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DESTRUCTURING DISABILITY: RATIONING OF HEALTH CARE AND UNFAIR DISCRIMINATION AGAINST THE SICK

David Orentlicher*

Introduction

As this country faces rising health care costs, it has become increasingly clear that we cannot afford all medically beneficial care. Advances in technology are pushing health care costs to an unsustainable level¹—spending on health care has reached nearly fourteen percent of this country's Gross Domestic Product (GDP).² Some savings can be achieved by eliminating waste in the health care system. The health care system is plagued by a good deal of excess capacity³ as well as considerable inefficiency in administrative activities.⁴ Elimination of waste, however, would not free up enough resources to cover all potentially useful medical services.⁵ Moreover, the public has a host of welfare needs, including better housing, education, and environmental protection, but has a limited purse. If we are to have any money left to pay for these other goods, we must place greater limits on spending for health care services.⁶ In short, rationing of health care is inevitable.⁷ This Article will focus on a critical

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¹ William B. Schwartz, *The Inevitable Failure of Current Cost-containment Strategies: Why They Can Provide Only Temporary Relief*, 257 JAMA 220 (1987).

² TIMOTHY J. HAUSER & JAMES D. JAMESON, U.S. DEP'T OF COMMERCE, U.S. INDUSTRIAL OUTLOOK, 1993, 42-1 (1993).

³ See, e.g., Joseph A. Califano, Jr., *Rationing Health Care: The Unnecessary Solution*, 140 U. PA. L. REV. 1525, 1527-28 (1992); Victor R. Fuchs, *No Pain, No Gain: Perspectives on Cost Containment*, 269 JAMA 631, 632 (1993).

⁴ See, e.g., David U. Himmelstein & Steffie Woolhandler, *Cost Without Benefit: Administrative Waste in U.S. Health Care*, 314 NEW ENG. J. MED. 441 (1986); Califano, *supra* note 3, at 1528.

⁵ See, e.g., Jan Blustein & Theodore R. Marmor, *Cutting Waste by Making Rules: Promises, Pitfalls, and Realistic Prospects*, 140 U. PA. L. REV. 1543, 1564 (1992) (observing that eliminating all "wasteful" care means cutting some medically beneficial care); Michael J. Graetz & Jerry L. Mashaw, *Ethics, Institutional Complexity and Health Care Reform: The Struggle for Normative Balance*, 10 J. CONTEMP. HEALTH L. & POL'Y 93, 95 (1994).

⁶ See Leonard M. Fleck, *Just Health Care Rationing: A Democratic Decisionmaking Approach*, 140 U. PA. L. REV. 1597, 1603 (1992).

⁷ See David M. Eddy, *Health System Reform: Will Controlling Costs Require Rationing Services?*, 272 JAMA 324 (1994).

issue for health care rationing: How can we ration health care in a way that does not discriminate unfairly on the basis of sickness?

Historically, this country has rationed health care primarily on the basis of ability to pay. As sentiment grows for ensuring universal access to health care regardless of income or wealth, other bases for rationing will be needed, and alternative methods for rationing often distinguish on the basis of sickness.⁸ Many have argued that health care costs can be contained by eliminating care for patients who have poor prognoses and for whom health care yields less benefit than for other patients.⁹ Proposals to control health care costs also call for less coverage for some categories of illnesses than for others.¹⁰

These alternative methods for containing costs raise important concerns about equity. Differential funding by type of disease may reflect invidious biases against people who suffer from disfavored illnesses. For example, one employer provided maximum lifetime coverage of \$1 million to employees for medical expenses from cancer, heart disease, and

As the discussion suggests, this Article is using the term "rationing" to mean the denial of health care services because the services are unaffordable rather than because there is a natural shortage of the services, as with organ transplants. Some commentators object to characterizing rationing as a denial of services on cost grounds. See, e.g., Clark C. Havighurst, *Prospective Self-Denial: Can Consumers Contract Today to Accept Health Care Rationing Tomorrow?*, 140 U. PA. L. REV. 1755, 1758-64 (1992). We do not, for example, say that we are rationing houses or automobiles when people are unable to purchase their desired house or car. Nevertheless, the term "rationing" is commonly used to mean the denial of health care services because the services are unaffordable. See, e.g., Mark A. Hall, *Rationing Health Care at the Bedside*, 69 N.Y.U. L. REV. 693, 695 n.2 (1994); Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 492 (1995). Health care services are different from houses and automobiles because of the existence of health care insurance, which commonly promises to cover all "medically necessary" services. Since not all medically beneficial services can be covered, insurers must decide whether a particular service is medically necessary. Some patients will be denied medically unnecessary services because of the costs, but, since ability to pay is not a factor within a particular insurance plan, the denial of coverage raises the same issues and concerns as does a denial of treatment based on a natural shortage of resources.

⁸ See Eddy, *supra* note 7.

⁹ Health care is already being rationed by denying care to patients who will derive less benefit than other patients. For example, when decisions are made about allocating the limited supply of organs for transplantation, preference is given to the patients in whom the organs will survive the longest. Council on Ethical and Judicial Affairs, American Medical Association, *Ethical Considerations in the Allocation of Organs and Other Scarce Medical Resources Among Patients*, 155 ARCH. INTERNAL MED. 29, 36 (1995). Under some proposals, care would be withheld from the elderly, the terminally ill, or the permanently unconscious. See, e.g., Lawrence J. Schneiderman, Nancy S. Jecker et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990); Gov. Lamm Asserts Elderly, If Very Ill, Have "Duty to Die," N.Y. TIMES, Mar. 29, 1984, at A16; see generally DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1987).

¹⁰ For example, as many private health insurers currently do, President Clinton's health care reform proposal would have funded psychiatric care less generously than non-psychiatric care. See H.R. 3600, 103d Cong., 1st Sess. § 1115 (1993).

other serious illnesses but capped lifetime coverage to employees with AIDS at \$5,000.¹¹ Denial of care to patients who would gain less benefit from treatment appears to base rationing decisions on objectively fair criteria, but these differences in prognoses among patients often reflect the biases inherent in social policies and structures. A patient with a psychiatric disorder may realize little benefit from treatment primarily because the stigma of psychiatric illness has led researchers and funders of research to neglect psychiatric illness when developing treatments for disease. Moreover, patients may have a poor prognosis, not because their condition is inherently difficult to treat, but because it has been historically disfavored by the operation of society's policies and institutions.¹²

Anti-discrimination statutes, in their language and legislative history, recognize that persons with disabilities need protection not only against current invidious bias but also against discrimination arising out of biases inherent in social structure. Accordingly, the statutes include a principle of reasonable accommodations that requires the implementation of measures that will help compensate for these biases. While courts have interpreted anti-discrimination statutes in ways that respond to discrimination arising out of current invidious bias, they have not addressed the discrimination that arises from biases inherent in the social structure. This Article argues that courts have not given adequate recognition to the principle of reasonable accommodations embedded within the Americans with Disabilities Act of 1990 ("ADA")¹³ and the Rehabilitation Act of 1973,¹⁴ and therefore have not fulfilled congressional intent to prevent unfair discrimination on the basis of sickness. Similarly, while other scholars have criticized existing judicial standards and proposed modifications to those standards,¹⁵ they have failed to give full recognition to the principle of reasonable accommodations.

The inadequacy of judicial interpretations has critical implications. In many cases, rationing of health care involves a choice between who

¹¹ See *McGann v. H & H Music Co.*, 946 F.2d 401 (5th Cir. 1991), *cert. denied*, 113 S. Ct. 482 (1992) (holding that reducing maximum medical benefits given to an employee with AIDS was not unlawful discrimination under ERISA because the reduction applied equally to all employees).

¹² For example, patients with chronic lung disease may do poorly with some treatments for coronary artery disease because the treatments are designed on the assumption that coronary artery disease patients will have normal lung function. See, e.g., Roger W. Evans, *Need, Demand, and Supply in Organ Transplantation*, 24 *TRANSPLANTATION PROCEEDINGS* 2152 (1992).

¹³ 42 U.S.C. §§ 12101–12213 (Supp. 1993).

¹⁴ 29 U.S.C. § 794 (Supp. 1995).

¹⁵ See, e.g., Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 *COLUM. L. REV.* 1581, 1646–55 (1993); E. Haavi Morreim, *Futilitarianism, Exoticare, and Coerced Altruism: The ADA Meets Its Limits*, 25 *SETON HALL L. REV.* 883, 894–97, 922–25 (1995); Peters, *supra* note 7, at 523–25, 545–46.

shall live and who shall die. In other cases, rationing can have profound effects on a person's quality of life. When the stakes are this high, it is particularly important that the law offer maximum protection against unfair discrimination.

To remedy the deficiencies in existing standards, this Article proposes a new standard that is explicitly designed to address discrimination from biases inherent in the social structure. This "destructured disability standard" should more fully realize the goals that are an essential part of current anti-discrimination law.

I. Rationing Health Care

Inasmuch as we cannot avoid rationing, the question becomes how rationing should be implemented. The prevailing form of rationing is based on the ability to pay.¹⁶ If we move to a system of universal access to a package of basic health care benefits, however, we will have to make some very difficult decisions about what the basic benefits package will include. Even if we retain our current system, the need to contain health care costs will require a good deal of rationing on grounds other than ability to pay. For example, when people join a health maintenance organization (HMO) that promises all medically necessary care, the HMO must decide what is medically necessary. Likewise, when a hospital's intensive care unit (ICU) beds are oversubscribed, the hospital must decide which patients will be treated in the ICU and which patients will not.¹⁷

A number of potential methods for rationing are available to supplement or replace rationing on the basis of ability to pay. These alternative methods fall into two categories: rationing by type of patient and rationing by type of service. Rationing by type of patient may involve giving health care to those patients who will derive the most benefit from the care (for example, allocating coronary artery bypass surgery to persons who will gain the longest extension in life expectancy from the surgery) or by providing each person with identical benefits (for instance, limiting hospitalization to fourteen days a year¹⁸ or distributing insurance vouchers

¹⁶In addition to ability to pay, other factors have played an important role in determining access to care. Health care plans, both public and private, have denied coverage for treatments when costs are high and benefits uncertain. *See, e.g.*, William P. Peters & Mark C. Rogers, *Variation in Approval by Insurance Companies of Coverage for Autologous Bone Marrow Transplantation for Breast Cancer*, 330 *NEW ENG. J. MED.* 473 (1994) (reporting on the variability among private health insurers in approving coverage for breast cancer patients in clinical research trials).

¹⁷*See, e.g.*, Daniel E. Singer, Phyllis L. Carr, Albert G. Mulley, & George E. Thibault, *Rationing Intensive Care—Physician Responses to a Resource Shortage*, 309 *NEW ENG. J. MED.* 1155 (1983) (recounting one hospital's response to reduction in ICU capacity).

¹⁸Tennessee once took this approach to limit its Medicaid expenditures. *See Alexander*

worth \$3,500). Rationing by service may involve preferring certain kinds of care (for example, favoring preventive and early childhood services over expensive and aggressive treatments of the terminally ill).

A. Rationing by Patient

Rationing by patient occurs when a particular medical service is available, but not to everyone who might benefit from it. In general, rationing by patient conserves medical resources by favoring persons more seriously disabled by their illnesses. A health plan might cover lumbar spinal disc surgery for patients whose nerve compression causes severe pain, but not for those with mild lower back pain.¹⁹ Rationing by type of patient can also occur more subtly. Some health plans establish a total budget for health care services and require their physicians to operate within its constraints.²⁰ To ensure efficient use of the limited resources, physicians might offer lumbar spinal disc surgery to the more seriously affected patients but not to patients who are mildly disabled.

Rationing by patient, however, can also result in fewer services for patients who are more affected by illness. For example, a transplant program might deny a liver transplant to a patient who suffers from liver failure and schizophrenia in favor of a patient who suffers from liver failure only. Or, a transplant program might offer a liver transplant to patients with liver cancer when the cancer is detected relatively early but deny transplantation to patients with more advanced liver cancer. The rationale for denying treatment to the sicker patient is that the healthier patient gains a greater benefit from the treatment. This Article argues, however, that a rationing system that allocates care on the basis of degree of benefit will often result in unfair discrimination against sicker patients or patients with more disabling conditions.

B. Rationing by Service

Rationing by service occurs when only certain medical services are covered. For example, health care plans typically cover appendectomies and coronary artery bypass surgeries but not artificial reproduction. Plans might also cover unlimited hospitalization for physical illness but cap

v. Choate, 469 U.S. 287 (1985) (allowing a reduction in inpatient days covered by Medicaid).

¹⁹ See George W. Wood II, *Lower Back Pain and Disorders of Intervertebral Discs*, in CAMPBELL'S OPERATIVE ORTHOPAEDICS 3715 (A.H. Crenshaw ed., 8th ed. 1992) (discussing disc disease and its treatment).

²⁰ This is essentially how the British health care system works. See generally HENRY A. AARON & WILLIAM B. SCHWARTZ, *THE PAINFUL PRESCRIPTION: RATIONING HEALTH CARE* (1984).

coverage for psychiatric illness at sixty days per year.²¹ Rationing by service often conserves medical resources to protect those most disabled by illness. Yet rationing by service can also subject the sickest persons to unfair discrimination. Rationing by service may result in coverage for persons with a milder form of an illness while leaving those with a more severe form of the same illness uncovered. For example, a sixty-day cap on coverage for psychiatric hospitalizations would not provide sufficient coverage for many persons with serious psychiatric illnesses but would fully meet the needs of those with mild illnesses. Rationing by service also discriminates against sick persons when a health plan's coverage favors certain types of illnesses over others. If psychiatric coverage is capped, then persons with severe psychiatric disorders who need long-term hospitalization are deprived of necessary care while persons with severe heart or lung disease or persons with advanced cancer receive all necessary care.²²

II. Failure of Current Interpretations of Anti-Discrimination Law to Prevent Unfair Discrimination

A. Rationing by Patient

Because there are different statutory provisions for rationing by patient and rationing by service, and because the two types of rationing raise different ethical and medical considerations, this Article discusses the two types of rationing separately. Nevertheless, it concludes that a unified standard should be applied by the courts to the two types of rationing.

In analyzing rationing by patient, this Article focuses on the rationing by patient of kidneys, hearts, or other organs for transplantation.²³ In these situations, a patient might be denied an organ transplant or be assigned a

²¹ See, e.g., H.R. 3600, 103d Cong., 1st Sess. § 1115(c)(2)(D) (1993).

The Oregon Health Plan, which serves state Medicaid beneficiaries, presents another example of rationing primarily by service. Under the Oregon plan, 696 different health care services have been ranked in terms of priority, and coverage is provided through number 565. Michael Janofsky, *Oregon Starts to Extend Health Care*, N.Y. TIMES, Feb. 19, 1994, at 6.

²² As the preceding discussion suggests, when the issue is discrimination against persons with disabilities in access to health care, we are often dealing with comparisons between persons with different kinds of disabilities (for example, heart disease vs. psychiatric disease) or comparisons between persons with different degrees of the same disability (for example, mild vs. severe psychiatric disease), rather than simple comparisons between persons with or without disabilities. This is largely because most people who need medical treatment are considered disabled under the definitions of anti-discrimination law. See *infra* notes 35–38 and accompanying text.

²³ This analysis easily generalizes to other kinds of rationing decisions. Once we move to methods for rationing other than ability to pay, the issues and concerns that are raised by decisions about allocating limited resources are the same whether the resource is limited because of natural shortage or cost constraints. See *supra* note 7.

lower waiting-list priority because the patient also suffers from mental retardation, a psychiatric disability, or alcoholism.²⁴

1. Relevant Statutory Provisions

The relevant federal statutes for protecting the sick from unfair discrimination are the ADA and, to a much lesser extent, its predecessor law, the Rehabilitation Act of 1973. According to the legislative history of the ADA, it was enacted "to provide a clear and comprehensive national mandate to end discrimination against individuals with disabilities."²⁵ The two acts contain similar statutory language and very broadly prohibit discrimination against persons with disabilities in the areas of employment,²⁶ public²⁷ or private²⁸ education, transportation,²⁹ health care,³⁰ and in access to any other public or private services and programs.³¹ The Rehabilitation Act applies to federal executive agencies and to recipients of federal funding.³² The ADA applies to Congress and to all non-federal agencies or programs, public or private, whether or not they are recipients of federal funding.³³

To be protected by the ADA or Rehabilitation Act, individuals must show that they have been subjected to discrimination on the basis of their disability. Such a showing, however, does not end the inquiry. Because it sometimes makes sense to take a person's disability into account, discrimination can be justified on the ground that the disability makes the person a poor candidate for the job, program, or service at stake. Finally, even if individuals are poor candidates, they may not be denied access to the job, program, or service if reasonable accommodations³⁴ can help overcome their disadvantage.³⁵

The first issue, then, is whether an individual meets the statutory definition of a person with a disability. The definition of disability under the ADA and the Rehabilitation Act is broad and ordinarily will not hinder lawsuits claiming discrimination on the basis of sickness in health care rationing. According to the two acts, a disability exists when an individual

²⁴ See, e.g., James L. Levenson & Mary Ellen Olbrisch, *Psychosocial Evaluation of Organ Transplant Candidates: A Comparative Survey of Process, Criteria, and Outcomes in Heart, Liver, and Kidney Transplantation*, 34 *PSYCHOSOMATICS* 317 (1993).

²⁵ H.R. REP. NO. 485 (II), 101st Cong., 2d Sess., at 22 (1990).

²⁶ 42 U.S.C. §§ 12111-12117 (Supp. 1993).

²⁷ 42 U.S.C. § 12132 (Supp. 1993).

²⁸ 42 U.S.C. § 12181(7)(J) (Supp. 1993).

²⁹ 42 U.S.C. §§ 12132, 12184 (Supp. 1993).

³⁰ 42 U.S.C. § 12181(7)(F) (Supp. 1993).

³¹ 42 U.S.C. §§ 12132, 12182(a) (Supp. 1993).

³² 29 U.S.C. § 794(a) (West Supp. 1995).

³³ 42 U.S.C. §§ 12111(2), 12131(1), 12181(6),(7) (Supp. 1993).

³⁴ See *infra* notes 72-73 and accompanying text.

³⁵ See Peters, *supra* note 7, at 505-08.

has any illness, physical or psychological, that "substantially limits" a major life activity such as walking, learning, breathing, or working.³⁶ Persons with chronic lung disease are considered disabled because they are substantially limited in their ability to breathe;³⁷ persons with schizophrenia are considered disabled because they are substantially limited in their ability to work. Even if a person's disabling symptoms could be alleviated with treatment, the person would still be considered disabled.³⁸ A person also meets the legal definition of disability if that person has a history of a disabling condition (for instance, cancer in remission) or if others regard the person as having a disability that substantially limits a major life activity (for example, HIV infection).³⁹

Having met the statutory definition of a person with a disability, the potential claimant must then show discrimination on the basis of disability. This second inquiry is much more complicated.

In defining discrimination on the basis of disability, the ADA and Rehabilitation Act have different provisions for employers, governments, and private operators of public accommodations. Since these different provisions parallel each other,⁴⁰ this Article assumes for purposes of simplification that we are dealing with the allocation of organs by a transplant program at a private hospital, which constitutes a private operator of a public accommodation. This brings the analysis under Subchapter III of the ADA.⁴¹

Among the provisions of the ADA that prohibit discriminatory practices, two of those provisions might apply to denials of organs or assignments of lower priority on the waiting list by a private hospital. One provision prohibits discrimination "on the basis of disability in the full and equal enjoyment of the . . . services . . . of any place of public accommodation,"⁴² where hospitals are explicitly defined as public accommodations.⁴³ This provision suggests that hospitals must not condition eligibility for their organ transplant programs on the absence of disabling conditions. A hospital could not deny organ transplants to persons who are blind or paraplegic simply because of their blindness or paraplegia nor give them a lower priority on the waiting list.

³⁶ See 28 C.F.R. § 36.104 (1994); 29 C.F.R. § 1630.2 (1994).

³⁷ H.R. REP. NO. 485 (II), *supra* note 25, at 52.

³⁸ *Id.*

³⁹ 42 U.S.C. § 12102(2) (Supp. 1993). Common conditions that qualify as a disability include diabetes, 28 C.F.R. § 36.104, epilepsy, *id.*, alcoholism, *id.*, and morbid obesity, *Cook v. Rhode Island*, 10 F.3d 17 (1st Cir. 1993).

⁴⁰ See David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308, 309 (1994).

⁴¹ 42 U.S.C. § 12182(a) (Supp. 1993).

⁴² *Id.*

⁴³ 42 U.S.C. § 12181(7)(F) (Supp. 1993).

The second provision that applies to private entities addresses so-called "disparate impact" discrimination.⁴⁴ The ADA recognizes that much discrimination against the disabled does not come in the form of inferior treatment expressly on the basis of disability. Rather, discrimination often occurs when a program adopts seemingly neutral eligibility or screening criteria for access to the program that, when applied, tend systematically to disfavor persons with disabilities. Accordingly, the ADA generally prohibits the use of eligibility criteria by private operators of public accommodations when the criteria tend to have the effect of screening out persons with disabilities.⁴⁵

Despite this prohibition, many common eligibility criteria for organ transplantation either explicitly exclude or have a tendency to screen out persons with disabilities. For example, many transplant programs commonly exclude persons with schizophrenia or exclude people who do not comply with medication regimens since organ recipients must take certain medications for the rest of their lives.⁴⁶ Such noncompliance is common in people with psychiatric disorders.⁴⁷ Accordingly, the eligibility criterion of compliance has the effect of screening out persons disabled by psychiatric illness. Thus, on their face, these two provisions of the ADA appear to preclude the use of many common eligibility criteria for organ transplantation.

There are times, however, when it is appropriate to take a person's disability into account, and the ADA permits discriminatory treatment accordingly. First, the ADA allows hospitals, insurers, or similar organizations to engage in traditional risk classification practices as long as the practices are not designed as subterfuges to evade the purposes of the ADA.⁴⁸ Consequently, when an organ transplant program denies organs on the basis of sickness or based on criteria that screen out sicker persons, the program could justify its decisions in terms of traditional risk classification practices. If patients have sicknesses that compromise their ability to benefit from organ donation, then transplant program administrators could argue that it does not make sense to give such patients the

⁴⁴ Disparate impact discrimination occurs when a policy that is facially neutral with respect to a particular group nevertheless affects members of that group differently from others.

⁴⁵ 42 U.S.C. § 12182(b)(2)(A)(i) (Supp. 1993) (defining discrimination to include "the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability").

⁴⁶ See Levenson & Olbrisch, *supra* note 24, at 319. Potential rejection of a transplanted organ by the recipient's body is delayed or prevented by transplanting organs between people who are immunologically similar and by giving drugs to the recipient that block the immune system from rejecting the organ.

⁴⁷ See, e.g., Albert R. Jonsen, *Ethical Issues in Compliance*, in COMPLIANCE IN HEALTH CARE 114 (R. Brian Haynes et al. eds., 1979); David Orentlicher, *Denying Treatment to the Noncompliant Patient*, 265 JAMA 1579, 1580-81 (1991).

⁴⁸ 42 U.S.C. § 12201(c)(1) (Supp. 1993).

same priority on the organ transplantation list as persons who would gain a greater benefit.

The ADA also permits the use of eligibility criteria that exclude or tend to screen out persons with disabilities as long as the criteria are necessary for the operation of the program.⁴⁹ Transplant program administrators could then argue that they have an obligation to allocate organs where they will do the most good, and that their eligibility criteria are designed to serve that goal.

The preceding discussion illustrates the tension within the ADA between unjustified and justified discrimination against persons with disabilities. On the one hand, the ADA says that transplant programs cannot use eligibility criteria that deny organs or result in lower waiting list priorities on the basis of disability, nor can they use eligibility criteria that deny organs or result in lower waiting list priorities if the criteria tend to screen out persons with disabilities. On the other hand, the ADA says that transplant programs can use eligibility criteria even if they disadvantage persons with disabilities as long as the criteria are reasonable risk classification measures or are necessary for the operation of the organ transplant program. Taken together, these provisions suggest that transplant programs can use eligibility criteria as long as they really help distinguish among different candidates for organ transplantation in terms of the candidates' likelihood of benefiting from the transplant. If organ transplants are not as effective for people with schizophrenia,⁵⁰ then it may be permissible to take schizophrenia into account when allocating organs. Indeed, as the next section of this Article demonstrates, this conclusion is consistent with judicial opinions interpreting similar provisions in the Rehabilitation Act when rationing decisions have been challenged.

2. Judicial Interpretations of Relevant Statutory Provisions

Case law construing the ADA and the Rehabilitation Act is sparse for a variety of reasons. The ADA took effect only recently, so case law is still in its infancy. The Rehabilitation Act, by contrast, is more than twenty years old but has more limited coverage.⁵¹ In addition, in the first rationing cases to reach the federal appellate courts, the opinions construed the protections of the Rehabilitation Act narrowly, possibly discouraging later claims of discriminatory health care rationing. In spite of

⁴⁹ 42 U.S.C. § 12182(b)(2)(A)(i) (Supp. 1993).

⁵⁰ Transplanted organs may not function as long in persons with schizophrenia because they are less likely than persons without schizophrenia to take the anti-rejection drugs.

⁵¹ See text accompanying note 32.

these limitations, the existing case law serves to underscore the importance of likelihood of benefit in upholding rationing criteria.

The leading case in this area, *United States v. University Hospital*,⁵² is one of the so-called "Baby Doe" cases from the 1980s involving newborn infants with severely handicapping medical problems. *University Hospital* and the other Baby Doe cases were brought because newborns were denied aggressive surgical procedures that could prolong their lives (although the procedures would have little effect on the newborns' quality of life).⁵³ The baby in *University Hospital*, in addition to having physical problems, was thought to have such compromised mental function that she would "never interact with her environment or other people."⁵⁴ The *University Hospital* court upheld the denial of treatment in an opinion that suggests many possible reasons for the decision. Consequently, the case has been characterized in a number of ways.

a. Anti-Discrimination Law Was Not Intended to Apply to Medical Decisions

University Hospital rested in part on the view that the anti-discrimination laws were not meant to apply to *medical* judgments as distinguished from other kinds of judgments.⁵⁵ According to this line of reasoning, judgments about eligibility for medical treatment are qualitatively different from judgments about eligibility for education or employment.⁵⁶ While a physician's outright refusal to provide any treatment to a person because of their disability would be prohibited,⁵⁷ anti-discrimination law would not reach a physician's judgment that a person's disability disqualified the person from a particular treatment. The basis for this distinction between medical and non-medical decisions is not clear, but it may reflect the court's view that medical decisions are objective and scientific.

Judgments about eligibility for medical treatment, however, are no different in kind from the cost/benefit analyses that employers make in deciding whether to hire a person with a disability. An employer looks at the expected productivity of the applicant and discounts it by the costs of employing him or her. Similarly, eligibility criteria for medical care generally take into account the expected medical benefit from the treatment

⁵² 729 F.2d 144 (2d Cir. 1984).

⁵³ See *id.* at 146.

⁵⁴ *Id.* Both the parents and the physicians agreed not to treat the infant.

⁵⁵ *Id.* at 156-60.

⁵⁶ See *id.* at 156.

⁵⁷ For example, a physician would be prohibited from entirely refusing to provide care to persons with HIV infection. See *United States v. Morvant*, 843 F. Supp. 1092, 1094-96 (E.D. La. 1994) (holding that a dentist could be liable under the ADA for denying services on account of a patient's HIV infection).

discounted by the costs of providing it, where costs include not only financial costs but also the risks of injury to the patient. Rationing decisions reflect not only technical medical judgments but also value judgments about the proper balance between medical costs and benefits.

The following example illustrates how some medical judgments are similar to other value judgments. Generally, obstetricians offer amniocentesis to check for Down syndrome in pregnant women without a family history of Down syndrome only if the women are at least thirty-five years old.⁵⁸ This general rule reflects, in part, the fact that when the woman is age thirty-five or over, the risk that the fetus will suffer from Down syndrome is equal to or greater than the risk that the amniocentesis will inadvertently abort the fetus.⁵⁹ In other words, the medical community has concluded that women should be offered amniocentesis only when the risk of detecting a Down syndrome fetus equals or exceeds the risk of aborting a normal fetus. While this may be a reasonable balance to draw, it is also the case that many women may have very strong feelings about not having a Down syndrome child and may therefore wish to undergo amniocentesis unless the risk of an abortion is five, ten, or even twenty times the risk of giving birth to a Down syndrome fetus. These women might reason that they can always try to become pregnant again, but they cannot undo the birth of a child with Down syndrome. Reasonable people can differ on the appropriate place to draw the balance, and medical expertise does not help us settle the question.

b. Relatedness of the Need for Treatment to the Person's Disability

The *University Hospital* court also suggested that a denial of treatment raises discrimination concerns only when the person's need for treatment is independent of the person's disability.⁶⁰ According to the court, when the condition requiring treatment is related to the disability, "it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.'"⁶¹ Thus, for example, if a blind person is denied a kidney transplant on account of her congenital blindness, there might be unlawful discrimination, since the need for a kidney transplant is independent of the blindness. However, if a child with a severe developmental disability is denied a surgical procedure to treat the disability, there would be no

⁵⁸ Joe Leigh Simpson, *Genetic Counseling and Prenatal Diagnosis*, in *OBSTETRICS: NORMAL AND PROBLEM PREGNANCIES* 269, 278 (Steven G. Gabbe et al. eds., 2d ed. 1991).

⁵⁹ Susan P. & Stephen G. Pauker, *Prenatal Diagnosis—Why Is 35 a Magic Number?*, 330 *NEW ENG. J. MED.* 1151 (1994).

⁶⁰ See *University Hospital*, 729 F.2d at 156 ("[The Rehabilitation Act] prohibits discrimination against a handicapped individual only where the individual's handicap is unrelated to . . . the services in question."); Crossley, *supra* note 15, at 1648–50.

⁶¹ *University Hospital*, 729 F.2d at 157.

unlawful discrimination because the need for the surgical procedure arises out of the disability itself. This distinction between conditions that are independent of the disability and those that are related to the disability is made on the ground that anti-discrimination law is designed to ensure that similarly situated persons receive the same treatment. When the need for treatment arises out of the disability, as when a severely disabled newborn needs a surgical procedure, there is no similarly situated person without the disability who needs the same surgical procedure.⁶²

There are important problems with this approach. First, it leads to unacceptable distinctions based on quality of life. Consider the example of a newborn with Down syndrome who has an intestinal blockage that can be surgically eliminated. If untreated, the blockage would result in the infant's death. Intestinal blockage is more than 100 times as common in newborns with Down syndrome than in other newborns.⁶³ Thus, under the relatedness approach, it would be permissible to deny surgery to the Down syndrome child even though relief of the blockage would allow the child to live a life with considerable benefits for decades.

The relatedness approach is also problematic because of its narrow scope. Because the human body is a highly integrated organism and not compartmentalized into relatively independent parts, a disabling illness generally has a wide-ranging effect on that person's needs for medical treatment. Accordingly, situations of complete independence between a disability and a need for treatment are rare, and much discrimination would be deemed lawful under the relatedness standard.⁶⁴

c. *The "Bona Fide Medical Judgment" Standard*

The *University Hospital* opinion also suggests a third justification for denying treatment—an alternative conception of the relatedness approach. Under the "bona fide medical judgment standard," the issue is not whether the person's *need for treatment* is related to the disability but whether the *ability to benefit from treatment* is related to the disability. On this reading, the *University Hospital* court upheld the denial of treatment on the ground

⁶² See *Bowen v. American Hospital Association*, 476 U.S. 610, 654–55 (1986) (White, O'Connor, and Brennan, JJ., dissenting).

⁶³ While fewer than 1 in 1000 persons are born with an obstruction of their small intestine, see Deborah C. Rubin, *Small Intestine: Anatomy and Structural Anomalies*, in *TEXTBOOK OF GASTROENTEROLOGY* 1555, 1567 (Tadataka Yamada et al. eds., 2d ed. 1995), more than 1 in 10 infants with Down syndrome are born with such an obstruction. MARK SELIKOWITZ, *DOWN SYNDROME: THE FACTS* 85–86 (1990).

⁶⁴ Physicians could, for example, deny dialysis or laser treatment to prevent loss of vision to patients with diabetes. Cf. Crossley, *supra* note 15, at 1649–50 (discussing how HIV-infected children might not be protected against unfair denials of immunization since the decision to immunize would likely be affected by the child's compromised immune status).

that the decision was a "bona fide medical judgment" in which the denial of treatment on the basis of the baby's disabilities was not based on characteristics of the baby that were irrelevant to the treatment decision but on medical implications of the disability that were critical to the decision whether treatment was medically indicated. It was because the disabilities gave the baby such a grim prognosis that it did not make sense to provide certain treatments to the baby; there would not be sufficient benefits from the treatments to justify their use.⁶⁵ Similarly, a federal district court has indicated that, if a person's HIV-related disease decreases the person's ability to benefit from ear surgery, then the HIV disease may disqualify the person as a candidate for the surgery.⁶⁶ In other words, the patients are not being denied treatment because of invidious prejudice or even unthinking inattention to the needs of the disabled but because of relevant "medical effects" of their sicknesses.⁶⁷ Proponents of this view might argue that it is more like refusing to hire a blind person to drive a bus rather than like refusing to hire a blind person to be a telephone operator. As long as the decisionmakers give appropriate, individualized⁶⁸ weight to the medical implications of the person's disability and do not use it as a pretext to discriminate, they would not be guilty of unlawful discrimination.⁶⁹

⁶⁵ Physician prognostications in these cases may be inaccurate. In one case, physicians predicted that the baby would have no self-awareness, would experience only pain, and would live for only a short time, yet an article recently reported that the child was 10 years old and attending a school for developmentally disabled children. See B.D. Colen, *What Ever Happened to Baby Jane Doe?*, 24(3) HASTINGS CENTER REP. 2 (1994).

⁶⁶ Glanz v. Vernick, 756 F. Supp. 632, 638 (D. Mass. 1991).

⁶⁷ See Crossley, *supra* note 15, at 1650-55 (arguing for this approach and calling it "The Medical Effects Approach"); Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449, 1515 n.205 (1994).

⁶⁸ Glanz, 756 F. Supp. at 638.

⁶⁹ In the Baby Doe cases, the parents declined surgery for their children. *Johnson v. Thompson*, 971 F.2d 1487, 1491 (10th Cir. 1992); *United States v. University Hospital*, 729 F.2d 144, 146 (2d Cir. 1984). Subsequent court decisions have suggested that the Baby Doe courts found no unlawful discrimination because there was no denial of treatment by the physicians or hospitals; rather, the babies were not treated because their parents decided against treatment. See *In re Baby "K"*, 832 F. Supp. 1022, 1028 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994); Glanz v. Vernick, 750 F. Supp. 39, 46 (D. Mass. 1990). However, the Baby Doe opinions are written as if treatment were denied by the health care providers. Moreover, as Justice White wrote, anti-discrimination law is concerned not only with physicians' decisions but also their advice or recommendations to patients. *Bowen v. American Hospital Association*, 476 U.S. 610, 653 n.7 (1986) (White, J., dissenting). Patients and families are heavily influenced by the recommendations of their physicians. Indeed, in one of the cases, parents who originally agreed with the physicians' recommendations later brought a suit charging unlawful discrimination. *Johnson*, 971 F.2d at 1491. In many cases, the patients and families will not realize that the physician's recommendations may reflect value judgments about quality of life with which the patient or family disagrees. See, e.g., *Johnson*, 971 F.2d at 1491; see also David Orentlicher, *The Illusion of Patient Choice in End of Life Decisions*, 267 JAMA 2101 (1992); David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1280-88 (1994) (both articles discussing studies that have demonstrated that

In terms of the example of organ transplantation, the bona fide medical judgment standard suggests that courts *will* invoke the ADA to protect persons from eligibility criteria that give them less access to organ transplants because of their illnesses when these persons would do as well with a transplant as other people. For instance, a transplant program cannot deny a liver transplant because of alcoholism if, as some studies suggest,⁷⁰ transplanted organs survive as long in alcoholics as they do in non-alcoholics.

3. Failure of Current Judicial Interpretations to Adhere to the Principle of Reasonable Accommodations

Each of the aforementioned standards suffers from a failure to recognize a fundamental element of the ADA: the principle of reasonable accommodations.⁷¹ The principle is incorporated in the ADA for private hospitals and other public accommodations operated by private entities as follows: unlawful discrimination exists if the entity fails "to make reasonable modifications in [its practices] when such modifications are necessary to afford [its services] to individuals with disabilities, unless . . . making such modifications would fundamentally alter the nature of [the services]."⁷² The entity must also make auxiliary services available to ensure disabled persons equal access to the entity's services unless doing so would "fundamentally alter the nature" of the services or "would result in an undue burden."⁷³

The principle of reasonable accommodations goes beyond the requirement that employers, providers of public services, and private operators of public accommodations refrain from discrimination when a person's disabilities are irrelevant. The principle also requires that affirmative steps be taken to integrate persons with disabilities more fully into society even when their disabilities compromise their ability to work or their ability to benefit from public services or accommodations.⁷⁴

decisions about life-sustaining medical treatment reflect the values and preferences of physicians much more than those of their patients or their surrogate decisionmakers).

⁷⁰ See, e.g., Shashi Kumar et al., *Orthotopic Liver Transplantation for Alcoholic Liver Disease*, 11 HEPATOLOGY 159 (1990). But see Steven Schenker et al., *Should Patients with End-Stage Alcoholic Liver Disease Have a New Liver?*, 11 HEPATOLOGY 314 (1990).

⁷¹ For example, when Crossley argues for the bona fide medical judgment standard, she concedes its inconsistency with the ADA's principle of reasonable accommodations. Crossley, *supra* note 15, at 1654-55 & n.280.

⁷² 42 U.S.C. § 12182(b)(2)(A)(ii) (Supp. 1993).

⁷³ 42 U.S.C. § 12182(b)(2)(A)(iii) (Supp. 1993).

⁷⁴ For example, employers engage in unlawful discrimination if they do not make "reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or an employee." 42 U.S.C. § 12112(b)(5)(A) (Supp. 1993). Similarly, providers of public services must make "rea-

The principle of reasonable accommodations recognizes that society has developed its structures and policies on the basis of the needs of persons without disabilities. For example, people who use canes may have trouble crossing the street safely because the walk signal does not last long enough for them to reach the other side. Likewise, people whose psychiatric difficulties result in poor compliance with their medical regimens may make them poorer candidates for organ transplantation.⁷⁵ In short, much of the disadvantage of a disability is not inherent in the disability itself but is a result of social attitudes, policies, and institutions erected around the norm of a person without disabilities.⁷⁶ Accordingly, if we prohibited discrimination only when disabilities had no effect on a person's functioning, we would do nothing to counteract the fact that our social structures are inherently biased against persons with disabilities. Treating people with disabilities equally when they start out with an unfair disadvantage simply perpetuates the original disadvantage. Thus, the principle of reasonable accommodations requires that reasonable steps be taken to counteract the inherent biases of social structure.⁷⁷

As the Supreme Court has observed, the principle of reasonable accommodations is an integral part of the legal framework protecting the

sonable modifications to rules, policies, or practices" to enable persons with disabilities to receive their services or participate in their programs. 42 U.S.C. § 12131(2) (Supp. 1993); see also Peters, *supra* note 7, at 507-08 (describing the principle of reasonable accommodations).

⁷⁵Psychiatric illness interferes with a person's ability to follow routines and keep schedules. Consequently, people with psychiatric illness usually need more external guidance in exercising control over their lives. These individuals could have better compliance with medical regimens if they were able to live in a more structured environment. Yet our society has evolved with a low level of external structure because most people can muster high levels of internal structure. Had we designed our society with the needs of the disabled in mind, we would have a society in which disabilities had much less of an impact on a person's ability to function.

⁷⁶See MARTHA MINOW, MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW 21-22 (1990); Cass R. Sunstein, *Why Markets Don't Stop Discrimination*, in REASSESSING CIVIL RIGHTS 22, 33 (Ellen Frankel Paul et al. eds., 1991) (discussing how "markets incorporate the norms and practices of advantaged groups").

⁷⁷Race-based affirmative action programs apply this principle in recognizing that it is not enough simply to cease racial discrimination; it is also necessary to compensate for the effects of past discrimination. Glen Loury, *Why Should We Care About Group Inequality?*, 5 Soc. PHIL & POL'Y 249 (1987). Similarly, the Supreme Court has upheld federal statutes that compensate for past discrimination against women when the statutes have been challenged as discriminating against men. See *Califano v. Webster*, 430 U.S. 313, 318 (1977) (allowing Congress to exclude more lower-earning years for women than for men when calculating average monthly wages for Social Security retirement benefits in order to compensate for historical gender discrimination in well-paying jobs); *Schlesinger v. Ballard*, 419 U.S. 498, 508 (1975) (allowing Congress to give female officers in the Navy a longer period of active service than male officers before mandatory discharge for lack of promotion, because women generally had fewer opportunities for the kind of accomplishments that would lead to a promotion).

disabled from discrimination. Quoting from the legislative record of the Rehabilitation Act,⁷⁸ the Court in *Alexander v. Choate*⁷⁹ recounted the evidence of congressional intent to eradicate the discrimination caused by social structures, such as architectural and transportation barriers, and other social arrangements, such as job qualification criteria, that are designed around a norm of a person without disabilities, albeit without any actual intent to disfavor those with disabilities.⁸⁰ Indeed, the *Choate* Court observed that Congress viewed discrimination against the disabled as being caused most often not by invidious animus but by society's indifference to the needs of disabled persons.⁸¹

4. Recognizing the Principle of Reasonable Accommodations

a. The Principle of Reasonable Accommodations and Current Judicial Interpretations

In spite of the *Choate* Court's recognition of a principle of reasonable accommodations in the disabilities context, the principle has received minimal consideration in decisions involving health care rationing.⁸² Instead, as the *Choate* opinion suggests, the courts have developed the principle of reasonable accommodations primarily in non-medical contexts.⁸³ For example, the Tenth Circuit has held that primary public schools must provide special education services and adopt modifications of their educational programs to ensure that children with disabilities receive an educa-

⁷⁸The interpretations of the Rehabilitation Act are important because the ADA includes a provision stating that it should be construed to apply no more lenient a standard than that applied under the Rehabilitation Act. 42 U.S.C. § 12201(a) (Supp. 1993); see also *Myers v. Hose*, 50 F.3d 278, 281 (4th Cir. 1995) (holding that "whether suit is filed against a federally-funded entity under the Rehabilitation Act or against a private employer under the ADA, the substantive standards for determining liability are the same").

⁷⁹469 U.S. 287 (1985) (upholding Tennessee's 14-day annual cap on coverage for hospitalization under Medicaid against a claim that the cap amounted to discriminatory rationing by service against persons with disabilities, given the greater need of such persons for hospitalization).

⁸⁰*Id.* at 296-97.

⁸¹*Id.* at 295-96.

⁸²This lack of consideration appears to reflect both the paucity of rationing cases decided under anti-discrimination law and the view that anti-discrimination law has little to say about rationing by patient. The *Choate* case is the only Supreme Court case to address rationing decisions on substantive grounds. The Court summarily rejected the plaintiffs' reasonable accommodation claim on the ground that their proposed remedy would impose unduly burdensome administrative costs but provided little evidence for such a holding. *Choate*, 469 U.S. at 306-09.

⁸³See, e.g., *New Mexico Ass'n for Retarded Citizens v. New Mexico*, 678 F.2d 847 (10th Cir. 1982); *Prewitt v. United States Postal Service*, 662 F.2d 292 (5th Cir. 1981).

tion appropriate to their needs, as long as the financial burden is not excessive.⁸⁴

If the principle of reasonable accommodations were applied to health care rationing decisions as it has been applied in non-medical contexts, health care programs might have to provide support services that would allow certain patients to receive benefits they might not otherwise receive. For example, organ recipients have many responsibilities to ensure survival of their organs. Those responsibilities might not be feasible for a disabled person alone, but they might become feasible if the organ transplant program provided support services. Some transplant centers have been able to overcome compliance problems by having frequent contact with their patients.⁸⁵ If interpreted as it has been in non-medical contexts, reasonable accommodations would likely require the provision of these support services as long as it would not be unduly burdensome for the transplant program to do so.⁸⁶

b. Recognizing the Effects of Social Forces on Disabilities Through the Principle of Reasonable Accommodations

A more expansive interpretation of the ADA and Rehabilitation Act would better realize the purposes of the principle of reasonable accommodations. The principle of reasonable accommodations recognizes two important truths. First, it recognizes that disability is not simply an intrinsic characteristic of a person but is the result of the interaction between a person's intrinsic qualities and the environment.⁸⁷ Second, the principle recognizes that the environment is shaped not simply by natural, inevitable forces but also has been shaped to serve the interests of some segments of society at the expense of others. The socio-political environment cannot

⁸⁴ *New Mexico Ass'n for Retarded Citizens*, 678 F.2d at 854-55.

⁸⁵ See S. Takemoto & P.I. Terasaki, *A Comparison of Kidney Transplant Survival in White and Black Recipients*, 21 *TRANSPLANTATION PROCEEDINGS* 3865, 3866 (1989).

⁸⁶ See Peters, *supra* note 7, at 529 (arguing that the principle of reasonable accommodations may impose such a requirement); cf. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 295-96 (3d ed. 1989) (arguing that principles of justice may require the provision of support services to organ recipients).

⁸⁷ See JEROME E. BICKENBACH, *PHYSICAL DISABILITY AND SOCIAL POLICY* 11 (1993). This is not to say that there is no measurable biological component to disability. Indeed, persons with disabilities often do have an identifiable abnormality, but the mere existence of a biological component does not tell us what its functional effects will be. *Id.* at 14. Accordingly, in its definitions, the United Nations distinguishes between the existence of an abnormality of a person's structure, an "impairment," and the effects that result from the interaction of the abnormality with the person's environment, a "handicap." Susan Wendell, *Toward a Feminist Theory of Disability*, in *FEMINIST PERSPECTIVES IN MEDICAL ETHICS* 63, 65 (Helen B. Holmes & Laura M. Purdy eds., 1992) (quoting United Nations definitions).

always be justified by the operation of neutral or objective principles or by principles that are otherwise morally valid.⁸⁸

Indeed, there is nothing "natural" or ineluctable about the fact that most aspects of socio-political organization respond primarily to the needs of persons without disabilities,⁸⁹ just as there is nothing inevitable about the fact that the post office and many businesses cease operations on Sunday, the Christian Sabbath, rather than on Saturday, the Jewish Sabbath, or Friday, the Moslem Sabbath. Social norms develop not because they are pre-ordained, but because they serve the needs of social groups that are dominant either in numbers or power.

Often, social arrangements develop around a social norm of a person without disabilities because of inattention to the needs of persons with disabilities. In addition, in some cases, society purposefully creates its institutions for the convenience of persons without disabilities while aware of the hardship imposed on persons with disabilities. For example, it is commonly the case that mentally retarded persons are perceived to be physically unattractive. Yet, with a little assistance in grooming, many of these individuals can take on an "attractive" appearance.⁹⁰ Some institutions for the mentally retarded have intentionally neglected the grooming of their wards to discourage them from entering into romantic or sexual relationships.⁹¹ The operators find that such relationships complicate their work; in addition, non-retarded persons are often unwilling to permit sexual or romantic activity by retarded persons.⁹² In short, persons without disabilities may compromise the interests of persons with disabilities for their own convenience and psychological comfort.

How a social norm develops, then, may depend much more on considerations of popularity or political power than upon alternative visions of distributive justice that often have greater moral weight. Because socio-political forces frequently exacerbate the impact of a disability without sufficient moral justification, anti-discrimination law requires

⁸⁸ See Sunstein, *Why Markets Don't Stop Discrimination*, in REASSESSING CIVIL RIGHTS, *supra* note 76, at 33.

⁸⁹ See, e.g., Harlan Hahn, *The Politics of Physical Differences: Disability and Discrimination*, 44 J. SOCIAL ISSUES 39, 40 (1988); Wendell, *supra* note 87, at 63, 67-70 (claiming that prior policy decisions create a subsequent environment with discriminatory effects on people with disabilities).

⁹⁰ CAROLYN L. VASH, *THE PSYCHOLOGY OF DISABILITY* 72-73 (1981) (describing an experiment with mentally retarded persons who were perceived to be unattractive but, after 20 minutes of grooming and coaching, were perceived as attractive).

⁹¹ *Id.*

⁹² See *id.*; see also *Buck v. Bell*, 274 U.S. 200 (1927) (upholding the sterilization of a mentally retarded woman); Robert L. Hayman, Jr., *Presumptions of Justice: Law, Politics, and the Mentally Retarded Parent*, 103 HARV. L. REV. 1201, 1243-47 (1990) (arguing that presumptions about the retarded lead to assumptions about parental fitness).

modifications of social policies to ameliorate the deleterious effects of socio-political forces on disability.⁹³

(i) How the Magnification Effect of Social Forces on Disability Influences Rationing Decisions

Because social organization can aggravate the impact of disabilities, socio-political factors will likely compromise the access to health care of persons with disabilities when health care is rationed. Allocation decisions will be based both on length and quality of life. Some treatments will be funded because they can save lives; others will be funded because they can diminish pain or improve the ability of patients to think, walk, or breathe. Moreover, the greater the improvement in quality or length of life from a treatment, the more likely that the treatment will be funded. Social organization may act on this relationship between quality of life and likelihood of funding to the detriment of persons with disabilities. The more that social organization exacerbates the impact of a disability on a person's quality of life, the more the quality of life resulting from the disability will be diminished. As a result, persons with disabilities will often receive a smaller improvement in quality of life from treatment than persons without disabilities and will therefore be less likely to receive funding for treatment.

The relationship between rationing and disability reflects not only the effects on disability of concrete social structures, it also reflects the effects of disability on people's perceptions.⁹⁴ As the Supreme Court observed in *School Board of Nassau County v. Arline*, discrimination on the basis of disability exists in large part because persons without disabling diseases often have unfounded views about such illnesses.⁹⁵ For example, people have been known to avoid persons with cancer out of fear that the cancer was contagious.⁹⁶ This example demonstrates that people become disabled not only because they are actually hampered by an illness but also because other people treat them as if they are disabled.⁹⁷ Perceptions about dis-

⁹³ See Sunstein, *Why Markets Don't Stop Discrimination, in* REASSESSING CIVIL RIGHTS, *supra* note 76, at 34–36 (arguing that one of the purposes of anti-discrimination law is to eliminate the caste-like effects of social arrangements being structured around the norms of advantaged persons).

⁹⁴ See Hahn, *The Politics of Physical Differences, supra* note 89, at 42–45; HARLAN HAHN, *THE ISSUE OF EQUALITY: EUROPEAN PERCEPTIONS OF EMPLOYMENT FOR DISABLED PERSONS* 12 (1984) (both works observing that persons with disabilities are subject to discrimination because of economic and social systems that favor able-bodied persons and because able-bodied persons feel psychologically threatened by the existence of persons with disabilities).

⁹⁵ 480 U.S. 273, 284–85 (1987).

⁹⁶ Susan Sontag, *ILLNESS AS METAPHOR* 6 (1978). Persons with HIV infection may also suffer ostracism due to exaggerated fears of contagion.

⁹⁷ HAHN, *ISSUE OF EQUALITY, supra* note 94, at 15. Similarly, a study of persons with

ability are relevant to rationing decisions because such decisions often hinge on estimates of the quality of life enjoyed by persons with disabilities. When persons without disabilities are asked to estimate the quality of life of persons with disabilities, their estimates are often considerably lower than the ratings given by persons with disabilities when they are asked to evaluate their own quality of life.⁹⁸ This underestimation may cause those without disabilities to assign less benefit to, and therefore less funding for, treatments for persons with disabling conditions.⁹⁹

(ii) *The Causation Effect of Social Forces on Disability*

Not only can social factors magnify the impact that a disabling condition has on a person's ability to function, but the very existence of a disabling condition may be a consequence of the commissions or omissions of society.

Social forces cause disability by commission when environmental pollution leads to lung diseases or cancers, when lead-based paint damages the neurological systems of children, or when unchecked violence results in traumatic injury.

Social organization causes disability by omission when priorities are established for medical research and treatment. Some illnesses, such as heart disease and cancer, are the subject of vast research expenditures, while other illnesses receive disproportionately little federal research funding.¹⁰⁰ Patients with intensively studied diseases are much more likely to be saved from disabling symptoms than patients with neglected diseases. In addition, efforts to develop treatment for a particular illness often focus

visual impairment suggests that the extent to which a visually impaired person's activities are compromised may depend less on the person's actual degree of visual impairment than on the fact that the attitudes of others toward visual impairment socialize the person into the role of a blind person. See ROBERT A. SCOTT, *THE MAKING OF BLIND MEN: A STUDY OF ADULT SOCIALIZATION* 71-89, 105-21 (1969).

⁹⁸ See, e.g., Norman F. Boyd et al., *Whose Utilities for Decision Analysis?*, 10 MED. DEC. MAKING 58 (1990); Arnold M. Epstein et al., *Using Proxies to Evaluate Quality of Life: Can They Provide Valid Information About Patients' Health Status and Satisfaction with Medical Care?*, 27 MED. CARE S91 (1989); Robert A. Pearlman & Richard F. Uhlmann, *Quality of Life in Chronic Diseases: Perceptions of Elderly Patients*, 43 J. GERONTOLOGY M25 (1988).

⁹⁹ For example, it is less likely that chemotherapy or cardiac surgery will be provided to persons who are mentally disabled than to persons who have average intellectual skills. See, e.g., *In re Phillip B.*, 156 Cal. Rptr. 48 (1979), cert. denied, 445 U.S. 949 (1980) (withholding corrective surgery for heart defect from a Down syndrome child); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977) (withholding chemotherapy for leukemia from mentally retarded patient); see also Levenson & Olbrisch, *supra* note 24, at 318.

¹⁰⁰ In fiscal year 1989, for example, federal spending for research on, education about, and prevention of cancer exceeded that for Alzheimer's disease by a factor of 10 (\$1.45 billion vs. \$127 million). See Victor F. Zonana, *Staggering Costs; AIDS Care: Who'll Pick up the Bill?*, L.A. TIMES, Aug. 7, 1989, at Metro 1.

on a treatment that is effective only for some of those with the illness, leaving the most disabled without any therapeutic option. Experience with heart transplant as a treatment for end-stage heart disease demonstrates this type of bias. Some patients have such severely compromised cardiac function that a heart transplant appears to be the only treatment left, yet they do not have high enough priority on the waiting list to receive a transplant.¹⁰¹ Recent research on these patients has shown that unusually aggressive medical therapy is much more effective than previously used regimens and that the newly aggressive approach often obviates the need for transplantation.¹⁰² Had fewer resources been devoted to developing surgical approaches that benefit only certain patients and more resources been devoted to medical therapies that benefit all patients with severe heart disease, effective treatment would likely have become available sooner to a much broader range of patients who are more severely disabled by their illnesses.¹⁰³ Moreover, when treatments are developed for a particular disease, they are often based on the norm of a patient without any coexisting illnesses. As a result, patients with multiple illnesses are less able to benefit from treatment. For example, persons with chronic lung disease are less likely to be viewed as appropriate candidates for coronary artery surgery. These situations are analogous to the phenomenon of medical treatments often being more effective for men than women. Because research studies have typically used only men as subjects, the

¹⁰¹The waiting list for a heart transplant greatly exceeds the number of hearts available for transplantation, so most persons who would benefit from a transplant never receive one. See Roger W. Evans, *Need, Demand, and Supply in Organ Transplantation*, 24 *TRANSPLANTATION PROCEEDINGS* 2152 (1992) (indicating that, in 1990, over 45,000 persons needed a heart or heart-lung transplant, but that there were fewer than 4500 organ donors).

¹⁰²See Sandra Blakeslee, *High Doses of Drugs Forestall Heart Transplants*, N.Y. *TIMES*, Oct. 20, 1992, at C3.

¹⁰³It is not surprising that greater efforts have been devoted to developing surgical rather than non-surgical treatments. Historically, insurers have reimbursed physicians at much higher rates for performing tests or procedures than for prescribing medications. See Robert A. Berenson, *Payment Approaches and the Cost of Care*, in *PAYING THE DOCTOR: HEALTH POLICY AND PHYSICIAN REIMBURSEMENT* 63, 65-67 (Jonathan D. Moreno ed., 1991). Yet there is nothing "natural" or inevitable about the higher reimbursement rates for tests and procedures. See Jon R. Gabel & Michael A. Redisch, *Alternative Physician Payment Methods: Incentives, Efficiency, and National Health Insurance*, 57 *MILBANK MEMORIAL FUND QUARTERLY/HEALTH AND SOCIETY* 338, 348, 352-54 (1979) (observing that insurers have traditionally reimbursed technologically oriented and institutionally based physician services more generously than primary care services). The higher rates arose at least in part for idiosyncratic reasons. See Mark S. Blumberg, *Provider Price Charges for Improved Health Care Use*, in *HEALTH HANDBOOK* 1049, 1065, 1086 (George K. Chacko ed., 1979). Moreover, the rate differentials have since been perpetuated by private and public health care insurers because insurers have tended to reimburse physicians on the basis of their usual and customary fees. See Gabel & Redisch, *Alternative Physician Payment Methods*, at 339-40.

treatments developed are based on a male model and are often not as effective for treating women.¹⁰⁴

Social organization also affects the cost of treatment. When fewer resources are devoted to the understanding and treatment of a particular condition, there is less to offer patients with that condition, and treatment of that condition often ends up costing more. Cost of care is essentially the flip-side of benefit of care. Accordingly, just as considerations of medical benefit are not "neutral" measures for allocation decisions, neither are considerations of cost.

All of the disadvantaging aspects of social structure that this Article has discussed may act to limit a disabled person's access to organ transplants. If there had been more aggressive efforts in the past to treat disabling conditions targeted by eligibility criteria for transplantation, they would not now have as much effect as they do on organ transplant success. Unfortunately, much of the neglect of certain diseases reflects the invidious prejudices that people have about those diseases. Psychiatric illnesses have not often been viewed as real illnesses, for example; other diseases, like obesity, have been ignored because they have been viewed as self-inflicted.

(iii) A New Standard for the Principle of Reasonable Accommodations—Deconstructed Disability

If courts gave adequate recognition to the principle of reasonable accommodations, they would conclude that even meaningful medical differences among organ transplant candidates cannot form the basis for preferring one person over another, and that meaningful medical differences may have resulted from past invidious bias or other unfair biases in social structure. To compensate for these biases, this Article proposes a deconstructed disability standard which would require physicians to discount the significance of medical differences among patients when allocating organs for transplantation.

The difficult question is how much physicians should discount medical differences among patients. It is impossible to measure the precise effects of unfair biases or to know what the world would look like if society had evolved with fairer policies and structures. Nevertheless, we must make some efforts to overcome the biases of social structure. That we cannot tailor our remedy to the problem precisely should not prevent us from trying to remedy it as best we can.

¹⁰⁴ See, e.g., Marcia Angell, *Caring for Women's Health—What Is the Problem?*, 329 *NEW ENG. J. MED.* 271 (1993); Milo Gibaldi, *Drug Development and Women: An Overview*, 12 *PHARMACOTHERAPY* 365 (1992); Nanette K. Wenger, *Cardiovascular Drugs: The Urgent Need for Studies in Women*, 46 *J. AM. MED. WOMEN'S ASS'N* 117 (1991).

To some extent, the statutory language provides an answer. The ADA and Rehabilitation Act do not require that employers, governments, or private operators of public accommodations undertake unlimited measures to accommodate persons with disabilities. The obligation to accommodate ceases when the accommodations would be unduly burdensome or would result in a fundamental alteration of the workplace, service, or public accommodation.¹⁰⁵ This limit on the obligation to undertake reasonable accommodations likely reflects a tension between the egalitarian spirit of anti-discrimination law and utilitarian concerns. It also undoubtedly reflects the fact that not all effects of disability are a consequence of biased social structure, and that in some cases, the debilitating effects of a disability result primarily from its inherent nature.¹⁰⁶ In the context of rationing by patient, a court would likely limit the obligation to accommodate when medical care provided minimal benefit and did so at a high financial cost.¹⁰⁷

These considerations suggest the following “destructured disability” standard for the principle of reasonable accommodations: if a disabling illness *seriously* compromises a person’s ability to benefit from an organ transplant, a physician could deny the person an organ. Otherwise, the physician should give the person the same opportunity as other candidates to benefit from a transplant. In other words, if the disabling illness prevents the person from realizing a reasonable minimum level of benefit from treatment, it would be permissible for physicians to deny the treatment to the patient because of the illness. Thus, if a person’s lung disease prevents the person from gaining a reasonable minimum level of benefit from a heart transplant, the person could be denied a new heart.

What would constitute a reasonable minimum level of benefit, like many other legal standards, is not easily reduced to a precise formula. Courts will have to rely to some extent on physician discretion, but it is also important that they set the threshold low enough to ensure that it provides meaningful protection for persons with disabilities. Thus if an organ transplant program excluded persons whose coexisting illnesses prevented them from gaining more than a few months of benefit from an organ, there should be no problem with the exclusion. If, however, a

¹⁰⁵ See *supra* notes 72 and 73 and accompanying text.

¹⁰⁶ For example, an anencephalic infant’s lack of a brain and, thus, consciousness would be a devastating disability under any social structure. Steven G. Gabbe et al., *OBSTETRICS NORMAL AND PROBLEM PREGNANCIES* 291–92 (2d ed. 1991) (describing the development and prospects of anencephaly).

¹⁰⁷ Cf. *Myers v. Hose*, 50 F.3d 278, 283 (4th Cir. 1995) (holding that, given governmental fiscal constraints, reasonable accommodation does not require a county to grant an employee extended paid leave while the employee attempts to control his medical problems); *Treadwell v. Alexander*, 707 F.2d 473, 478 (11th Cir. 1983) (holding that employer was not obligated to have other workers assist disabled employee with his tasks given the small staff and limited resources).

program excluded persons who would gain a few years of benefit on the ground that other persons would gain even more, that kind of exclusion should not be permitted.

This is not to say that the person with the coexisting disabling illness will necessarily receive the organ transplant when that person's coexisting illness is eliminated from consideration. There will not be enough organs for everyone who would receive more than a reasonable minimum level of benefit. Accordingly, some method must be used to distinguish among the different qualifying candidates for an organ transplant. The most promising option is to employ some type of equal opportunity approach, such as a lottery system that could be used to choose among all patients who would gain more than a reasonable minimum level of benefit.¹⁰⁸

Random selection and similar equal opportunity mechanisms are valuable for at least two reasons. First, as indicated, they reduce the possibility that rationing decisions will be based on unjustified effects of socio-political factors on persons with disabilities. Second, if decisionmakers realize that they cannot fully control the outcome of rationing decisions and that therefore treatments they might need when they become patients might be denied, they might be more generous in allocating resources for health care coverage. Decisionmakers and others with disproportionate influence will not be able to game the system and skew the allocation of resources toward their own particular needs.¹⁰⁹ Equal opportunity mechanisms, in short, bring us closer to approximating the veil of ignorance.¹¹⁰

¹⁰⁸ It is more difficult to use a random selection method for general rationing than with allocation of kidneys or other organs. Since organs have to be allocated quickly to be usable, there is a well-defined list of potential recipients. With general rationing, on the other hand, current patients are in competition with unascertained future patients. Several measures could help overcome this problem. First, the priority list for patients could be developed by using a lottery to rank month and date of birth, as with the draft lotteries. Future patients, then, would be assigned a place in the ranking based on their month and date of birth. Second, based on historical trends, it is possible to estimate how many patients would need different kinds of care each month. Funds could be budgeted in a way to ensure that there were resources for as many patients in December as in January.

¹⁰⁹ See Hank Greely, *The Equality of Allocation by Lot*, 12 HARV. C.R.-C.L. L. REV. 113, 118-20 (1977).

¹¹⁰ JOHN RAWLS, *A THEORY OF JUSTICE* (1971). Lotteries have been criticized as a mechanism for allocating scarce medical resources on the ground that it is irresponsible to rely on mere chance to make such momentous decisions and that people will feel dehumanized if they are subject to the arbitrariness of a lottery. See, e.g., GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* 134 (1978); Elhauge, *supra* note 67, at 1500-02. Yet it would be even more irresponsible to allocate limited resources on the basis of criteria that incorporate unfair biases against certain people. It is also more dehumanizing to deny people care because of unfair biases than because of the operation of a lottery. I do not advocate a lottery as a better approach than one based on some morally valid criteria for choosing among different patients; I simply argue that, in the absence of an approach that relies on morally valid criteria, a lottery should be used.

Not only would the destructured disability standard help compensate for society's structural biases against persons with disabilities, it could also create a strong incentive for society to begin the process of creating more equitable social structures. Because people want society to realize the greatest benefit possible from its limited medical resources, they may try to ensure that the recipients of medical care can gain as much benefit as possible.

Clearly, this Article's argument can apply to other areas of social need. Nonetheless, the argument for equitable social structures has special force in the health care arena. In addition to generating the positive incentive for society to create more equitable social structures, the destructured disability standard does not entail the usual negative incentives that exist with other programs of welfare distribution. As Einer Elhauge and Gregory Kavka have observed, we do not have to worry as much about perverse incentives in health care as we do with other social goods. When indigent persons are given welfare payments, they may have a diminished incentive to seek employment. Perverse incentives are of less concern in allocating health care because it is better to remain healthy than to become sick to gain greater access to health care.¹¹¹

Compensating for disabilities differs from compensating for disadvantages in education and employment in another important respect. A program to compensate people who lack certain academic and job skills would require identification and labeling of those people as lacking such skills.¹¹² The stigma that this kind of identification carries would often outweigh the benefits of the compensatory program. Since disabilities are often discernible even in the absence of compensatory programs, the provision of such programs would not add as much in the way of stigmatization costs.¹¹³

¹¹¹ See Elhauge, *supra* note 67, at 1486-92 (justifying why health care deserves special treatment among social goods when deciding society's obligation to provide for those in need); Gregory S. Kavka, *Disability and the Right to Work*, 9 Soc. PHIL. & POL'Y 262, 279 (1992) (discussing how social subsidies to compensate for disability do not encourage people to seek greater subsidies through increasing their disabilities).

An important problem with incentives remains, however, even in the health care arena. If health care is subsidized, people will demand excessive levels of care. Consequently, limits must be placed on the availability of health care, and some alternative mechanism other than people's willingness to purchase must be used to ensure that too much health care is not provided. Some countries, like Canada and Great Britain, use waiting lists to keep health care supply within reasonable limits. See, e.g., Peter C. Coyte et al., *Waiting Times for Knee-Replacement Surgery in the United States and Ontario*, 331 NEW ENG. J. MED. 1068 (1994) (finding that Canadians wait longer than U.S. citizens for knee-replacement surgery).

¹¹² See Kavka, *supra* note 111, at 282.

¹¹³ *Id.*

(iv) Potential Criticisms of the Destructured Disability Standard

At first glance, it appears that the destructured disability standard would take the principle of reasonable accommodations in a very different direction from its interpretation in other contexts such as employment. Yet the application of the principle of reasonable accommodations differs little between the two contexts. Under the ADA, employers not only must hire persons with disabilities when they would be as productive in the workplace as other persons, they must also undertake reasonable accommodations to make the workplace accessible to persons with disabilities. When society requires employers to hire persons with disabilities even though it costs employers more to do so, society sacrifices some overall economic benefit in order to ensure greater access to jobs for persons with disabilities. Similarly, when society requires physicians to give medical care to persons with disabilities even though there will be less of an improvement in health, society sacrifices some overall medical benefit in order to ensure greater access to medical care for persons with disabilities. In both contexts, there is a trade-off between economic efficiency and respect for the individual.¹¹⁴

Another potential problem with the destructured disability standard is that, while it offers greater protection against discrimination than existing standards, it does not go far enough to protect against discrimination arising from biases in social structure. As indicated, the standard would allow denial of treatment when a disability seriously compromises that person's ability to benefit from medical care. Yet those who have a seriously compromised ability to benefit may be the ones who have suffered the most discrimination. The greater the neglect of a particular disease by society, the more likely it is that people with that disease will not be helped significantly by medical care.¹¹⁵ This is an important point, but its implications cannot realistically be addressed. If persons with little to gain from treatment are nevertheless entitled to treatment because their lack of benefit is the result of unfair bias in the past, then there would be almost no limit on the obligation to accommodate, and the qualification that the accommodations be "reasonable" would be vitiated. This becomes particularly apparent in the context of rationing by service. If, simply because their illness had been socially disfavored, persons with certain

¹¹⁴In fact, there may not be any loss in overall welfare when society accounts for social biases against persons with disabilities. While my approach is primarily based on distributive justice, a utilitarian argument can bring us to the same conclusion. Allocating medical resources purely in terms of medical benefit ignores other important values, such as inclusiveness, that contribute to overall social utility. See Kavka, *supra* note 111, at 268-70.

¹¹⁵I am indebted to Professor Susan Hoffman Williams, Indiana University School of Law-Bloomington, for this point.

psychiatric diseases were entitled to treatment even when the treatment was costly and provided little benefit, it is hard to see how health care costs could be reasonably constrained or rationally allocated.

Nevertheless, even with its requirement of a reasonable minimum level of benefit, the corrective effects of the destructured disability standard will help those whose diseases have been especially neglected by society and who therefore gain little benefit from medical care. Because many people with those diseases will satisfy reasonable minimum thresholds for treatment and will receive treatment under the destructured disability standard, the incentive for society to create more equitable social structures would operate to some degree, and society would be more likely to devote more resources to the understanding and treatment of the diseases.

B. Rationing by Service

The courts' treatment of rationing by service, like their treatment of rationing by patient, is also problematic. In the context of rationing by service, the courts have developed a standard that fails to recognize adequately not only the principle of reasonable accommodations, but also the fact that the ADA and Rehabilitation Act, like other anti-discrimination laws, extend their protections beyond the aggregate level to protect the individual. Even if a policy does not discriminate against a particular group, it is not permissible for the policy to discriminate against individuals within that group. Discrimination against one person with a disability cannot be offset by favoritism toward another disabled person. In addition, while the courts' standard for rationing by service may ensure *decent* treatment of persons with disabilities, it does not ensure *equal* treatment.

To focus the analysis of rationing by service, this Section discusses the use of fixed caps on the amount of a particular service available to patients. For example, coverage for mental health treatment in a psychiatric hospital might be available for no more than sixty days a year.¹¹⁶ For the sake of simplicity, this Section also assumes that we are dealing with health care coverage provided by an employer and thus covered by the employment section of the ADA.¹¹⁷

1. The Relevant Statutory Provision

At first glance, the ADA would appear to have little to say about fixed caps on the amount of a medical service covered by employer-provided insurance. The employment section of the ADA prohibits discrimination

¹¹⁶ See, e.g., H.R. 3600, 103d Cong., 1st Sess. § 1115(c)(2)(D) (1993).

¹¹⁷ 42 U.S.C. §§ 12111-12117 (Supp. 1993).

in compensation and "other terms, conditions, and privileges of employment" on the basis of the employee's disability.¹¹⁸ This provision suggests that while employers would not be able to single out persons with disabilities for limitations on services, they would be able to impose limits that apply to everyone.

Indeed, this view has been taken by the Equal Employment Opportunity Commission ("EEOC") in its guidelines for employer-based health insurance.¹¹⁹ According to the EEOC, if employer-provided health insurance includes a cap on the amount of a health care service covered, the cap does not violate the ADA as long it is applied to everyone. Thus, even if an across-the-board cap has a disparate impact¹²⁰ on persons with disabilities, there would be no violation of the ADA.¹²¹ Under the EEOC view, the cap would violate the ADA only if it resulted in disparate *treatment* of persons with disabilities.¹²² For example, if an employer caps hospital coverage for treatment of HIV infection without imposing a comparable cap on treatment of other infectious diseases, cancer or heart disease, then the cap presumptively violates the ADA by selectively imposing the cap on hospital services on persons who are infected with HIV.¹²³

The problem with the EEOC view is that it misconceives the concept of equal treatment when it interprets the requirement that employers give equal treatment in health care coverage to persons with disabilities. Like any other requirement of equal treatment, the requirement of equal access to health care benefits does not simply mean that different persons must receive exactly the same benefits.¹²⁴ If we treat people in exactly the same way, there will be greater hardship on some persons than on others. As the Supreme Court has observed, "[s]ometimes the greatest discrimination can lie in treating things that are different as though they were exactly the same."¹²⁵ For example, if all persons are denied leave for pregnancy, women suffer greater harm than men.

¹¹⁸ 42 U.S.C. § 12112(a) (Supp. 1993).

¹¹⁹ The guidelines can be found at EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, INTERIM ENFORCEMENT GUIDANCE ON THE APPLICATION OF THE AMERICANS WITH DISABILITIES ACT OF 1990 TO DISABILITY-BASED DISTINCTIONS IN EMPLOYER PROVIDED HEALTH INSURANCE, No. N-915.002, *reprinted in* EEOC COMPL. MAN. (CCH) ¶ 6902, at 5313-19 (June 8, 1993).

¹²⁰ See *supra* note 44.

¹²¹ See INTERIM ENFORCEMENT GUIDANCE, *supra* note 119, at 5315 n.7. The EEOC cites *Alexander v. Choate*, 469 U.S. 287 (1985), for this proposition even though the *Choate* Court indicated that the law reaches at least some cases of disparate impact discrimination against persons with disabilities. *Id.* at 299.

¹²² See *supra* note 44.

¹²³ See INTERIM ENFORCEMENT GUIDANCE, *supra* note 119, at 5316.

¹²⁴ See Ronald Dworkin, *What Is Equality? Part 1: Equality of Welfare*, 10 PHIL. PUB. AFF. 185, 185 (1981) (observing that equality can take many different, mutually exclusive forms).

¹²⁵ *Jenness v. Fortson*, 403 U.S. 431, 442 (1971) (making this observation in the context of a challenge to election procedures).

Consider another example involving two patients with appendicitis. One patient is otherwise healthy and will be ready for discharge from the hospital within five days of the appendectomy. The second patient has a coexisting medical problem (for example, diabetes) that causes recovery from the surgery to take ten days.¹²⁶ If a health plan limited reimbursement across the board to seven days of hospitalization after surgery, the people with coexisting medical problems would be disadvantaged.

Sometimes we need to take people's differences into account when deciding how to treat them. To ensure that people are treated as equals, it is often necessary to treat people differently.¹²⁷ Consequently, the requirement of equal treatment would invalidate at least some fixed caps on medical services that had a disparate impact on persons with disabilities, even though the caps were applied uniformly.¹²⁸

2. *Judicial Interpretation of the Relevant Statutory Provision: The Meaningful Access Standard*

An alternative approach for rationing by service is suggested by the Supreme Court's opinion in *Alexander v. Choate*.¹²⁹ In *Choate*, disabled persons challenged a Medicaid provision in Tennessee under the Rehabilitation Act.¹³⁰ In Tennessee, Medicaid would reimburse hospitals for no more than fourteen days of inpatient care a year for any one Medicaid recipient. The plaintiffs argued that the fourteen-day limitation would discriminate against persons with disabilities because such persons are more likely to need prolonged hospitalization,¹³¹ and that the state's across-

¹²⁶The longer time needed for recovery reflects in part the fact that coexisting medical problems inevitably complicate a person's health. However, the difference in recovery time also reflects the fact that socio-political factors may have caused the coexisting medical problem or that surgeons have developed their techniques for appendectomies on the basis of a norm of a patient whose appendicitis was not complicated by other medical problems.

¹²⁷See LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 1437-39 (2d ed. 1988) (discussing the distinction between the equal treatment of persons and the treatment of persons as equals).

¹²⁸The courts' treatment of across-the-board rules that have a disparate impact on members of minority religious groups also demonstrates the unfairness of the EEOC view. As Martha Minow has observed, courts have sometimes interpreted unemployment benefits law to compensate for the fact that social organization often favors persons who are secular, Catholic, or members of the dominant Protestant faiths. MINOW, *supra* note 76, at 69; see, e.g., *Sherbert v. Verner*, 374 U.S. 398 (1963) (holding that a state may not deny unemployment benefits to an individual who declined a job opportunity because it conflicted with her chosen Sabbath day).

¹²⁹469 U.S. 287 (1985).

¹³⁰This case preceded the enactment of the ADA and thus was brought under the Rehabilitation Act. The provisions of the two laws are nonetheless sufficiently similar for the distinction to be irrelevant for purposes of this analysis.

¹³¹For example, in 1979-80, among hospitalized Medicaid patients in Tennessee, 27.4% of patients with disabilities needed more than 14 inpatient days while only 7.8% of patients without disabilities needed more than 14 days. *Choate*, 469 U.S. at 289-90.

the-board cap on hospital days would therefore have a disparate impact on persons with disabilities.

The Supreme Court found no violation of the Rehabilitation Act, however, because every patient received the same number of hospital days per year. Drawing on *Southeastern Community College v. Davis*,¹³² the Court held that service rationing that has a disparate impact¹³³ is permissible as long as persons with disabilities still have "meaningful access" to their health care program.¹³⁴ In *Choate*, the Court found meaningful access on the ground that even with the fourteen-day limitation, hospitalization needs would be unsatisfied for only five percent of disabled persons eligible for Medicaid in Tennessee.¹³⁵

3. *Inadequacies of the Meaningful Access Standard*

In one sense, the meaningful access standard seems to be an appropriate way to carry out the purposes of the ADA. If everyone is entitled to meaningful access, then persons with disabilities should be protected from excessive deprivations of health care benefits.

However, several problems with the meaningful access standard ultimately render it inadequate. An extension of the logic employed by the Court in *Choate* indicates just how problematic it is to employ a meaningful access standard. If, as in our example, a health plan limits coverage for mental health treatment to sixty hospital days per year without capping hospital days for cancer, heart disease, or other non-psychiatric illnesses, the limitation would particularly disadvantage persons with psychiatric disorders. Yet health plan administrators could argue that because these persons still had full access to other health care services, they had meaningful access to health care generally, even though they might not have had meaningful access to psychiatric care. Moreover, while the meaning-

¹³²442 U.S. 397 (1979) (finding no violation of § 504 of the Rehabilitation Act of 1973 when a school required reasonable physical qualifications for admission to a clinical training program).

¹³³The *Choate* Court also cited with approval a lower court disparate treatment decision: *Doe v. Colautti*, 592 F.2d 704 (3d Cir. 1979) (upholding Pennsylvania's cap on coverage for psychiatric illness despite the absence of a comparable cap on coverage for physical illness).

¹³⁴See James V. Garvey, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled be Afforded?*, 68 NOTRE DAME L. REV. 581, 607-10 (1993).

¹³⁵It is true that patients who needed more than 14 days of hospitalization were not necessarily deprived of the care they needed. This case was about Medicaid coverage, not strictly about access to care. Public hospitals provide care to people who have no insurance coverage, whether private or public. Nevertheless, studies have demonstrated that patients with no health care coverage fare less well than patients with at least some coverage. See, e.g., J. Hadley et al., *Comparison of Uninsured and Privately Insured Hospital Patients: Condition on Admission, Resource Use, and Outcome*, 265 JAMA 374 (1991).

ful access standard is compatible with the principle of reasonable accommodations, the Supreme Court has applied the standard with minimal consideration of the obligation to reasonably accommodate. In *Choate*, the Court summarily rejected the plaintiffs' alternative to Tennessee's cap with little support for its rejection and without explaining why it would not be reasonable for Tennessee to adopt the suggested alternative approach (which had been adopted by other states).¹³⁶

Even if courts give meaningful access sufficient substance, it is still the wrong standard. First, it is not really an equal treatment standard. Equal treatment requires that whatever level of benefit is provided must be provided equally. A meaningful access standard, on the other hand, permits unequal treatment as long as everyone receives a decent minimum level of the benefit. The meaningful access standard is thus an entitlement standard. Such a standard would allow an employer or a government to define two levels of health care benefits: a bare-bones level that provides meaningful access and that avoids discriminatory impact, and a second level of benefits which can be allocated in a way that favors persons who are not disabled (or who are less disabled). This is not only unequal treatment, it turns the concept of equitable allocation of health care upside down. Patients who are sicker need greater care but would often receive less care.

The second problem with a meaningful access standard is that the fairness of a particular rationing by service decision is judged by its aggregate impact rather than by its impact on the individual. In *Choate*, the fourteen-day cap on hospitalization was upheld because it was adequate for 95% of all disabled persons, producing an overall good result, even though many individual patients did not receive adequate care. Indeed, there was inadequate care for 27.4% of patients with disabilities who received some hospital care. Rationing by service is a form of rationing that is fair on average but that may not be fair in an individual case. As the Supreme Court has observed in cases involving sex-based discrimination,¹³⁷ the federal statutes prohibiting discrimination do so in terms of the *individual*. For example, the ADA states that employers shall not "discriminate against a qualified *individual* with a disability because of the disability of such individual,"¹³⁸ and the Rehabilitation Act states that "[n]o otherwise qualified *individual* with a disability . . . shall, solely

¹³⁶ See *supra* note 79.

¹³⁷ *Public Employees Retirement System of Ohio v. Betts*, 492 U.S. 158 (1989); *Arizona Governing Committee for Tax Deferred Annuity and Deferred Compensation Plans, etc. v. Norris*, 463 U.S. 1073 (1983); *City of Los Angeles Dep't. of Water and Power v. Manhart*, 435 U.S. 702 (1978); see Kimberly A. Ackourey, *Insuring Americans with Disabilities: How Far Can Congress Go to Protect Traditional Practices?*, 40 EMORY L.J. 1183 (1991).

¹³⁸ 42 U.S.C. § 12112(a) (Supp. 1993) (emphasis added).

by reason of her or his disability" be subjected to discrimination.¹³⁹ Because the ADA, like other anti-discrimination laws, operates at the individual level, it is essential to employ a standard for interpreting the ADA that meets individual needs.¹⁴⁰

This Article now examines this second problem in more detail, using the example of a sixty-day cap on mental health treatment in a psychiatric hospital. With such a limitation, the employer is saying in effect that treatment beyond sixty days in one year does not tend to provide sufficient benefit to justify the cost. Yet for many patients who have severe psychiatric disorders that do not respond quickly to treatment, treatment beyond sixty days may be very beneficial. Moreover, it may be more beneficial than treating less severely affected persons beyond thirty days. With rationing by service, then, there may be serious inequities in care, with some patients receiving too little care (those who gain great benefit from more than sixty days of care) and others receiving too much (those who gain great benefit from thirty days of care but only mild to moderate benefit from thirty-one to sixty days of care).

Such a result is both inefficient and unfair to many individuals. Consequently, courts generally have attempted to prevent this kind of result when interpreting other anti-discrimination statutes. For example, in challenges to pension plans that required larger contributions from or paid smaller annual benefits to women on the ground that women live longer than men and therefore receive more annual pension payments after they retire, the Supreme Court has invalidated the differential treatment and insisted that women and men make the same contributions and receive the same annual payments.¹⁴¹ As the Court observed, not all women live longer than men. Treating all women the same thus violates the requirement that women be treated as individuals.¹⁴² Just as it is no answer to the women who pay too much that other women pay too little, it is no answer to those persons who have unsatisfied health care needs that other disabled persons receive more than adequate care.¹⁴³

¹³⁹ 29 U.S.C. § 794(a) (1988 & Supp. 1993) (emphasis added).

¹⁴⁰ See Peters, *supra* note 7, at 531-33. This is not to say that the generally accepted and reasonable practice of predicting patient outcomes on the basis of general characteristics is totally unacceptable. Doctors, like employers, could not operate if they were forbidden from acting at least partly on the basis of reasonably valid generalizations. For example, physicians can only estimate the likelihood that a treatment will succeed for a patient by considering how the treatment generally works in other, similar patients. Nevertheless, often more refined predictions can easily be made by subcategorizing classes of patients.

¹⁴¹ See *Arizona Governing Comm. v. Norris*, 463 U.S. 1073 (1983); *City of Los Angeles Dep't. of Water and Power v. Manhart*, 435 U.S. 702 (1978).

¹⁴² *Manhart*, 435 U.S. at 707-08.

¹⁴³ This point is similar to the employment discrimination law principle that was developed in *Connecticut v. Teal*, 457 U.S. 440 (1982). In that case, the Supreme Court held that employers could not use selection criteria that disfavored a protected minority

4. *An Alternative to the Meaningful Access Standard: The Principle of Public Consent*

In developing an alternative to the meaningful access standard it is useful to consider approaches that have been suggested by other scholars for rationing health care. Several commentators who have studied the question have developed proposals based on a principle of public consent. These proposals call for rationing only when rationing guidelines result from the explicit or presumed consent of the public to which those guidelines will be applied. Building on the work of David Eddy and Norman Daniels, for example, Leonard Fleck argues for an "informed democratic consensus model" in which public representatives would engage in serious and well-informed deliberations and come to an agreement about the guidelines that will be used by physicians to ration health care.¹⁴⁴ Observing that explicit consent is not achievable, Paul Menzel and Ronald Dworkin recommend a model of presumed consent in which society would adopt a basic benefits package of health care to which all persons would be entitled. The basic benefits would be defined by what people would likely choose for their health care coverage in advance of their actual need for treatment if confronted at that time with a choice of different possible benefits packages and their different costs.¹⁴⁵

While these consent-based approaches help resolve many of the difficult choices in rationing health care, they nevertheless fail to account for the problem of discrimination against persons with disabilities, particularly those arising from socio-political factors.¹⁴⁶ Since people must make their decisions about which treatments should be covered before the need for treatment actually arises, this approach assumes that everyone starts out without any disabilities and makes his or her choices from that position. Accordingly, it cannot help us compensate for the fact that social organization is skewed by the norm of the person without disabilities. Some commentators conclude that people will take into account the needs of persons with disabilities because they could become disabled themselves at a later date.¹⁴⁷ However, people are at different risks for different

at one stage of the promotion process even if the overall result of the process was non-discriminatory. The requirements of employment discrimination law still would not be satisfied if favoritism to one member of the minority compensated for discrimination against another member of the minority. *Teal* emphasized the fact that employment discrimination law protects the *individual* from discrimination. *Id.* at 453-54.

¹⁴⁴ Fleck, *supra* note 6, at 1617-34.

¹⁴⁵ See PAUL T. MENZEL, *STRONG MEDICINE: THE ETHICAL RATIONING OF HEALTH CARE* 22-36 (1990) (describing a model of presumed consent); Ronald Dworkin, *What Is Equality? Part 2: Equality of Resources*, 10 PHIL. PUB. AFF. 283, 296-304 (1981); Ronald Dworkin, *Will Clinton's Plan Be Fair?*, N.Y. REV. BOOKS, Jan. 13, 1994, at 20, 22 (advocating in both articles a model based on the insurance principle).

¹⁴⁶ MENZEL, *supra* note 145, at 16.

¹⁴⁷ See Elhauge, *supra* note 67, at 1516-17.

conditions. As a result, a person at low risk for developing a particular disability will discount the needs of persons with that disability.

Even if we take into account, when defining the basic benefits package, the fact that some persons will be born with disabilities, the amount of coverage desired for persons with disabilities will depend on the nature of socio-political factors. For example, if society has not funded research into a particular disease and there is little treatment available for the disease as a result, the basic benefits package is less likely to include coverage for that disease than for other diseases for which successful treatments are available.¹⁴⁸ So while rationing proposals based on a model of public consent offer useful insights into the rationing problem, they do not tell us how to protect persons with disabilities from unfair denials of care.

5. An Appropriate Standard for Rationing by Service: The Destructured Disability Standard

The problems with the EEOC, meaningful access, and public consent standards can be corrected if rationing by service is judged in essentially the same way as this Article has suggested for rationing by patient. We need an equal protection standard, rather than an entitlement standard, that responds to biases in social structure and that operates at the individual level. The destructured disability standard for rationing by patient meets all three of these requirements.

According to the destructured disability standard, a patient may not be denied a treatment that is available to other patients because of illness unless the illness seriously compromises the patient's ability to benefit from the treatment (that is, the illness prevents the patient from receiving a reasonable minimum level of benefit from the treatment). This is not an entitlement standard; there is no requirement of any absolute level of care. It is, however, an equal protection standard because it looks to whether different patients are receiving the same level of care. In addition, it responds to biases in social structure by limiting the freedom of physicians to consider the effects of a disability on the patient's ability to benefit from care before the care can be denied (for example, by giving due weight to the principle of reasonable accommodations). Finally, it operates on the individual level by focusing on whether any particular patient is denied a medical service available to other patients.

Some modification of the destructured disability standard is required to use it as a standard for service-based, rather than patient-based, ration-

¹⁴⁸ See Dworkin, *Equality of Resources*, *supra* note 145, at 299 (observing that society will choose a higher level of insurance for blindness if the money recovered from such insurance could be used to pay for technologies that offset the disabling effects of blindness).

ing. With rationing by patient, the question is whether the patients who are denied a particular service are as deserving of the service as other patients. With rationing by service, the question is whether some of the patients who need the denied service are as deserving of that service as other patients are who need the services that are offered. In other words, while with rationing by patient we are comparing two patients who need the same service, with rationing by service, we are comparing two patients who need different services.

For rationing by patient, treatment may be denied on account of illness if the illness prevents the patient from realizing a reasonable minimum level of benefit from the treatment. The analog for rationing by service would be to prohibit the denial of a service if some people who need the service would realize a reasonable minimum level of benefit from it.¹⁴⁹ With this standard, employers would be unable to cap hospital days for mental illness at sixty per year if some patients would gain a reasonable minimum level of benefit from more than sixty days.

Such a standard would not prevent employers from containing their health care costs. The destructured disability standard does not dictate any particular level of health care spending. It only requires that, if health care is provided, it must be provided equitably. Accordingly, if adding care for persons who previously were denied care would be unaffordable without making any other changes, then the employer could reallocate its current health care spending rather than increase its spending. As with rationing by patient, if care could not be provided to all patients who would gain more than a reasonable minimum level of benefit, some equal opportunity mechanism, such as the lottery, could be used to determine whether a patient would receive care.

One concern with the destructured disability standard is whether physicians could possibly make the kinds of comparisons required among patients who need different services. It is relatively simple when dealing with just one service, like an organ transplant, to compare the needs of different patients, but it is substantially more complicated to compare the needs of different patients when they need different services. Nevertheless, physicians already make these kinds of comparisons on a daily basis.¹⁵⁰ Indeed, in some ways, the standard may simplify matters. Physi-

¹⁴⁹ Even when an employer could not entirely deny a service, the employer would not have to offer the service to all who might benefit from it. The employer would still be able to employ rationing by patient to ration the service.

¹⁵⁰ No physician can give every patient all the attention that would benefit the patient. Time constraints require physicians to limit the amount of time they spend with some of their patients so they will have a reasonable amount of time for others. See Susan Dorr Gould & Howard Brody, *Rationing Decisions in Managed Care Set-ups: An Ethical Analysis*, in *HEALTH CARE CRISIS? THE SEARCH FOR ANSWERS*, 135, 137-38 (Robert, I. Misbin, et al., eds. 1995). Moreover, physicians must allocate their time among patients with very different conditions. While there will be some overlap in the illnesses affecting

cians will no longer need to rank their patients in terms of how much they will benefit from the physician's time. Instead, physicians will need to determine only whether their patients will gain a reasonable minimum level of benefit and then give all of those patients an equal opportunity for the physician's time.

As the preceding discussion suggests, the destructured disability standard would allow little room for rationing by service. It would be very difficult to justify the kind of flat caps that have been used, such as Tennessee's fourteen-day hospital cap or a sixty-day hospital cap for treatment of mental illness. The kinds of rationing by service that would be allowed are primarily those that are designed to conserve resources for persons with disabilities. For example, a denial of coverage for cosmetic surgery would not be prohibited by the ADA because it does not discriminate on account of disability, nor does it have a disparate impact on persons with disabilities.

A limited role for rationing by service would serve not only the goal of respect for the individual, but it would also serve the goal of efficiency. Society's limited health care resources will be most efficiently used if rationing occurs by type of patient. When rationing occurs by service, health care planners must choose between alternative treatments for a particular condition, making one treatment available and others unavailable. In such cases, planners will choose the treatment that provides the most benefit *on average*. For some patients, however, an excluded treatment will provide more benefit than the available treatment. Accordingly, greater benefit could be realized if the health plan made available a broad range of treatments and, for each patient, covered the treatment that was most beneficial for that particular patient (for example, rationing by patient).¹⁵¹

C. Inadequacies of Anti-Discrimination Law for the Disabled

Although the destructured disability standard comes closer than existing standards to fulfilling the purposes of anti-discrimination law, justice may require even more to ensure fair treatment of all persons. This

the physicians' patients, the patients will also have a variety of illnesses needing different intensities of treatment.

¹⁵¹There are some efficiency gains from rationing by service because it may entail fewer administrative costs than rationing by patient. It is simpler to evaluate the benefit of a treatment according to the average patient and cover only the treatments that yield a high average benefit per patient. It is also simpler to decide whether a patient qualifies for coverage if rationing is done by service rather than by patient. Physicians are accustomed to rationing their time and treatments by patient, however, and if rationing is done only partially by service, physicians will still have to make the kinds of comparisons that rationing by patient entails. Accordingly, it is unlikely that the administrative efficiency of rationing by service will outweigh the loss of clinical efficiency.

Article has argued that anti-discrimination law is designed to prevent decisionmakers from denying medical care to persons with disabilities on two grounds. First, the law precludes decisionmakers from acting out of invidious bias to deny care to an individual on account of the person's disability. Accordingly, persons with disabilities would be assured of treatment when their disability has no effect on their ability to benefit from the treatment. Second, the law includes a principle of reasonable accommodations to compensate for the fact that, when persons with disabilities gain less benefit from treatment than persons without disabilities, the smaller benefit results not just from the operation of a natural lottery or some other fair allocation of advantages and disadvantages, but often from the unfair operation of socio-political forces. Yet even if we could be sure that one person gained greater benefit from treatment than another and that this difference resulted from the operation of a natural lottery rather than arbitrary socio-political constructs, it would not automatically follow that treatment should be given to the person who would benefit more from the treatment.

Welfare maximization is an important goal, but it is not the only goal of medical treatment.¹⁵² The equal worth of each individual suggests that we may want to give two persons equal opportunity for a particular treatment even if one would gain a smaller benefit from the treatment because of a coexisting disability. Indeed, in general, we may want to give priority when allocating resources among different services and different patients to the persons whose health is worse to begin with even if those persons would benefit less from treatment.¹⁵³ On many accounts of justice, there is a fundamental obligation to give some preference to those who are more disadvantaged when limited resources are being allocated.¹⁵⁴

Conclusion

In the coming years, health care rationing will become increasingly common. Because of their substantial health care needs and weak political power, persons with disabilities are at high risk of bearing more than their fair share of health care cost containment. Accordingly, legal protections must be in place to prevent unfair discrimination against persons with disabilities.

Although Congress has enacted the Americans with Disabilities Act and the Rehabilitation Act to ensure fair treatment of persons with dis-

¹⁵²See BICKENBACH, *supra* note 87, at 214–20 (1993); Norman Daniels, *Rationing Fairly: Programmatic Considerations*, 7 *BIOETHICS* 224, 225–28 (1993); Ronald Dworkin, *What Is Equality? Part 1: Equality of Welfare*, 10 *PHIL. PUB. AFF.* 185 (1981).

¹⁵³Daniels, *supra* note 152, at 228.

¹⁵⁴MICHAEL WALZER, *SPHERES OF JUSTICE* 31–94 (1983); Charles J. Dougherty, *Ethical Values at Stake in Health Care Reform*, 268 *JAMA* 2409, 2410 (1992).

abilities, judicial interpretations have given inadequate recognition to the protections embodied in those Acts. When deciding the validity of measures that involve rationing by patient, courts have properly insisted that invidious discrimination be eliminated. However, courts have not adequately implemented the statutory principle of reasonable accommodation, which requires health care decisionmakers to compensate for the structural biases in society that also disadvantage persons with disabilities.

When deciding the validity of measures that involve rationing by service, courts have used a meaningful access standard that fails on three grounds: such a standard is an entitlement standard rather than an equal protection standard; it does not meet the statutory requirement that the ADA and Rehabilitation Act operate on the individual level rather than the group level; and it has been implemented with minimal consideration of the principle of reasonable accommodations.

It is essential that courts modify their interpretations of existing anti-discrimination law by adopting the destructured disability standard for both rationing by patient and rationing by service. Such a standard responds to current deficiencies in judicial interpretations of anti-discrimination law because it gives full recognition to the principle of reasonable accommodations, acts as an equal protection standard, and operates at the individual level. By adopting this standard, courts will ensure that the law fulfills its goal of protecting persons with disabilities not only from discrimination based on invidious bias but also discrimination that arises from socio-political factors.

