must be viewed as lexically prior to utilitarian considerations.²³⁴ Similarly, those who argue that saving identifiable lives is a higher-order value than mere life-extension or life-enhancement sometimes favor giving lexical priority to the saving of identifiable lives.²³⁵

Giving interventions that save identifiable lives necessary lexical priority poses very significant problems, however. As an initial matter, according absolute priority to lifesaving may have a very short-term orientation. "Saving" the life of one very sick individual three times over the course of six months (for a total of three lives saved) is valued more highly than saving the lives of two other individuals, each for ten years (for a total of two lives saved).²³⁶ Moreover, even assuming that we accorded lexical priority only to lifesaving interventions that restored life of a reasonable quality for some significant period of time (say one year or more), it is by no means clear that such prioritization would be feasible financially. In light of the range of expensive technology that has been, and will be, developed to keep people alive for significant periods of time, giving lexical priority even to interventions that save life for a significant period of time might well exhaust our health care resources, leaving no money to save non-identifiable lives or to achieve other health goals. Ultimately, even proponents of lexical ordering acknowledge this point.²³⁷

2. Lexical Ordering and the Oregon Plan

The results of Oregon's decision to revise its original list so as to give priority to lifesaving interventions provide a concrete illustration of these arguments. Following widespread charges that its list failed to account for the symbolic significance of saving identifiable lives,²³⁸ the Oregon Health Services Commission ("HSC") abandoned traditional cost-effectiveness. Instead, the HSC Commissioners formulated seventeen categories of medical interventions and ranked these categories according to criteria derived from "community health

incommensurability of friendship with money); Pildes & Anderson, *supra* note 213, at 2150 (discussing claim that human life is a higher-order value than economic growth).

234. See RAWLS, *POLITICAL LIBERALISM*, *supra* note 78, at 297; RAWLS, *A THEORY OF JUSTICE*, *supra* note 233, at 542 (arguing that basic rights are lexically prior to income after a threshold level of income has been achieved); see also Sunstein, *supra* note 213, at 833 (noting that lexical priority reflects claims about incommensurability).

235. See, e.g., Harris, *supra* note 231, at 118, 120. David Hadorn makes a similar argument in endorsing Oregon's decision to revise its original list of covered interventions so as to ensure that interventions for acute, life-threatening conditions were given lexical priority. See generally Hadorn, *supra* note 227. Oregon's revision of its original list is discussed *infra* Part III.B.2.

236. For a similar point, see Elhauge, *supra* note I, at 1506.

237. Hadorn, *supra* note 227, at 2225 (noting that giving priority only to highly beneficial interventions does not address the problem of highly beneficial but very expensive interventions that will be developed in the future); see also Gibbard, *supra* note 227, at 177 (noting that, with the development of effective, extraordinarily expensive treatments, the economic cost of maintaining the illusion that we can save all identifiable lives will become prohibitive).

238. See *supra* notes 229-30 and accompanying text.

care values" expressed at public hearings and meetings.²³⁹ The Commissioners did not include cost as a ranking criterion.²⁴⁰ In the final ranking of categories, treatment that prevented death with full recovery was ranked as category number one and treatment that prevented death without full recovery was ranked as category number three.²⁴¹ Because the ranking of categories resulted in lexically ordered condition/treatment ("CT") pairs (all treatments that were assigned to a higher priority category were ranked ahead of treatments in the next priority category), treatments that prevented death were given either first priority or third priority.²⁴²

The prioritization that emerged was sufficiently skewed that the HSC Commissioners had to reintroduce some of the cost considerations that they had previously abandoned. Considerations of cost were reintroduced to some extent through hand-adjustments of the list.²⁴³ This reintroduction of cost considerations was not enough, however, to save the Oregon plan from being criticized for failing sufficiently to contain costs. The OTA's analysis of the plan noted that because Oregon gave priority to lifesaving treatments, it covered costly, "heroic" procedures for terminally ill patients.²⁴⁴

Oregon's lexical prioritization of lifesaving treatment forced public assessments of treatment effectiveness to be abandoned along with cost. The OTA's analysis of the Oregon plan emphasized that "the net benefit term associated with a given CT pair ultimately had surprisingly little effect on the

239. OTA EVALUATION, *supra* note 158, at 4.

240. The criteria used by the HSC to rank categories were: 1) the category's perceived value to the individual; 2) the category's value to society; 3) the "necessity of the category." Hadorn, *supra* note 227, at 2220.

241. Maternity and newborn treatment was ranked number two. The lowest ranked category, category 17, comprised treatment for fatal or nonfatal conditions that resulted in minimal or no improvement in the quality of life. OTA EVALUATION, *supra* note 158, at 6. In theory, category 17 could have included many treatments that averted death for only a short period of time or with minimal improvement in quality of life. In practice, however, because category 17 judgments regarding quality of life and life span were left to the HSC Commissioners, Hadorn, *supra* note 227, at 2220-24, it appears that even treatments that temporarily averted death for terminally ill individuals were ranked highly. See OTA EVALUATION, *supra* note 158, at 21 (noting that last-minute, lifesaving measures for terminally ill individuals were ranked highly).

242. Even within categories, highly beneficial treatment that embodied "Rule of Rescue" values, see *supra* note 228, was given priority; CT pairs within categories were ranked only on the basis of the benefit or effectiveness portion of the cost-effectiveness data that the HSC had gathered. OTA EVALUATION, *supra* note 158, at 7.

243. Hadorn, *supra* note 227, at 2220. The Commissioners moved CT pairs both within categories and between categories; 53% of the CT pairs moved up or down at least 25 places and 24% moved at least 100 places. OTA EVALUATION, *supra* note 158, at 9.

244. OTA EVALUATION, *supra* note 158, at 21. Oregon did limit treatment that was less immediately lifesaving, such as therapy for the terminal condition itself. See David Hadorn, *The Oregon Priority Setting Exercise: Quality of Life and Public Policy*, HASTINGS CENTER REP., May-June 1991 (Supp.), at 11, 12 (noting that therapy for terminal AIDS and cancer patients was ranked low).

final ranking of that CT pair on the prioritized list.”²⁴⁵ Given Oregon’s lexical ordering scheme, the OTA’s conclusion that assessment of benefit was abandoned is not at all surprising. Consider, for example, the previously mentioned example of “last minute,” lifesaving measures for a terminally ill patient. These heroic measures would be unlikely to produce a significant QALY benefit—let us suppose an additional life expectancy of six months with a quality adjustment of 0.3, for a total QALY gain of 0.15. Nonetheless, because such heroic measures would likely fall under category three, they would be ranked above other measures—for example, preventive care for children (which the HSC Commissioners designated as category four)—that would produce a much more significant QALY gain.²⁴⁶

It could be argued that Oregon should have respected the symbolic value of saving identifiable lives by engaging in a ranking based solely on net effectiveness (again, without taking cost into account). Unlike straightforward lexical prioritization of lifesaving interventions, ranking based on net effectiveness assumes that the symbolic value of saving of identifiable lives should be dispositive only when life of a certain quality can be saved for a significant period of time. Nonetheless, even this restricted interpretation of the symbolic value cannot operate regardless of cost. Thus, even assuming *arguendo* that Oregon had used lexical ordering only to the extent that it yielded a ranking based on net effectiveness—in other words, that Oregon had given priority only to those lifesaving interventions that produced significant improvements in quality of life and life span—it is by no means clear that even this ranking would ultimately have been feasible financially. Even an advocate of the Oregon revision concedes that “eliminating services deemed to offer inadequate benefit will not protect society’s purse from the highly beneficial (and often expensive) services that will be developed in the coming years.”²⁴⁷

3. Respecting Higher-Order Values

Some commentators who argue in favor of the hierarchical incommensurability of saving lives recognize that lexical ordering is not a feasible mechanism for protecting this higher-order value. They argue that, in any given situation, the value of life is properly respected not through protection against all trade-offs (which is what lexical ordering accomplishes) but through an open-ended, contextualized, and qualitative elaboration of the expressive or symbolic concerns regarding life that are at stake.²⁴⁸ Only through this type of elaboration

245. OTA EVALUATION, *supra* note 158, at 9. The OTA’s conclusions call into question the argument, made by proponents of Oregon’s revision process, that lexical ordering produced rankings based primarily on net benefit or effectiveness. See Hadorn, *supra* note 227, at 2221.

246. OTA EVALUATION, *supra* note 158, at 9-11.

247. Hadorn, *supra* note 227, at 2225.

248. See, e.g., Pildes & Anderson, *supra* note 213, at 2148-58. Pildes’s and Anderson’s discussion focuses on the symbolic value of life generally, not on the specific symbolic value of saving identifiable lives. See also Sunstein, *supra* note 213, at 833-34 (arguing that, in order to respect higher-order values properly, we must protect them against trade-offs unless the competing interests are of a certain qualitative sort and are “extraordinary in amount or level”).

can one determine whether a particular trade-off of life for some other benefit expresses improper contempt for life.²⁴⁹

It is difficult to imagine how the principles that would guide such an elaboration could be established *ex ante*. Indeed, some proponents of incommensurability specifically assert that, when hierarchically incommensurable values are at stake, a proper understanding of the relevant principles cannot be established *ex ante*.²⁵⁰ What, then, to do when confronted with the dilemma of health care rationing, which requires individual rationing choices to be made *ex ante*? One possible response would be to disavow any individual role in rationing—some individuals might choose to delegate rationing decisions to the physician, in the hope that the ethic of the medical profession, which places a high premium on acting to promote the patient's medical interests,²⁵¹ would promote respect for the value of saving identifiable lives. Many individuals might prefer, however, to have some role in choosing rationing principles. For these individuals, there would be no way to recognize perfectly the qualitatively distinct value of saving lives—individuals simply could not anticipate, and provide a unique qualitative decision structure for, each of the many different situations in which life would have to be traded off against other health values.²⁵² Rather, decision principles broad enough to be useful *ex ante* would have to be modified to incorporate, in some very rough fashion, the symbolic value of saving lives.

It would be difficult to use some *ex ante* decision principles (e.g., age-based rationing) to incorporate, even in a rough manner, the symbolic value of saving lives. In contrast, the QALY metric could be modified for this purpose. As a consequence, many individuals—including proponents of hierarchical incommensurability—might choose the QALY metric.

In order for quality-adjustment measurements to incorporate the symbolic value of saving lives, those responsible for developing the measurements would have to confront interviewees with the trade-offs between saving life and other health benefits entailed by QALY-based allocation. Indeed, a central problem with many attempts to develop quality-adjustment ratings (including Oregon's attempt) has been that they have not confronted interviewees with these trade-offs. Interviewees have not been made aware, for example, that assigning a quality-adjustment value of (say) 0.67 to the condition of chronic nausea and vomiting means that (assuming equivalence of costs) restoring three people who suffer chronic nausea and vomiting to full health (quality-adjusted state of 1) is equivalent to preventing the death of one fully healthy person.²⁵³ A question that would frame the trade-off more clearly might ask "assuming costs were the same, if you had a choice between restoring *X* individuals who suffer from nausea and

249. Pildes & Anderson, *supra* note 213, at 2148-58.

250. *See id.* at 2154.

251. *See, e.g.,* BEAUCHAMP & CHILDRESS, *supra* note 21, at 271-73 (discussing physician obligations of beneficence).

252. This limitation of *ex ante* decisionmaking also arises with respect to incommensurable health states. *See generally supra* Part III.A.3.

253. For a clear discussion of this deficiency in traditional quality-adjustment measurement, see MENZEL, *supra* note 20, at 84-86.

vomiting to full health or of preventing the death of one fully healthy person, how large a number would X have to be to make you indifferent to the alternatives?"²⁵⁴ The quality-adjustment value assigned to a health state of nausea and vomiting would then be $1-1/X$ (i.e., if $X = 1$, then nausea and vomiting gets a quality-adjustment weight of 0; if $X = 2$, then nausea and vomiting gets a quality-adjustment weight of .5; if X is infinite, then nausea and vomiting has a quality-adjustment value of 1).²⁵⁵ Quality-adjustment values that emerged from this type of questioning would, in all likelihood, better comport with public attitudes toward saving identifiable lives.²⁵⁶

IV. DO QALYS DISCRIMINATE AGAINST THE AGED AND DISABLED?

Thus far the Article has addressed arguments against QALY maximization that can, in the main, be addressed through the framework of choice. Significantly, the choice-based defense of QALY maximization developed thus far does not work against charges that it discriminates against certain groups, principally the aged and the disabled. Indeed, there are good reasons for restricting all rationing choices to the extent necessary to prevent discrimination. A forceful argument can be made that discrimination is a moral wrong irrespective of whether individuals have consented to it.²⁵⁷ Moreover, if discrimination is allowed, individual "consent" to discrimination may mean little; individuals may not have any non-discriminatory alternatives to which to give consent.

Nonetheless, in the context of allocating scarce health care resources, discrimination charges cannot be taken at face value. All methods of resource allocation that, like QALY-based rationing, attempt explicitly to choose between various alternative uses of resources will be vulnerable to such charges. Systematic allocation methods will inevitably direct resources away from certain groups of individuals and toward other groups of individuals. As a consequence, a determination that QALY-based allocation is discriminatory cannot be made without considering whether alternate resource allocation schemes would be

254. For a similar phrasing of this tradeoff, see Eddy, *supra* note 166, at 2140.

255. The quality-adjustment calculation could also accommodate directly the symbolic benefit individuals derive from saving identifiable lives. Rather than being asked simply to evaluate the outcome of death, individuals could be asked to evaluate separately an "anonymous death" and an "identifiable death." *Id.* In addition, because the Rule of Rescue value applies not only to treatment that saves identifiable lives but also to treatment for nonfatal conditions that confers significant benefit on identifiable individuals, see Hadorn, *supra* note 227, at 2219, it may also be useful to give added weight to the large QALY gain conferred by treatment for nonfatal conditions. Squaring the benefit term would, for example, enhance the weight given to large benefits (and, relatively speaking, diminish the weight given to small QALY benefits).

256. I do not mean to suggest, however, that all individuals would necessarily attach a large symbolic value to saving identifiable lives. To the contrary, questions that directly confronted individuals with trade-offs between life and other health benefits might reveal a variety of different attitudes towards the saving of identifiable lives.

257. See Dworkin, *supra* note 111, at 111 (noting that discrimination harms the class to which the individual belongs as well as society generally).

more or less discriminatory. Ultimately, given the reality of constrained resources, the very definition of what is discriminatory must turn upon a consideration of the alternatives.

A. Discrimination Against the Elderly

As a general matter, medical interventions will yield fewer life years of lesser quality for the elderly than for the young.²⁵⁸ This reality has led some critics to charge that QALY-based allocation “discriminates” against the elderly.²⁵⁹ As with many assertions of discrimination, however, this assertion ignores the question of whether alternate resource allocation schemes would similarly “discriminate” against other groups. Thus, for example, alternate measures of health benefit, such as lives saved, could be viewed as “discriminating” against the young, by directing resources away from the young and towards elderly individuals whose lives are more likely to be in danger.²⁶⁰ Moreover, there are powerful justice-based arguments that suggest individuals beyond a certain age should not receive the same types of aggressive interventions that younger individuals receive.²⁶¹

In addition, the use of QALYs would not necessarily result in severe deprivations for the elderly. The use of QALYs to ration resources away from the elderly has to be considered in light of the initial allotment of purchasing resources the elderly would receive through the risk-adjustment procedure. Because risk adjustment would principally be based on age and disability,²⁶² the risk-adjustment procedure would allocate more money to elderly individuals (particularly unhealthy elderly individuals) than to younger individuals.²⁶³ With this additional money, the elderly might be able to buy interventions with ratios of cost to QALY benefit slightly higher than those bought by the non-elderly.²⁶⁴

258. Because benefits such as life years are typically discounted, however, *see* Weinstein & Stason, *supra* note 141, at 719-20, the difference between what the young and the old typically gain in terms of life years is not as significant as one might initially think. For example, at a 5% discount rate, the discounted life years available to a 5 year old with an additional life expectancy of 70.6 years and an 80 year old with an additional life expectancy of 8.1 years are 19.4 and 6.6 respectively. *See* H. Gilbert Welch, *Comparing Apples and Oranges: Does Cost-Effectiveness Analysis Deal Fairly with the Old and Young?*, 31 GERONTOLOGIST 332, 333 (1991).

259. *See, e.g.*, Avorn, *supra* note 59, at 1298-99.

260. *See, e.g.*, Elhauge, *supra* note 1, at 1512.

261. *See supra* note 128 and accompanying text.

262. *See supra* note 121.

263. The elderly might do particularly well if risk-adjustment determinations were made by a body that was directly susceptible to political pressure. This fact may counsel, however, in favor of a process for making risk-adjustment decisions that is not very susceptible to direct political pressure. *See supra* note 129.

264. Critics of QALY-based rationing have also charged that the quality-adjustment calculation itself discriminates against the elderly, who often have disabling diseases. Avorn, *supra* note 59, at 1299. This charge is, however, essentially a claim of discrimination against the disabled. I address claims of discrimination against the disabled *infra* Part IV.B-C.

I do not address here legal issues that might arise if a QALY-based health care rationing scheme were considered an employment benefit that fell within the purview of the Age

*B. Discrimination Against the Disabled: The Ethical
Analysis*

Much more than claims of ageism, charges that QALY-based rationing discriminates against the disabled have been widely discussed.²⁶⁵ One set of charges attacks the use of QALYs as a matter of moral principle. A second set attacks QALY-based rationing as a violation of federal statutes prohibiting discrimination against the disabled. Although the legal charges are, in some respects, less fundamental, they have, as we shall see, proved to be the most substantial practical obstacle to the implementation of QALY-based rationing. In this Part, I propose a modified form of QALY-based rationing that addresses the moral claims. In the next Part, I argue that federal anti-discrimination law can, and should, be interpreted in a manner that allows for this modified form of QALY-based rationing.

Critics have argued that bias against the disabled inheres in the very idea of quality adjustment. On this view, quality adjustment based on the views of the majority necessarily reflects the negative attitudes that nondisabled people have toward individuals with disabilities. This criticism is, to some extent, supported by empirical data. The views that disabled persons have of their state appear to differ, at least in some contexts, from the views that nondisabled persons have.²⁶⁶ Thus, any proposal for a QALY-based option must address the conceptual question of whose quality-adjustment ratings should be used.

This question, in turn, revolves around the issue of whose quality-adjustment ratings would best approximate the *ex ante* perspective.²⁶⁷ On first examination, the health valuations of the nondisabled might be thought to reflect the *ex ante* perspective better than the health valuations of those who were in specific disabled states. The valuations of nondisabled individuals would, however, be only a rough approximation of the *ex ante* position—the preferences being averaged would be those of individuals who *did* know, at least to some extent, what their health status would be. For example, nondisabled individuals would

Discrimination in Employment Act. Under the proposal made in this Article, health care benefits would not be linked to employment.

265. See, e.g., Hadorn, *supra* note 195; Paul T. Menzel, *Oregon's Denial: Disabilities and Quality of Life*, 22(6) HASTINGS CENTER REP. 21 (1992) (discussing claims that QALYs result in discrimination against persons with disabilities); Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491 (1995).

266. See Peters, *supra* note 265, at 534 n.200 (collecting empirical studies that show differences in evaluation in certain circumstances and no differences in evaluation in other circumstances). *But see* Hadorn, *supra* note 195, at 1455 (arguing that there is substantial evidence that values of disabled people do *not* differ from those of nondisabled people).

267. Using the *ex ante* perspective would be important because the essence of insurance is before-the-fact protection against risk. We would not want individuals who knew their particular disability to “game” the system by assigning quality-adjustment ratings for the specific purpose of directing resources only toward their particular disability.

Of course, if genetic technology develops to the point where most, if not all, individuals can predict all aspects of their future health, the very notion of health insurance may become antiquated. That question is, however, beyond the scope of this Article.

know that they would not be the victims of early onset genetic disabilities. Thus, for any particular health state, the best approximation of an ex ante valuation would probably be achieved by combining, through some sort of average or weighted average, the evaluations of those who had experienced the health state in question and those who had not.²⁶⁸

Admittedly, any such combination process would be vulnerable to criticism.²⁶⁹ Consequently, it is fortunate that close analysis of the discrimination question reveals that the crux of the problem does not lie with biased quality-adjustment measurements. Rather, it lies in certain uses of QALY-based allocation. Indeed, for the purposes of just health care distribution, the debate about biased quality-adjustment ratings is fairly tangential. If QALY-based allocation is used in the manner proposed below, even biased quality-adjustment measurements would not generally discriminate against individuals with disabilities. To the contrary, the use of biased quality-adjustment ratings would be likely, on balance, to result in favorable treatment of individuals with disabilities.²⁷⁰

As an initial matter, because QALY-based allocation is based on *changes* between health states, the relevant discrimination question is not whether absolute quality-adjustment ratings are biased, but, rather, whether, (and how) these biased ratings affect the amount of QALY change. Favorable treatment based on biased quality-adjustment ratings would occur in situations where disabled individuals who were assigned low quality-adjustment ratings by the general population could achieve large QALY gains from interventions that improved their status—they would realize a large QALY gain precisely because of their initially low quality-adjustment rating.²⁷¹

Indeed, there are only two circumstances in which the use of biased quality-adjustment ratings would discriminate against the disabled; neither of these

268. Paul Menzel argues that for individuals who have congenital or early onset disabilities, the ex ante perspective should not be used. See Menzel, *supra* note 265, at 23. Rather, because these individuals “have not been able to share in the before-the-fact, risk-taking perspective from which people can make fair quality of life assessments,” *id.*, we should use these individuals’ ex post quality-of-life adjustments. The exemption from ex ante quality-of-life judgments that Menzel gives to individuals with congenital or early onset disabilities is a subset of the general exemption from the ex ante perspective that Menzel gives to such individuals. See MENZEL, *supra* note 20, at 99-100 (arguing that rationing based on ex ante consent should not apply to individuals with congenital disabilities because they know their disabilities at birth and thus would not consent to restrictions on their care at that point). The response to Menzel’s argument in this specific context (as in the more general context) is that he gives no reason why individuals should be exempt from ex ante allocation decisions just because their disabilities set in at birth rather than at some point later in life. For a similar point, see Elhauge, *supra* note 1, at 1536-37.

269. See *supra* note 173 and accompanying text (noting criticism of Oregon’s averaging of disparate quality-of-life preferences).

270. This is, of course, not an argument for the use of biased quality-adjustment ratings but, rather, simply an argument that bias in quality-adjustment ratings is not the central discrimination issue.

271. Several commentators who are otherwise wary of QALY-based allocation have acknowledged that, for certain treatments, even QALY-based allocation that relies on “biased” quality-of-life estimates will be favorable to individuals with disabilities. See Menzel, *supra* note 265, at 23; Peters, *supra* note 265, at 543-45.

circumstances invalidates the use of quality-adjustment ratings, even quality-adjustment ratings that might be considered biased. The first circumstance would involve conditions that could be treated, but only incompletely—the treatment would leave behind residual disabilities. If the residual disability state were given an inappropriately low quality-adjustment rating, the quality-of-life (and QALY) improvement associated with the treatment would also be inappropriately low. The discrimination concerns raised by such undervaluation are not insignificant. Thus, the use of quality-adjustment valuations that accurately reflect an unbiased *ex ante* perspective is important. Nonetheless, for individuals with disabilities, the detriment imposed by biased quality adjustments in this context might well be balanced by the benefit conferred by biased quality adjustments in other contexts.²⁷²

The other circumstance in which biased quality-adjustment ratings would be detrimental to the disabled would arise if an individual with a health problem were denied medical intervention for that problem because she had an *unrelated* disability that necessarily caused her to achieve a smaller QALY gain from that intervention than a person without that disability. In that case, however, any use of conventional QALY-based allocation would be suspect in the first instance. Using QALY-based allocation in that circumstance would systematically direct resources away from *all* individuals with disabilities. The question of whether biased or unbiased quality-adjustment ratings were being used would be irrelevant.

This point becomes readily apparent when it is made in concrete terms. Consider a choice between two candidates for a liver transplant. One of them has full mobility; the other needs the assistance of a cane in walking. Even if the transplant would be equally successful in restoring liver function in either candidate, conventional QALY maximization would require that the transplant be given to the nondisabled candidate: because the nondisabled candidate would be returned to a cane-independent state, she would necessarily achieve a larger QALY gain from the transplant than the disabled candidate (who could only be returned to a cane-dependent state). Cane dependence is, however, entirely unrelated to the medical success of the transplant operation. Quality adjustment should not, therefore, be used to allocate livers away from those who walk with canes. Invoking quality adjustment in this and similar situations would systematically allocate medical resources away from all individuals with disabilities, no matter how amenable their other health difficulties were to medical treatment.²⁷³ This systematic diversion would occur irrespective of

272. See *supra* note 271 and accompanying text. In addition, because disabled individuals would receive a larger risk-adjusted voucher than nondisabled individuals, they might be able to buy interventions with ratios of cost to QALY benefit slightly higher than those bought by nondisabled individuals.

273. Einer Elhauge has made a similar point. See Elhauge, *supra* note 1, at 1514-16; see also Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1650-55 (1993) (arguing that disability should be considered only if it has a "medical effect" on the treatment plan).

whether the quality-adjustment ratings being used were biased.²⁷⁴ Indeed, quality-adjustment ratings would be used not for the limited purpose of judging the medical efficacy of particular interventions in treating particular disabilities, but for the much broader, highly problematic purpose of categorically judging all persons with disabilities less worthy than nondisabled persons of receiving any sort of medical treatment. For these reasons, QALY-based allocation should not be utilized to allocate interventions for individuals with disabilities when the medical efficacy of the intervention is in no way related to the disability.

Because this "relatedness" requirement is critical, it is important to emphasize precisely what it would mean in particular cases. For example, certain disabilities are so pervasive that virtually all medical treatments needed by an individual with that disability should be considered related to the disability. Hence, virtually all medical treatments required by an anencephalic child, an individual in a persistent vegetative state ("PVS"), or an individual in the final stages of a terminal illness, should probably be considered related to the anencephaly, PVS, or terminal illness, in the sense that the efficacy of the medical treatment will almost certainly be affected by those conditions. Similarly, it is well accepted that a patient with diabetes or pulmonary disease will be a poorer candidate for coronary artery bypass surgery than a patient who is otherwise healthy.²⁷⁵ In making a determination regarding such surgery, diabetes and pulmonary disease should therefore be considered related conditions.

Admittedly, imposing this "relatedness" requirement on QALY-based allocation represents a considerable departure from straightforward QALY maximization. Consider the choice between a Down's Syndrome baby and a nondisabled newborn, both of whom are candidates for a lifesaving operation to unblock an esophagus.²⁷⁶ Under the modified form of QALY-based allocation proposed here, if the operation would work equally well to unblock the esophagus of either newborn, the operation would not be given preferentially to the nondisabled newborn. This would be the case even though, under conventional QALY maximization, the Down's Syndrome baby would realize significantly fewer QALYs from the operation than the nondisabled newborn. This departure from straightforward utility maximization would be necessary, however, in order that QALYs not be used to relegate all persons with disabilities to a status inferior to that of nondisabled persons.

274. I assume that even an "unbiased" quality-adjustment rating for most disabilities would be less than one.

275. See Hadom, *supra* note 195, at 1457-58; see also Orentlicher, *supra* note 185, at 310.

276. This example is taken from a real incident. In that incident, because the parents of a Down's Syndrome newborn refused to consent to the esophageal operation, the baby died. See *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 617-18 (1986) (summarizing case). In response to this incident, which occurred in the early 1980s, the Department of Health and Human Services issued the so-called "Baby Doe" regulations, which prohibited "discrimination" in the provision of medical care to handicapped infants. Various versions of these rules were struck down as improperly promulgated under the Rehabilitation Act of 1973. *Id.* at 617-47 (striking down "Baby Doe" rules as without rational and factual basis and noting previous court decision striking down rules as arbitrary and capricious). For further discussion of the Rehabilitation Act and its application to disabled individuals, see *infra* Part IV.C.

By contrast, if QALY-based allocation is used to allocate medical treatment preferentially towards disabilities that are likely to be ameliorated by the treatment, it discriminates not against persons with disabilities but between particular disabilities. Consider two individuals (*A* and *B*) with different types of cancer. Assume that the only available treatment is chemotherapy. Without chemotherapy, both *A* and *B* will die. With chemotherapy, *A* will live an additional ten years of 0.8 quality (for a gain of 8 QALYs), while *B* will live an additional six years of 0.8 quality (for a gain of 4.8 QALYs). Using QALY-based rationing in this situation, to favor *A* over *B*, would discriminate not against persons with disabilities—both *A* and *B* are, after all, disabled with cancer—but between disabilities—between a type of cancer that is more amenable to treatment and a type that is less amenable.

So long as unbiased quality-adjusted ratings are used, this use of QALYs would be no different from the use of any other measure of health benefit, including health benefit measures such as two-year and five-year survival rates that are commonly used in the medical profession. No matter what measure of health benefit is used (e.g., lives saved, survival rates), maximizing that benefit discriminates against individuals who lack the capacity to achieve that health benefit measure.²⁷⁷ Of course, some commentators believe that all schemes of benefit maximization are suspect because they direct resources away from those who lack the requisite capacity to benefit. This argument is not, however, a reasonable one: under a scheme that preferentially allocated resources to those diseases that were the most intractable, society would spend all its resources on a few individuals, produce relatively minimal benefit for those individuals, and ignore the claims of those individuals whose conditions could have been improved significantly.²⁷⁸

It is important to emphasize the effect of this Article's proposal for a modified form of QALY-based allocation on the use of lifesaving interventions. Critics of QALY-based allocation have argued that the use of such allocation in life threatening situations necessarily implies that the life of a disabled person is worth less than the life of a nondisabled person.²⁷⁹ This is because saving the life of the nondisabled person always yields a larger quality-adjustment gain than saving the life of the disabled person.²⁸⁰ On this view, QALY-based allocation should be restricted to interventions that are not lifesaving.²⁸¹

The significant distinction, however, is not between lifesaving interventions and interventions that are not lifesaving but between interventions that are related to the disability in question and those that are not. Application of the

277. See, e.g., Peters, *supra* note 265, at 533 (noting that maximizing survival rates will result in exclusion of individuals who lack capacity to achieve those survival rates).

278. See *supra* note 41.

279. See, e.g., Peters, *supra* note 265, at 535-45; see also Menzel, *supra* note 265, at 23 (noting that QALY-based allocation would disfavor individuals with disabilities in the context of lifesaving or life-extending care).

280. Denial of lifesaving treatment means death (quality adjustment of zero). Thus the quality-adjustment difference with and without treatment is the same as the individual's absolute quality-adjustment rating.

281. Peters, *supra* note 265, at 535-45.

modified QALY-based allocation scheme presented here would mean that disabled persons would have the same access to lifesaving measures as nondisabled people *so long as* the disability did not affect the medical efficacy of the intervention. Thus, as discussed above, a Down's Syndrome baby would be as likely to receive a lifesaving operation to unblock its esophagus as a non-Down's Syndrome baby. On the other hand, if the lifesaving intervention was necessary precisely because of the disability—say intervention to save the life of a premature 500 gram baby—then the likelihood of benefit from such an intervention (as well as its cost) would have to be assessed. If the intervention were denied, it would be denied not because of the disability itself, or because the disabled person's life was worth less than that of a nondisabled person, but because the disability was one for which there was no treatment sufficiently effective to justify its cost.

C. Modified QALYs and the Disability Laws

The argument that QALY-based allocation discriminates against the disabled first achieved prominence in a legal context when the Bush Administration rejected the revised Oregon Medicaid proposal²⁸² on the grounds that its use of quality-of-life measures²⁸³ violated the Americans with Disabilities Act ("ADA").²⁸⁴ The Bush Administration's decision brought to an abrupt halt efforts by a large number of states to ration Medicaid services through the use of QALYs.²⁸⁵ Indeed, since the decision, neither the public nor private sector has attempted to put forth plans that explicitly utilize QALYs as a rationing criterion. Thus the question of whether the modified QALY-based scheme I have proposed would satisfy the requirements of federal law prohibiting discrimination against the disabled is a critical one. I argue below that, although the language of the relevant federal statutes is subject to divergent interpretations, modified QALY-based rationing can, and should, withstand scrutiny. Moreover, applying these

282. As discussed *supra* Part III.B.2, the Oregon prioritization scheme had been revised in response to charges that it did not value sufficiently interventions that saved identifiable lives.

283. Oregon's revised proposal used quality-of-life judgments in two ways. First, most of the 17 categories into which services were placed were defined in terms of quality of life. For example, the top-ranked category was for treatment that prevented death with "return to previous health." In addition, within service categories, treatments were ranked by the number of QALYs they produced. Hadorn, *supra* note 152, at 11-12.

284. See Letter from Louis W. Sullivan, M.D., Secretary of Health and Human Services, to Barbara Roberts, Governor of Oregon (Aug. 3, 1992), reprinted in 9 ISSUES L. & MED. 397, 409 (1994). Because Medicaid is largely a state-run program, the ADA, rather than the Rehabilitation Act, was applicable. In order to implement its Medicaid proposal, however, the state of Oregon had to obtain a waiver from the federal government. See 42 U.S.C. § 1315(a) (1988).

285. Prior to the federal government's rejection of the Oregon plan, 18 other states had proposed health care reform modeled on the Oregon plan. Eric L. Robinson, Note, *The Oregon Basic Health Services Act: A Model for State Reform?*, 45 VAND. L. REV. 977, 978-79 (1992). After the Bush Administration's rejection of the use of quality-of-life measures, Oregon altered its plan to remove all references to quality of life, and the other states also redesigned their rationing schemes.

statutes to QALY-based rationing can help illuminate the manner in which the central terms in these statutes should be interpreted with respect to health care resource allocation more generally. Interpretations of the statutes that would altogether preclude the use of QALYs would also preclude all use of capacity-to-benefit criteria and would call into serious question the significant efforts that are being made to systematize medical decisionmaking through the use of clinical effectiveness data.

1. Laws Prohibiting Disability-Based Discrimination

The ADA²⁸⁶ and the Rehabilitation Act of 1973²⁸⁷ are parallel statutes that respectively bar discrimination against persons with disabilities²⁸⁸ in federally funded programs and non-federally funded programs. Under the choice-based system that I have proposed, a modified QALY-based rationing plan might be subject to scrutiny under the Rehabilitation Act or the ADA.²⁸⁹ I thus analyze the provisions of both statutes.

As a preliminary matter, it is important to note that the language of the ADA as well as its legislative history demonstrate that it should be interpreted consistently with the Rehabilitation Act.²⁹⁰ This parallel interpretation is

286. 42 U.S.C. §§ 12101-12213 (1994).

287. 29 U.S.C. §§ 701-797(b) (1994).

288. In both the ADA and the Rehabilitation Act, the definition of disability is very broad. It includes individuals who have "a physical or mental impairment which substantially limits a major life activity," who have "a record of such impairment," or who are "regarded as having such an impairment." 29 U.S.C. § 706(8)(B) (1994) (Rehabilitation Act); 42 U.S.C. § 12102(2) (1994) (ADA). Physical and mental impairments include physiological disorders or impairments that affect any body system as well as psychological disorders such as learning disabilities and mental illness. *See, e.g.*, 28 C.F.R. § 35.104 (1996) (ADA regulations for state and local government services); 45 C.F.R. § 84.3(j)(2)(i) (1996) (Rehabilitation Act regulations). Regulations promulgated under section 504 of the Rehabilitation Act define major life activities to include walking, learning, breathing, working, or participating in community activities. 45 C.F.R. § 84.3(j)(2)(ii) (1996). The legislative history of the ADA endorses this definition. H.R. REP. NO. 101-485, pt. 2, at 51-52 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 333-34. Finally, the major life activity requirement is not a significant limitation on the scope of the disability laws. Indeed, in the context of the Rehabilitation Act, the Supreme Court has stated that the fact that an individual has been hospitalized is "more than sufficient" to establish that the condition substantially limits major life activities. *School Bd. v. Arline*, 480 U.S. 273, 281 (1987).

289. QALY-based plans administered by private insurance companies might be subject to either Rehabilitation Act or ADA requirements (depending on whether federal money was allocated directly to the plans or was given to individuals in the form of vouchers). Plans administered by the federal government would be subject to Rehabilitation Act requirements. Plans administered by state governments would be subject to ADA requirements.

290. *See, e.g.*, 42 U.S.C. § 12117(b) (1994) (stating that standards for employment discrimination actions under Title I of the ADA should be consistent with those of the Rehabilitation Act); *id.* § 12201(a) ("Nothing in this Act shall be construed to reduce the scope of coverage or apply a lesser standard than the coverage required under title V of the Rehabilitation Act . . ."); H.R. REP. NO. 101-485, pt. 2, at 50 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 332 (defining the term "disability" in ADA as comparable to that of "individual with handicaps" in the Rehabilitation Act); *id.* at 67, *reprinted in* 1990

particularly important because the large body of case law under the Rehabilitation Act can inform the analysis of the more recently enacted ADA.

Sections 501 and 503 of the Rehabilitation Act prohibit the federal government and federal contractors from discriminating in employment.²⁹¹ Section 504 of the Rehabilitation Act goes beyond employment and bars discrimination by any federal program or any program receiving federal financial assistance against an "otherwise qualified" individual with a disability "by reason of his or her disability."²⁹² The ADA extends this protection against discrimination "on the basis of disability"²⁹³ to the following areas potentially relevant to health care: private employment (Title I),²⁹⁴ public services and programs provided by state and local governments (Title II),²⁹⁵ and "public accommodations" (Title III),²⁹⁶ a broadly defined category that includes insurance offices and the "professional office of a health care provider."²⁹⁷ Consequently, disability laws potentially cover federally funded health programs, state funded programs, benefits provided by private employers, other types of private insurance,²⁹⁸ and physician services. Because the choice-based rationing that I have proposed would not, however, be funded or implemented by employers,²⁹⁹ I will not focus on the legal complexities particular to the application of disability law in the employment area.

Under both statutes, a central question for the discrimination analysis is whether the person is a "qualified individual with a disability"³⁰⁰—that is,

U.S.C.C.A.N. at 349 ("undue hardship" standard under Title I of the ADA derived from agency regulations interpreting sections 501 and 504 of Rehabilitation Act); *id.* at 84, *reprinted in* 1990 U.S.C.C.A.N. at 366-67 (extending anti-discrimination provision of section 504 of Rehabilitation Act to cover state and local governments under Title II of the ADA); H.R. REP. NO. 101-485, pt. 3, at 32-33 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 455 (stating that "qualified individual with a disability," used in Title I, is same concept used in regulations implementing sections 501 and 504 of the Rehabilitation Act); *id.* at 51, *reprinted in* 1990 U.S.C.C.A.N. at 474 (noting that with respect to program access under Title II, ADA incorporates regulations applicable to federally conducted activities under section 504).

291. 29 U.S.C. §§ 791, 793 (1994).

292. *Id.* § 794(a).

293. *See* 42 U.S.C. § 12101(a)(4) (1994).

294. *Id.* §§ 12111-12117.

295. *Id.* §§ 12131-12165.

296. *Id.* §§ 12181-12189.

297. *Id.* § 12181(7)(F). The various titles contain slight variations on the general prohibition of discrimination "on the basis of" disability. *See* Title I, *id.* § 12112(a) (barring discrimination in private employment "because of the disability"); Title II, *id.* § 12132 (barring discrimination in state and local public programs and services "by reason of" disability); Title III, *id.* § 12182(a) (barring discrimination in public accommodations "on the basis of disability").

298. The ADA's coverage of insurance programs is, however, limited by the exemption it gives to insurance underwriting activities carried on by insurance programs. *See infra* notes 314-17 and accompanying text.

299. *See generally supra* Part I.B.2 (noting that plans would be federally funded and would be administered by private insurance companies as well as by federal and state governments).

300. This is the language used in Titles I and II, the employment and public services titles of the ADA. *See* 42 U.S.C. §§ 12111(8) (employment), 12131(2) (public services). Similarly, the Rehabilitation Act discusses discrimination against "otherwise qualified" individuals. *See* 29 U.S.C. § 794(a). Title III, the public accommodation title of the ADA, does not use the

whether, with reasonable accommodation or modification of the program in question, the person can meet the program's "essential eligibility requirements."³⁰¹ Reasonable accommodations or modifications are those changes that are not "fundamental" or that can be undertaken without causing "undue burden" to the program or activity in question.³⁰²

"qualified" language; rather, it discusses discrimination "on the basis of disability." See 42 U.S.C. § 12182(b)(1)(A)(i). The Supreme Court has held, however, that conduct that discriminates "on the basis of" disability is the same as conduct that discriminates against a "qualified" disabled individual. See *Alexander v. Choate*, 469 U.S. 287, 299 n.19 (1985).

This focus on "qualified" individuals with disabilities signals an important difference between laws governing disability discrimination and other types of anti-discrimination law, particularly laws governing discrimination on the basis of race. While discrimination on the basis of race is presumptively illegal, discrimination against an individual with a disability is illegal only if the individual is "qualified."

301. The Department of Health and Human Services ("HHS") regulations implementing the Rehabilitation Act define a "qualified handicapped person" as one "who meets the *essential eligibility requirements* for the receipt of such services." 45 C.F.R. § 84.3(k)(4) (1996) (emphasis added) (applying to services other than employment or education); see also 45 C.F.R. § 84.3(k)(1) (With respect to employment funded by HHS, a qualified handicapped person is one who, with reasonable accommodation, can perform the "essential functions" of the job.). Title II of the ADA, which governs public services, refers to "an individual with a disability who, with or without reasonable modifications to rules, policies, or practices . . . meets the *essential eligibility requirements* for the receipt of services or the participation in programs or activities provided by a public entity." 42 U.S.C. § 12131(2) (emphasis added). Title III, which governs public accommodations, permits the use of "necessary" eligibility criteria. 42 U.S.C. § 12182(b)(2)(A)(i). Finally, Title I of the ADA, which regulates employment, refers to "an individual with a disability who, with or without reasonable accommodation, can perform the *essential functions* of the employment position that such individual holds or desires." 42 U.S.C. § 12111(8) (emphasis added). The Title I reference to "essential functions" is, of course, a reference to job functions, not health insurance functions. Although it is not entirely clear whether, and how, this "essential function" requirement would apply to employer-provided health insurance benefits, there is no reason to believe that Congress intended to impose a more stringent anti-discrimination prohibition on employers than it imposed on public services and public accommodations that provide health insurance and health care. See *Peters, supra* note 265, at 512 (suggesting that courts would interpret the Titles similarly, so as to apply an "essential function" requirement to the receipt of employer provided health benefits). In any event, because this Article proposes that health care benefits be provided independent of employment, the issue is not critical for the analysis here.

302. See *Southeastern Community College v. Davis*, 442 U.S. 397, 410 (1979) (interpreting Rehabilitation Act as not requiring accommodations that alter the "fundamental . . . nature of a program"). As for the ADA, the language of the reasonable accommodation or modification requirement varies to some extent depending on which Title of the ADA is involved. The reasonable accommodation requirement under Title I of the ADA stops short of accommodations that could cause "undue hardship." See 42 U.S.C. §§ 12111(10), 12112(b)(5)(A) (1994). Such "undue hardship" is measured by looking at various factors, including the nature and cost of the accommodation and the overall financial resources and structure of the covered entity. *Id.* § 12111(10). Title II uses a "reasonable modification" standard; reasonable modifications are modifications that do not cause "undue hardship." H.R. REP. NO. 101-485, pt. 1, at 50-51 (1990), reprinted in 1990 U.S.C.C.A.N. 445, 473-74 (discussing Title II employment). Title III of the ADA, which governs public accommodations, requires "reasonable modifications," so long as these modifications do not "*fundamentally alter* the nature of such goods, services, facilities, privileges, advantages, or accommodations." 42

2. Discrimination Challenges to Health Care Rationing

The Rehabilitation Act and ADA provide two bases for a claim of discrimination against individuals with disabilities in health care rationing schemes. Disabled individuals could charge either that a particular rationing scheme treated them disparately or that it had a disparate impact on their ability to receive health care services.³⁰³ The availability of a disparate treatment claim is clear from the disability laws' definition of a "qualified individual with a disability" as an individual who, with reasonable accommodation, can meet the "essential eligibility requirements" of a program.³⁰⁴ If a rationing scheme had disability-based eligibility requirements that were not "essential" or "necessary" for the operation of the scheme, it would violate the disability laws. The rationing scheme would also violate the disability laws if there were a reasonable accommodation that could be made so that the disabled person would meet the scheme's essential eligibility requirements.

The other type of claim that could be made under the disability laws would be a disparate impact claim. In *Alexander v. Choate*,³⁰⁵ the Supreme Court suggested that some conduct that has a disparate impact on individuals with disabilities may be challenged under the Rehabilitation Act.³⁰⁶ The Court established a denial of "meaningful access"³⁰⁷ standard as the test for determining whether a particular

U.S.C. § 12182(b)(2)(A)(ii) (emphasis added). Some commentators have argued that the "fundamental alteration" limit creates a more exacting standard than the "undue hardship" limit. Robert L. Burgdorf, Jr., *The Americans with Disabilities Act*, 26 HARV. C.R.-C.L.L. REV. 413, 462 (1991). However, the legislative history indicates that the standards are the same. The history defines "undue hardship" as "action . . . that will *fundamentally alter* the nature of the program." H.R. REP. NO. 101-485, pt. 2, at 67 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, at 349 (emphasis added).

303. See Note, *The Oregon Health Care Proposal and the Americans with Disabilities Act*, 106 HARV. L. REV. 1296 (1993) (discussing disparate treatment and disparate impact claims under the ADA). See generally *Alexander v. Choate*, 469 U.S. 287, 292-99 (1985) (discussing, and distinguishing between, action that discriminates against the handicapped by design and by effect).

304. See *supra* notes 300-01 and accompanying text.

305. 469 U.S. 287 (1985).

306. *Id.* at 299 ("[W]e assume without deciding that Section 504 [of the Rehabilitation Act] reaches at least some conduct that has an unjustifiable disparate impact."); see also Note, *supra* note 303, at 1300-01 (describing contours of denial of meaningful access claim). Although *Choate* was a case brought under the Rehabilitation Act, the legislative history of the ADA demonstrates that Congress explicitly adopted the reasoning of *Choate* as applicable to claims brought under the ADA. H.R. REP. NO. 101-485, pt. 2, at 61, *reprinted in* 1990 U.S.C.C.A.N. at 343 (noting that section 102(b)(3) of Title 1 of the ADA, which prohibits "utilizing standards, criteria, or methods of administration that have the effect of discrimination on the basis of disability" incorporates disparate impact standard of *Choate*); *id.* at 84, *reprinted in* 1990 U.S.C.C.A.N. at 367 (stating that section 202 of the ADA, which defines discrimination in public services, should be interpreted consistently with *Choate*); see also *supra* note 290 and accompanying text (observing that the ADA's discrimination standards are parallel to those of the Rehabilitation Act).

307. *Choate*, 469 U.S. at 301.

program violates the Rehabilitation Act. Moreover, to assure meaningful access, "reasonable accommodations in the grantee's program or benefit may have to be made."³⁰⁸

Meaningful access is, however, quite a narrow safeguard. It ensures only the same benefit, not equality of results. In *Choate*, the Court addressed a Rehabilitation Act challenge to Tennessee's proposal to reduce Medicaid coverage from twenty inpatient hospital days a year to fourteen hospital days. The proposal was challenged on the grounds that it discriminated against individuals with disabilities, who typically spend more time in the hospital than nondisabled patients.³⁰⁹ The Court held that the proposal did not deny "meaningful access" to individuals with disabilities, even though it did impact these individuals disparately. The proposal provided meaningful access by giving to each individual the same "identical and effective hospital services"—fourteen days of paid inpatient care a year.³¹⁰ The Court explicitly rejected the argument that, given the greater medical needs of individuals with disabilities, Tennessee had to provide the individuals with disabilities more than fourteen days of coverage in order to provide them meaningful access. The Court emphasized that "[t]he Act does not . . . guarantee the handicapped equal results . . . even assuming some measure of equality . . . could be constructed."³¹¹ The Court also emphasized the enormous administrative and adjudicative difficulties that would be involved if all federal actions had to be evaluated for their effect on the handicapped.³¹² Responding to the alternative argument that any limitation on payment for inpatient care would disparately impact the handicapped in violation of the Rehabilitation Act, the Court sounded a similar theme. It noted that:

[T]o require the sort of broad-based distributive decision at issue in this case always be made in the way most favorable, or least disadvantageous, to the handicapped, even when the same benefit is meaningfully and equally offered to them, would be to impose a virtually unworkable requirement on state Medicaid administrators.³¹³

The scope of these disparate treatment and disparate impact claims is also limited by an ADA provision that exempts insurance underwriting practices from scrutiny under the ADA. Under this exemption, the ADA titles governing employment, public services, and public accommodations do not bar insurance plan terms that are based on "underwriting risks, classifying risks, or

308. *Id.*

309. In the 1979-80 fiscal year, 27.4% of disabled individuals required more than 14 days of hospital care, as contrasted with only 7.8% of nondisabled individuals. *Id.* at 290.

310. *Id.* at 302.

311. *Id.* at 304.

312. *Id.* at 298-99 ("Had Congress intended § 504 to be a National Environmental Policy Act for the handicapped, requiring the preparation of 'Handicapped Impact Statements' before any action was taken by a grantee that affected the handicapped, we would expect some indication of that purpose in the statute or its legislative history.") (footnote omitted).

313. *Id.* at 308; *see also* *Doe v. Colautti*, 592 F.2d 704 (3d Cir. 1979) (upholding regulations that limited private inpatient psychiatric care to 60 days even though regulations set no limit on duration of coverage for physical illnesses).

administering such risks.³¹⁴ As a consequence, policies that treat individuals with disabilities disparately or have disparate impact—policies that, for example, deny or limit coverage for treatments necessitated by certain disabilities, that charge different premiums because of the disabilities, or that altogether exclude coverage for the disabilities—are sanctioned so long as the justification for their existence is cost.³¹⁵ Thus, for example, an insurance policy could permissibly cover only a specified number of transfusions per year, even though such a policy would disparately impact hemophiliacs.³¹⁶ Indeed, the insurance plan could even eliminate all coverage of transfusions.³¹⁷

3. Application to Modified QALY-Based Rationing

a. Discrimination Against Disabled Individuals Generally

In its rejection of the Oregon proposal, the Bush Administration charged that Oregon's use of quality-adjustment ratings discriminated against all disabled individuals, in violation of the ADA; the Administration argued that such ratings are "based . . . on the 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."³¹⁸

314. 42 U.S.C. § 12201(c)(1), (2) (1994).

315. H.R. REP. NO. 101-485, pt. 3, at 37-38 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 460-61; H.R. REP. NO. 101-485, pt. 2, at 136-38 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 419-21.

316. H.R. REP. NO. 101-485, pt. 3, at 38, *reprinted in* 1990 U.S.C.C.A.N. at 460-61. Even without the insurance exemption, such limitations would probably be permissible because disabled individuals would have "meaningful access" to the limited benefit. *See supra* notes 309-13 and accompanying text (discussing Supreme Court's definition of meaningful access in *Alexander v. Choate*, 469 U.S. 287 (1985)).

317. H.R. REP. NO. 101-485, pt. 3, at 38, *reprinted in* 1990 U.S.C.C.A.N. at 460-61. Again, even without the insurance exemption, elimination of transfusion coverage would probably be acceptable so long as hemophiliacs had "meaningful access" to other treatments that were covered by the insurance plan.

318. Analysis Under the Americans with Disabilities Act ("ADA") of the Oregon Reform Demonstration (Attachment to Letter from Louis W. Sullivan to Governor Barbara Roberts (Aug. 3, 1992)), *in* 9 ISSUES L. & MED. 397, 410 (1994) [hereinafter ADA Analyses]. Some critics of quality-adjustment measures have argued that quality-adjustment measures should reflect the views that disabled individuals have of their own health states. The Bush Administration alleged, however, that *any* use of quality-adjustment measures would violate the ADA.

The Bush Administration also suggested that Oregon's quality-of-life figures violated the ADA because they embodied stereotyped assumptions about individuals with disabilities. ADA Analyses, *supra*, at 410. In the modified QALY-based allocation scheme discussed here, the use of possibly biased quality-adjustment ratings would not necessarily allocate treatments away from individuals with disabilities. *See supra* note 271 and accompanying text. Nonetheless, the use of quality-of-life measures that accurately reflect an unbiased ex ante perspective is important, in order that treatment that offers only an incomplete cure is not inappropriately downgraded. This unbiased ex ante valuation would, however, be very different

Taken at face value, this charge betrays a fundamental misunderstanding of the manner in which quality-adjustment ratings are used. Absolute quality-adjustment ratings have no significance; only changes in quality adjustment are important. On its face, this charge also does not allege the basic elements of a Rehabilitation Act or ADA violation. A violation of these disability laws cannot occur absent deprivation, on the basis of disability, of some tangible benefit (in this case a health care benefit). Moreover, to the extent that the charge alleges that QALY-based allocation schemes violate the disability laws because they necessarily distribute health care benefits in a manner that implies that the lives of disabled individuals are worth less than those of nondisabled individuals,³¹⁹ this simply does not have to be the case. As discussed earlier,³²⁰ QALY-based allocation values the life of a person with a disability less than that of a person without a disability in only one circumstance—if it is used to deny care *unrelated* to the disability. As such, the modified QALY-based allocation scheme proposed here does not violate the disability laws by discriminating against disabled individuals generally.

b. Discrimination Against Particular Disabled Individuals

Although individuals with disabilities could not, as a group, challenge the modified QALY-based allocation scheme proposed here, individuals with particular disabilities that were difficult to treat might attempt to challenge such allocation. Even modified QALY-based allocation would, after all, systematically allocate resources away from individuals who had disabilities that were particularly difficult to treat. Depending on the details of the rationing, disabled individuals might attempt to bring either a disparate treatment or disparate impact claim. As an example of the former, Oregon's rationing decision to deny treatment to infants under 500 grams could have been challenged as illegitimate disparate treatment of that group of infants.³²¹ Similarly, if a plan denied coverage for a particular treatment, say coronary artery bypass surgery, for patients who had comorbid conditions such as diabetes that diminished the efficacy of the surgery (and hence the number of QALYs they could realize from the surgery), such patients could charge that they had been treated disparately on the basis of their comorbidity, in violation of the disability laws.

from the Bush Administration's position that all health states are equally valuable. *See* ADA Analyses, *supra*, at 410 (suggesting that all health states should be rated at 0.5).

319. The Bush Administration's rejection of the Oregon plan also charged that quality-adjustment ratings "expressly value a person without a disability more highly than a person with a disability *in the allocation of medical treatment.*" ADA Analyses, *supra* note 318, at 411 (emphasis added).

320. *See supra* notes 273-74 and accompanying text.

321. The Bush administration pointed to this decision as an example of how Oregon's use of quality-of-life measures violated the ADA. ADA Analyses, *supra* note 318, at 411-12. The ADA does not, however, necessarily support such a conclusion. *See infra* notes 325-42 and accompanying text.

Of course, even if modified QALY-based allocation did not specifically exclude particular patients with comorbidities or disabilities that reduced their likelihood of achieving a favorable health outcome, it could exclude the types of treatments needed by those patients. Under the reasoning of *Alexander v. Choate*,³²² however, unless a plan specifically excluded treatments that were needed only by individuals with particular disabilities—an exclusion for HIV-related treatment, for example—it would be difficult to make a disparate impact claim. In other circumstances, the plan would simply be excluding treatments that were needed both by disabled individuals and by individuals who were not disabled. Under *Choate*, the fact that disabled individuals might need a particular benefit more would not signal discrimination.³²³ Moreover, a challenge to exclusion of treatment needed exclusively for a particular disability would essentially be a disparate treatment challenge. Thus most viable disparate impact challenges would reduce to disparate treatment challenges.

Because the vast majority of discrimination claims would be disparate treatment claims—in other words, claims that a medical intervention was being denied to an individual with a disability for the specific reason that the disability could not significantly be ameliorated by the intervention—the central question would be whether capacity to achieve a QALY benefit was an “essential eligibility requirement” for the receipt of health care.³²⁴ This question, in turn, is essentially an inquiry into whether capacity to benefit generally should be considered an “essential eligibility requirement.” So long as unbiased quality-adjustment ratings are used, capacity to benefit in general and capacity to achieve a QALY benefit in particular are similar standards.³²⁵

322. 469 U.S. 287 (1985).

323. *See id.* at 302-03. It could be argued that to the extent facially neutral benefit exclusions were justified by considerations of cost, such exclusions might be protected not only by *Choate* but also by the insurance exemption of the ADA. This would be a difficult argument to make, however, if the methodology that led to the exclusion of particular treatments relied not only on cost considerations but also on quality-of-life considerations.

324. *See supra* note 304 and accompanying text. A corollary of that central inquiry, discussed further below, *see infra* Part IV.C.3.d, would be whether there was some reasonable accommodation or modification that could help individuals with relatively intractable disabilities meet that criterion.

The inquiry with respect to a disparate impact claim would be similar. Under *Choate*, a meaningful access claim can be made only if the individual is “otherwise qualified” for the program or benefit. *Choate*, 469 U.S. at 301. Moreover, an “otherwise qualified” individual is one who can meet the “essential eligibility requirements” of a program. *See supra* note 301. Significantly, both disparate treatment of, and disparate impact on, individuals with disabilities would be entirely acceptable under the ADA if the denial of service resulted from an actuarial classification—in other words, if the decision to deny the service was based entirely on cost considerations and not on efficacy. Indeed, under the insurance exemption, very effective services could be denied to individuals with disabilities on the grounds that they were too costly.

325. *See supra* note 277 and accompanying text.

c. Capacity to Benefit as an Essential
Eligibility Requirement

Although the application of the ADA and of the Rehabilitation Act to QALY-based rationing generally, as well as to the modified scheme I propose here, revolves around the concept of “essential eligibility requirements,” this concept is not well defined. The legislative history of the ADA notes ambiguously that an eligibility requirement is “necessary” if prohibiting such a requirement would cause a “substantial interference” with the operation of the program.³²⁶ Various cases that have examined eligibility requirements in the education and employment contexts have stated that eligibility requirements must be “legitimate” and “reasonable.”³²⁷

i. Medical Uses of Capacity to Benefit

Capacity to benefit hardly seems an unreasonable qualification for obtaining medical care. Indeed, if some type of capacity-to-benefit measure is not used as an eligibility criterion for receipt of medical care, we run the risk of allocating all of our resources towards the most intractable cases, leaving no resources available for the treatment of conditions that can more readily be ameliorated.³²⁸ Medical practice has recognized this reality—the routine medical use of such outcomes measures as survival rates depends on the assessment of capacity to benefit according to that measure. Moreover, there is no evidence that Congress, in enacting the disability laws, intended to invalidate the routine medical use of such outcomes measures. There is even less support for the idea that Congress intended to preclude use of such criteria in situations where scarce health care resources are being allocated.³²⁹ To the contrary, when Congress enacted the ADA, the Health Care Finance Administration (“HCFA”) was conditioning Medicare coverage of heart transplants on the requirement that the transplant center use criteria for selecting transplant recipients that excluded those recipients with disabilities that were likely to impair the survival of the

326. H.R. REP. NO. 101-485, pt. 4, at 58 (1990), reprinted in 1990 U.S.C.C.A.N. 512, 547.

327. See, e.g., *Southeastern Community College v. Davis*, 442 U.S. 397, 406, 414 (1979); *Rothschild v. Grottenthaler*, 907 F.2d 286, 290-91 (2d Cir. 1990).

328. See *supra* note 41 and accompanying text.

329. Even commentators who are skeptical of outcomes-based selection criteria acknowledge that the ADA’s legislative history has little to say about the use of such criteria for allocating scarce medical resources. See Peters, *supra* note 265, at 520-23 (noting that general congressional statements to the effect that the disabled should have “equal access” to health insurance coverage and “equal opportunity” to achieve the same results as the nondisabled do not consider the issue of scarce health care resources and therefore cannot be used to determine how Congress would address the question of allocating these resources).

transplant.³³⁰ In passing the ADA, Congress did not indicate any disapproval of this HCFA practice.

ii. The Case Law

The few court cases that have discussed the concept of eligibility or qualification requirements in the health care context suggest that, where an individual's disability is related to the intervention sought, capacity to benefit is a legitimate qualification requirement for medical care. In *United States v. University Hospital*,³³¹ the Second Circuit examined whether the Secretary of HHS had authority under section 504 of the Rehabilitation Act to investigate a decision by the parents of a child with multiple congenital birth defects to forego corrective surgery that would prolong the child's life but would not significantly improve her handicapping conditions.³³² The child's birth defects included spina bifida (a condition in which the spinal cord and membranes that envelop it are exposed), microcephaly (a small head), and hydrocephalus (accumulation of fluid in the cranial vault).³³³ HHS argued that it had authority to investigate because the child's handicapping condition was microcephaly, and the child was being denied the corrective surgery on the basis of her microcephaly. In response to this charge, the Second Circuit determined that although the child was a handicapped individual within the meaning of section 504, the decision not to treat did not discriminate improperly on the basis of her microcephaly. The appeals court observed that "section 504 prohibits discrimination against a handicapped individual only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question."³³⁴

Taken in isolation, the court's broad statement might suggest that an individual whose handicap is related to the medical treatment she seeks can *never* be considered to meet the essential eligibility requirements for the medical treatment. The court's broad statement, however, must be placed in the context of the facts of the case—the infant in *University Hospital* had little capacity to achieve a quality-of-life benefit from the corrective surgery. The *University Hospital* court also emphasized the "bona fide medical judgment"—presumably

330. Medicare Program; Criteria for Medicare Coverage of Heart Transplants, 52 Fed. Reg. 10935, 10949 (1987). Similarly, the current HCFA guidelines require that Medicare-designated transplant centers screen out candidates with the following 14 "strongly adverse factors": these include advanced age, severe pulmonary hypertension, irreversible renal or hepatic dysfunction, and various other systemic dysfunctions. Robert F. Leibenluft, Payment for Organ Transplantation, Session Z, Sixteenth Annual Institute on Medicare and Medicaid Payment Issues, Baltimore, Maryland, March 29-31, 1995, at 6.

331. 729 F.2d 144 (2d Cir. 1984).

332. *Id.* at 146. The case came to the attention of HHS when an unrelated attorney filed suit in the New York Supreme Court, seeking the appointment of a guardian ad litem who would consent to the performance of the corrective surgery. The trial court granted the requested relief, but the New York Court of Appeals ultimately reversed, on the grounds that the trial court should not have entertained a petition to initiate child neglect proceedings by a stranger. *See id.* at 146-47 (discussing state court proceedings).

333. As a result of the spina bifida, the baby's rectal, bladder, leg, and sensory functions were impaired. In addition, the combination of microcephaly and hydrocephalus created an extremely high risk of severe retardation. *Id.* at 146-47.

334. *Id.* at 156.

a medical judgment involving capacity to benefit—that was involved in determining that the infant was not a good candidate for surgery.³³⁵ *University Hospital* strongly suggests therefore that, in situations where a disability is related to the intervention in question, rationing schemes may use capacity-to-benefit criteria in determining whether the intervention should be provided.³³⁶

The reasoning of *University Hospital* was followed by the Tenth Circuit in *Johnson v. Thompson*.³³⁷ In that case, the court rejected a Rehabilitation Act challenge to the denial of corrective surgery to infants born with spina bifida. Citing *University Hospital*, the court noted that infants with serious disabilities could not readily be considered “otherwise qualified” for treatment that they needed precisely because of the existence of these disabilities.³³⁸ Again, this broad statement must be taken within the context of the case—the infants’ capacity to benefit from the surgery did not appear to be very large.³³⁹

335. *Id.*

336. In a subsequent case, *American Hosp. Ass’n v. Heckler*, 794 F.2d 676 (2d Cir. 1985), *aff’d sub nom.* *Bowen v. American Hosp. Ass’n*, 476 U.S. 610 (1986), the Second Circuit relied on the reasoning of *University Hospital* to strike down HHS regulations prohibiting hospitals from “discriminating” in the provision of medical care to disabled infants. A Supreme Court plurality affirmed the lower court’s decision, *see Bowen v. American Hosp. Ass’n*, 476 U.S. 610 (1986) (plurality opinion), but not on the grounds articulated in *University Hospital*. The Supreme Court plurality noted that it was not necessary to determine whether section 504 ever applied to medical treatment decisions involving disabled infants. *Id.* at 624. Rather, it was only necessary to determine whether the challenged HHS regulations were authorized under section 504. The plurality held that they were not. There was no evidence in the administrative record that *hospitals*—as contrasted with parents, who are not covered by section 504—had ever refused to provide medical treatment. *Id.* at 629-37. Justice White dissented, stating that the question before the Court was whether HHS had *any* authority to regulate medical treatment decisions concerning disabled infants. White argued that certain treatment decisions concerning disabled infants could violate section 504. But the example he gave to illustrate his point, of the Down’s Syndrome newborn who was denied surgery for an esophageal obstruction, *id.* at 655 (White, J., dissenting), is clearly an example of a situation where the disability was entirely *unrelated* to the treatment in question. As the plurality pointed out, this example bore no relation to the situation in *University Hospital*. *Id.* at 634 n.20. Justice White’s dissent does not, therefore, in any respect undermine the reasoning of *University Hospital*. Similarly, *Glanz v. Vernick*, 750 F. Supp. 39, 43-46 (D. Mass. 1990), a case in which the court found that an AIDS patient denied surgery for an ear perforation stated a Rehabilitation Act claim, does not undermine the reasoning of *University Hospital*. AIDS did not in any way impact the efficacy of the ear surgery.

337. 971 F.2d 1487 (10th Cir. 1992).

338. *Id.* at 1493-94.

339. Under the disability laws, the assessment of capacity-to-benefit may have to be made on an individualized basis. Some Rehabilitation Act cases have suggested that individualized assessment of how a disability affects qualifications for a program should be made if possible. *School Bd. v. Arline*, 480 U.S. 273, 287 (1987) (requiring individualized assessment of how the public health risk posed by a teacher’s tuberculosis affected her qualifications before removing her from the classroom); *see also Strathie v. Department of Transp.*, 716 F.2d 227, 231 n.7 (3d Cir. 1983) (stating that individual examination for hearing aid users applying for school bus drivers’ licenses does not create an “undue burden” under the Rehabilitation Act). The legislative history of Title I of the ADA, which governs private employment, cites these cases in support of its assertion that the determination of whether an individual with a disability

d. The Requirement of Reasonable
Accommodation

If capacity to benefit were held to be a legitimate qualification requirement (as it should be), the reasonable accommodation or modification inquiry would focus on whether there were any alterations that could be made to assist disabled individuals in achieving capacity to benefit. The limits to reasonable accommodation or modification would be the parallel standards of undue hardship (used in Title I of the ADA), undue burden (used in Title II), and fundamental alteration (used in Title III and cases interpreting the Rehabilitation Act).³⁴⁰

To the extent that affirmative measures could be taken to improve a particular individual's amenability to treatment, reasonable accommodation would probably require such measures.³⁴¹ On the other hand, reasonable accommodation would not require that a legitimate eligibility criterion such as capacity to benefit be eliminated in order to afford greater coverage for disabled persons with intractable disabilities. The plain language of the Rehabilitation Act and ADA requirements makes this clear. Under both statutes, the purpose of reasonable accommodation is to *assist* disabled individuals in meeting eligibility requirements: there is no suggestion that reasonable accommodation could require the elimination of these requirements. Moreover, because the reasonable accommodation test considers the benefit that the proposed modification will confer on the program participant,³⁴² abandonment of capacity-to-benefit criteria would be particularly problematic. Even if capacity-to-benefit criteria were eliminated, and disabled individuals with intractable difficulties were afforded treatment, they would receive little benefit from such treatment.

poses a safety threat to others in the workplace must be made on a case-by-case basis. H.R. REP. NO. 101-485, pt. 2, at 56-57 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 338-39 (citing *inter alia* *Arline*, 480 U.S. at 287, and *Strathie*, 716 F.2d at 227). The precise extent to which individualization requirements will be applied to capacity-to-benefit determinations is not altogether clear. While the Supreme Court has established a clear individualization standard in the area of age discrimination, *see* *Western Air Lines, Inc. v. Criswell*, 472 U.S. 400, 414 (1985) (holding that individual assessment should be made except when all or "substantially all" persons excluded by the age restriction are unable to perform the job safely or when individualized assessment is not feasible), it has established no similar standard for disability discrimination. Individualization might require, however, that at least some determinations of capacity-to-benefit be made by physicians on a case-by-case basis rather than through administrative rules. Such a requirement comports with this Article's suggestion that, in situations where the individual conditions covered by administrative rules are quite heterogeneous, QALY-based rationing criteria could be implemented by physicians on an individualized basis rather than through rules. *See generally supra* notes 180-82 and accompanying text.

340. *See supra* note 302.

341. Peters, *supra* note 265, at 529.

342. *Southeastern Community College v. Davis*, 442 U.S. 397, 410 (1979) (noting that even if nursing program were required to admit hearing-impaired applicant, she "would not receive even a rough equivalent of the training a nursing program normally gives").

4. The Effects of Precluding QALY Benefit Criteria

For the reasons discussed above, this Article's proposal for a modified form of rationing based on QALY benefit criteria should withstand scrutiny under the disability laws. The language of the laws is, however, open to divergent interpretations. Moreover, although the legislative history certainly does not preclude rationing based on capacity-to-benefit, it does not sanction such rationing. If courts ultimately interpret the disability laws to preclude the modified form of QALY-based rationing proposed here, the statutes should be amended to allow such rationing. This is the case for three reasons. First (and most importantly), the modified QALY-based rationing scheme proposed here simply does not discriminate in any invidious sense against persons with disabilities.³⁴³ Second, a prohibition against rationing based on capacity to achieve a QALY benefit would logically entail a prohibition against rationing based on any measure of health benefit, including such routine medical measures as survival rates. Third, a prohibition against using QALY benefit as a rationing criterion would call into question the significant efforts being made by the federal government and private organizations to rationalize medical decisionmaking through systematic research on the effectiveness of various medical interventions.³⁴⁴ The outcomes measures used in this effectiveness research often include quality-of-life factors, such as functional status and cognitive function.³⁴⁵

CONCLUSION

Most students of health law and policy recognize the pressing need to develop mechanisms for rationing health care. Current approaches to making cost-benefit trade-offs in health care are, however, highly suspect from a normative standpoint. In particular, managed care rationing typically assumes that cost-benefit trade-offs can be made without the benefit of any consultation with the individuals on whom the trade-offs will be imposed. Moral philosophers and other academic commentators have similarly tended to assume that all individuals would, or should, consent to a single allocation scheme. Yet moral philosophy is indeterminate; it yields no single normative standard for rationing health care.

In many allocational efforts, when normative analysis fails to yield clear allocation standards, we turn to democratic political procedures. Health care rationing differs, however, from other allocation efforts. Unlike these efforts, it does not require collective decisionmaking and consensus at all stages of allocation. To the contrary, at the micro-allocational level, collective procedures

343. See generally *supra* Part IV.B. Moreover, QALY-based rationing is likely to be a rationing scheme that is attractive to many individuals. See *supra* notes 219-21 and accompanying text.

344. See *supra* note 185 and accompanying text.

345. See, e.g., Arnold M. Epstein, *Sounding Board: The Outcomes Movement—Will It Get Us Where We Want to Go?*, 323 NEW ENG. J. MED. 266, 267 (1990); Salive et al., *supra* note 185, at 701.

are neither necessary nor desirable in health care. As a consequence, a system that allowed individuals to make rationing choices would represent a practicable and justifiable mechanism of rationing.

Allowing rationing by individual choice would not only resolve the general dilemma of how to ration care but would also transform fundamentally the debate over the most important and controversial systematic approach to rationing—cost-effectiveness analysis. Due to the prominence of the Oregon effort, and the necessarily centralized nature of efforts to use cost-effectiveness analysis in certain areas of resource allocation (such as environmental or health and safety regulation), most discussions of health care rationing based on cost-effectiveness have assumed that such rationing would inevitably involve a government-imposed effort to ration care. These discussions have not considered cost-effectiveness as an *ex ante* rationing choice. When offered as an *ex ante* choice, cost-effectiveness should be a highly desirable means of health care rationing for many individuals, including many individuals who oppose utilitarian methodology.

One final point bears mention. Although this Article has discussed choice generally, and the choice of cost-effectiveness in particular, in the context of a publicly-funded rationing system, arguments in favor of choice do not depend on the existence of public funding. Thus even if a scheme that was entirely publicly funded would not currently be feasible, the idea of providing rationing choices is one we should strive to implement even in our current system of mixed private and public funding.

