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WHEN PHYSICIANS BALK AT FUTILE CARE: IMPLICATIONS OF THE DISABILITY RIGHTS LAWS

*Philip G. Peters, Jr.**

Physicians and medical ethicists are currently engaged in a contentious debate over the obligation to offer "futile" care. As a consequence, a new class of disputes about the withholding of life-sustaining care is emerging. In this debate, providers are balking at family demands for life-sustaining care that they believe is medically inappropriate. This Article explores the limits that the disability rights laws place on these bedside decisions.

In some respects, the recent "futility" controversies surrounding Baby K,¹ Helga Wanglie,² Ryan Nguyen,³ and others⁴ are just the

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¹ *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

² *In re Wanglie*, No. PX-91-283 (Minn. Dist. Ct. 1991), *reprinted in* 7 ISSUES L. & MED. 369 (1991). Providers proposed to unplug the respirator and pull the feeding tubes from a non-terminally ill comatose patient over her husband's objections. The providers unsuccessfully sought a judicial determination that the patient's husband was not a competent decisionmaker, rather than raising the futility issue directly.

³ See Alexander M. Capron, *Baby Ryan and Virtual Futility*, HASTINGS CENTER REP., Mar.-Apr. 1995, at 20. According to this account, two hospitals refused to continue to provide dialysis for a premature newborn with brain damage, an intestinal blockage, and kidney malfunction because "long-term dialysis would not only be inappropriate but also would be immoral" because it would prolong the boy's agony with "no likelihood of a good outcome." The family obtained a court order for further treatment and eventually located a facility that would willingly provide Ryan with treatment. His condition then improved after intestinal surgery. The first hospital had contended that the family's request for aggressive care constituted child abuse.

⁴ For example, in 1992, a court in the United Kingdom ruled that a London hospital could withhold life support from a severely brain-damaged eighteen-month-old child on the ground that it had "too few resources to treat all the patients whom they would like to treat." *Re J [A Minor][Medical Treatment]*, C.A. (10 June 1992), *quoted in* Ross Kessel, *British Judges Cannot Order Doctors to Treat*, HASTINGS CENTER REP., July-Aug. 1992, at 3. A Georgia trial court refused the request of several doctors to withdraw life support from a teenager in a condition "between a stupor and a coma." *In re Doe*, C.A. No. D-93064 (Ga. Super. Ct. 1991), *reprinted in* 7 ISSUES L. & MED. 521, 531 (1992), *aff'd*, 418 S.E.2d 3, 7 (1992). A Texas court reportedly upheld a doctor's withdrawal of hemodialysis on the grounds of medical futility. See Mark A.

most recent stage of a long history of litigation over the circumstances in which life-sustaining treatment can be stopped—litigation in which concerns about improper discrimination against frail, elderly, or disabled patients have always been prominent. But in two crucially important senses, the current generation of cases is quite different.

First, the families and physicians have reversed their roles. In the early right to die cases like those of Karen Quinlan⁵ and Nancy Cruzan,⁶ patients or their families were resisting unwanted life-sustaining care. In the current generation of cases, by contrast, families are requesting care and physicians are resisting it. For purposes of the antidiscrimination laws, the difference is fundamental. Family decisions are not governed by the federal disability rights laws, but physician and hospital decisions often are. As a result, the substantive implications of the disability rights laws for bedside treatment decisions must now be unraveled.

A second distinctive feature of the current generation of bedside treatment cases is their underlying cost-consciousness. Surely, it is not coincidental that these disputes are arising at the same time that private and public benefits plans are tightening their cost controls and health policy analysts debate how much health care the nation can afford. The disability rights issues raised by these resource allocation decisions are novel and have not yet been considered by the courts.

The possibility of improper discrimination arises whenever a patient's disability plays a role in a physician's determination that life-sustaining care would be inappropriate. Yet, treating physicians will often feel that a patient's disability is relevant. At times, the disability itself may give rise to the need for treatment. At other times, it can reduce the likelihood that treatment for unrelated conditions will be effective. In both categories of cases, the patient's illness may so impair the patient's quality of life that her treating physicians conclude that life-extending care would be cruel, pointless, or wasteful. Taking disability into account in any of these ways can potentially violate the disability rights laws. But the deepest objections to taking disability into account arise when physicians act on their beliefs about a disabled patient's quality of life. For that reason, this Article uses quality-of-life considerations as the vehicle for examining the application

Hall, *Rationing Health Care at the Bedside*, 69 N.Y.U. L. REV. 693, 710 n.56 (1994) (citing *Duensing v. Southwest Tex. Methodist Hosp.*, No. SA-87-CA-1119 (W.D. Tex. Dec. 22, 1988) (granting defendant summary judgment)). For other examples, see *infra* text accompanying notes 26-33. Obviously, most unilateral decisions by providers to cut back on care are not litigated. See Hall, *supra*, at 723-24 (describing the medical literature acknowledging cessation of CPR efforts from debilitated patients and from severely ill newborns).

⁵ *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁶ *Cruzan v. Director, Mo. Dep't of Health*, 492 U.S. 261 (1990).

of the antidiscrimination laws to bedside disputes about life-sustaining care.

The courts have suggested two conflicting paradigms for analyzing medical treatment decisions under the disability rights laws. Each has serious shortcomings. One unwisely insulates from challenge all treatment decisions that arise out of the patient's disability, no matter how patent the prejudice. The other corrects that mistake, but inappropriately prohibits providers from taking a patient's disability into account under any circumstances. As a result, each approach is too blunt—one too restrictive and the other too permissive. In addition, neither of these approaches considers the unique issues raised when a treatment decision is based on resource allocation considerations, rather than on patient welfare.

A preferable approach to the futility cases would have three key components. First, the antidiscrimination laws would be applied to all bedside treatment decisions, even those which arise out of the patient's disability. Invidious discrimination can occur as readily when patients are denied treatment for a disfavored disability as when they request treatment for unrelated conditions. The administrative and conceptual concerns that have motivated courts to distinguish between related and unrelated care are not insignificant, but they are not insoluble either.

Second, physicians who believe that a requested treatment would result in an unacceptable quality of life should ordinarily defer to the preferences of their patients. When the patient's wishes are unknown, however, health care providers should be permitted to take disability-impaired quality of life into account when they genuinely and reasonably believe that treatment requested by a surrogate would be cruel. Under these circumstances, courts should permit physicians to opt out of the requested care as long as they cooperate with the transfer of the patient to a physician who shares the family's values. This compromise respects the consciences of physicians while preserving ultimate decision-making authority for patients and their families.

Third, when physicians balk at life-sustaining care because it seems a poor use of scarce health care resources, courts should closely examine the authority of the physician to make resource allocation decisions. In addition, the disability rights laws should prohibit consideration of disability-impaired quality of life except in the most extreme cases, that is, when doubts about the value of treatment are most serious and the costs are substantial.

Part I of this Article reviews the factual background of the futility debate. Part II introduces the antidiscrimination laws. Thereafter, Parts III, IV, and V examine the three components of the proposal suggested above.

I. BACKGROUND

A. *The Futility Debate*

The futility debate began as a reaction to the widespread use of cardiopulmonary resuscitation (CPR). After studies revealed that some groups of CPR patients, especially the elderly, rarely survived to discharge from the hospital,⁷ physicians began to question the propriety of routinely administering CPR to patients who were very unlikely to survive it.⁸ Physicians questioned not only their obligation to offer treatment under these circumstances, but also their duty to discuss the decision with the patient.⁹ Soon, physicians were asking the same questions about other treatments that were unlikely to succeed or whose anticipated benefits were less than the expected burdens.¹⁰

Physicians are deeply divided over these questions. According to one review of the medical literature, most physicians believe that they are under no obligation to render care that they perceive to be futile.¹¹ However, many others believe that these decisions involve value judgments that should be made by patients, not physicians.¹²

⁷ See, e.g., Susanna E. Bedell et al., *Survival After Cardiopulmonary Resuscitation in the Hospital*, 309 NEW ENG. J. MED. 569 (1983); William A. Gray et al., *Unsuccessful Emergency Resuscitation—Are Continued Efforts in the Emergency Department Justified?*, 325 NEW ENG. J. MED. 1393 (1991); Arnold L. Johnson et al., *Results of Cardiac Resuscitation in 552 Patients*, 20 AM. J. CARDIOLOGY 831 (1967); George E. Taffet et al., *In-Hospital Cardiopulmonary Resuscitation*, 260 JAMA 2069 (1988).

⁸ See, e.g., Donald J. Murphy, *Do-Not-Resuscitate Orders: Time for Reappraisal in Long-term-Care Institutions*, 260 JAMA 2098 (1988); Tom Tomlinson & Howard Brady, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276 (1990). For an extended review of the futility debate, see TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 212-14 (4th ed. 1994); Kathleen M. Boozang, *Death Wish: Resuscitating Self-Determination*, 35 ARIZ. L. REV. 23 (1993); Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179, 182-202 (1995); Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. A Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1248-59 (1993).

⁹ See, e.g., J. Chris Hackler & F. Charles Miller, *Family Consent Orders Not to Resuscitate: Reconsidering Hospital Policy*, 264 JAMA 1281 (1990); Murphy, *supra* note 8; Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990).

¹⁰ See, e.g., Schneiderman, *supra* note 9; *supra* text accompanying notes 2-4.

¹¹ Daar, *supra* note 8, at 1256-57 (citing Leslie J. Blackhall, *Must We Always Use CPR?*, 317 NEW ENG. J. MED. 1281, 1284 (1987) (arguing that when CPR is of no benefit, it should not be offered to patients)); Donald J. Murphy & David B. Matchar, *Life-Sustaining Therapy: A Model for Appropriate Use*, 264 JAMA 2103 (1990) (arguing that medically or economically inappropriate treatments should not be automatically offered); Schneiderman, *supra* note 9, at 949 (arguing that treatments that do not improve the person as a whole are futile and may be withheld by physicians); Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276, 1278-79 (1990) (arguing that physicians should be able to restrict alternatives offered to patients for sake of physician integrity and patient autonomy); see Murphy, *supra* note 8; Paris, *infra* note 33.

¹² See, e.g., John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81, 83 (1989); D.B. Waisel & R.D. Truog, *The Cardiopulmonary Resuscitation-Not-Indicated Or-*

In the course of this wide-ranging medical discussion about the circumstances in which physicians can withhold requested treatments, physicians have used the term "futility" to mean many different things. Medical ethicists Tom Beauchamp and James Childress offer a helpful list of treatments that have been labeled as futile: (1) treatments providing no physiological benefit, (2) treatments highly unlikely to be efficacious, (3) treatments offering a poor probable outcome, (4) treatments likely to be more burdensome than beneficial, and (5) unproven treatments.¹³ They could easily have added a sixth category comprised of treatments that will not provide sufficient benefit to the patient to justify the allocation of resources.¹⁴

Predictably, the least controversial of these categories involves treatments which simply do not produce the physiological effect desired by the patient.¹⁵ No one suggests that a patient can insist that her physician attempt to cure her stomach cancer with interferon, which has no effect on stomach cancer.¹⁶ But other usages of the futility label are much more controversial. Consider, for example, the medical studies about CPR which assume that resuscitation which rarely results in survival to discharge is futile.¹⁷ This superficially "scientific" judgment masks subjective assumptions about the value of short-term survival. As Beauchamp and Childress point out, "short-term survival may be the main objective for the patient or the family."¹⁸ Some patients may desire very much to live until a grandchild's birthday or to see another sunrise.¹⁹ Placing a value on short-term survival, therefore, requires more than a "medical" judgment.²⁰

Similar value judgments are necessary in order to determine whether treatments with a very small likelihood of success are worthwhile.²¹ Determining the desirability of these treatments requires consideration not only of the odds of success, but also of the quality of life that will be offered, and the burdens imposed by the treatment.

der: Futility Revisited, 122 ANNALS INTERNAL MED. 304 (1995); Stuart J. Youngner, *Who Defines Futility?*, 260 JAMA 2094 (1988).

¹³ BEAUCHAMP & CHILDRESS, *supra* note 8, at 212-13.

¹⁴ See *infra* text accompanying notes 225-30.

¹⁵ See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 8, at 212 (characterizing these treatments as optional); Daar, *supra* note 8, at 1255 ("If a treatment will not produce a benefit sought by the patient, it can be considered futile."). The AMA believes that treatments may be considered futile if they would not achieve the goals expressed by the informed patient. AMA COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, *Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders*, 265 JAMA 1868, 1870 (1991).

¹⁶ Steven H. Miles, *Medical Futility*, 20 LAW MED. & HEALTH CARE 310 (1992).

¹⁷ BEAUCHAMP & CHILDRESS, *supra* note 8, at 289 (describing this viewpoint); Gray, *supra* note 7.

¹⁸ BEAUCHAMP & CHILDRESS, *supra* note 8, at 289-90.

¹⁹ See Daar, *supra* note 8, at 1254; Youngner, *supra* note 12, at 2095.

²⁰ BEAUCHAMP & CHILDRESS, *supra* note 8, at 213.

²¹ *Id.* at 289.

Although the quantitative aspect of futility judgments based on low success rates gives them an air of medical objectivity, this facade masks very subjective value judgments.

The subjectivity of futility judgments is especially obvious when physicians conclude that the patient's quality of life makes further life-extending care inappropriate. Consider the case of Helga Wanglie, a Minnesota woman who was in her eighties.²² Following a cardiopulmonary arrest, Mrs. Wanglie suffered oxygen deprivation and was diagnosed as being in a persistent vegetative state. After she had spent several months on a respirator receiving tube feeding, her physicians felt that continued treatment was "inappropriate" and that it was "no longer serving the patient's personal medical interest."²³ Her husband Oliver strongly disagreed. Describing himself and his wife as "pro-lifers," he reportedly remarked that "only God can take life and . . . doctors should not play God."²⁴ The hospital attempted to have Mr. Wanglie removed as guardian, and a Minnesota probate court refused this request.²⁵ Although the case was legally framed as a dispute over Mr. Wanglie's decision-making competency, the central issue of this case was the disagreement between Mrs. Wanglie's husband and her doctors about the value of life with a severe disability.

B. Bedside Conflicts

In the past few years, providers have become increasingly resistant to family requests for care which they perceive to be inappropriate. Although Helga Wanglie's case is the most famous conflict between physicians and families, it is just one of many bedside disputes reported in the legal and medical literature. In Washington, D.C., for example, Dr. Murray Pollock went to court once and to a hospital ethics committee another time, trying to stop life-sustaining treatments for two newborns, one suffering from severe brain damage and the other dying of AIDS and heart disease.²⁶ According to a newspaper report about the second child, Baby Rena, "[w]hen nurses

²² A useful summary of her case appears in the Appendix of BEAUCHAMP & CHILDRESS, *supra* note 8, at 517. The probate court opinion is reprinted in 7 ISSUES L. & MED. 369 (1991). Further information can be found in Alexander M. Capron, *In re Helga Wanglie*, HASTINGS CENTER REP., Sept.-Oct. 1991, at 26; Ronald E. Cranford, *Helga Wanglie's Ventilator*, HASTINGS CENTER REP., July-Aug. 1991, at 23; and, Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512 (1991).

²³ Cranford, *supra* note 22, at 23.

²⁴ *Id.*

²⁵ After many conferences attempting to resolve this dispute, a physician at the medical center unsuccessfully attempted to have a conservator appointed for Mrs. Wanglie. Capron, *supra* note 22, at 26. The probate judge concluded that Mr. Wanglie was in the best position to protect his wife's preferences. *In re Wanglie*, reprinted in 7 ISSUES L. & MED. 369, 372 (1991).

²⁶ Benjamin Weiser, *A Question of Letting Go: Child's Trauma Drives Doctors to Reexamine Ethical Role*, WASH. POST, July 14, 1991, at A1.

performed even the simplest procedure, such as weighing her, her blood pressure shot up and tears streamed down her face."²⁷ She was constantly sedated for pain. Believing that artificial ventilation for Baby Rena was "making the child suffer,"²⁸ Pollock tried to convince the family to discontinue aggressive care.

The case of Baby Terry was similar. He was born prematurely at twenty-three weeks gestation.²⁹ Because of respiratory distress, he was put on a respirator. He also had bacterial and fungal infections, insufficient oxygen supply to the brain, bleeding on the brain, and a stomach fistula. His physicians predicted that "he wouldn't live a day" and recommended that artificial respiration be discontinued. Baby Terry was receiving pain medications for his discomfort, but his physicians apparently believed that his quality of life was too poor to warrant further life-extending care.³⁰ When Terry was one month old, the Genesee County Department of Social Services sought a judicial order of child neglect because Terry's parents insisted on aggressive care. The probate judge decided instead to treat the case as a challenge to the competency of Terry's custodial parent, ruling that his mother had "specific incompetence" to choose Baby Terry's medical treatment.³¹ Baby Terry's aunt was appointed guardian and reportedly consented to reduction of his oxygen supply from 100% to 20%. Baby Terry died in his mother's arms.

There are many other examples. Jane Doe was a thirteen-year-old girl with a severe, degenerative neurological disorder whose physicians felt that life-sustaining efforts were "so painful as to be abusive."³² Baby L was a blind, deaf, and quadriplegic two-year-old girl receiving nutrition through a gastrostomy tube. She had the mental status of a three-month-old and had daily seizures. At one time, she had required ventilator support and her physicians believed that re-instituting that support, should it become necessary, would be "inhumane."³³

²⁷ *Id.* She eventually died, but aggressive care was not withheld.

²⁸ *Id.*

²⁹ Baby Terry's litigation is described in James Bopp, Jr. & Richard E. Coleson, *Child Abuse by Whom?—Parental Rights and Judicial Competency Determinations: The Baby K and Baby Terry Cases*, 20 OHIO N.U. L. REV. 821, 825-27 (1994).

³⁰ *Id.* at 827, 835.

³¹ The Genesee Circuit affirmed the probate court ruling and denied a stay pending further appeal. *Id.* at 826-27.

³² Ronald Smothers, *Atlanta Court Bars Efforts to End Life Support for Stricken Girl*, N.Y. TIMES, Oct. 18, 1991, at A10. The hospital went to court seeking permission to cease aggressive care. Her mother did not object, but her father did. The court left the decision in the hands of the parents. *Id.*; *In re Doe*, C.A. No. D-93064 (Ga. Super. 1991), reprinted in 7 ISSUES L. & MED. 521 (1992), *aff'd*, 418 S.E.2d 3, 7 (1992).

³³ John J. Paris et al., *Physicians' Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. MED. 1012 (1990). Her physicians unsuccessfully urged her parents not to place her on a respirator in the event that she experienced breathing difficulties. The mother refused

The frequency with which disputes like these are being reported suggests that far more of them are occurring quietly in hospitals around the country.

C. The Disability Rights Issues

The possibility of improper discrimination arises whenever a patient's disability plays a role in the physician's determination that life-sustaining care would be inappropriate. That can occur often. Most obviously, a physician who is treating the disability itself must take that disability into account. Providers can hardly be expected to ignore a patient's AIDS when planning a course of treatment to delay its progress.³⁴ At other times, a disability, such as cancer, may reduce the efficacy of customary treatments for unrelated conditions, such as heart disease. For example, patients with severe diabetes or pulmonary disease have traditionally been considered poor candidates for coronary bypass surgery.³⁵ In addition, a disability may make a customary treatment more dangerous.³⁶ Yet, taking disability into account under any of these circumstances could, on the right set of facts, potentially violate the antidiscrimination laws.

The disability rights issues are most controversial when providers base an end-of-life treatment decision on their belief that a severely disabled patient has a poor quality of life.³⁷ When a severely disabled patient, like Helga Wanglie, is denied a life-saving or life-prolonging treatment that would be offered to other patients, the value of her life has effectively been discounted because of her disability. The more severely disabled the patient, the more likely that life-extending care

to consent and sought judicial protection. A pediatric neurologist retained by the guardian ad litem to evaluate the baby's condition agreed to assume the baby's care. Baby L's expenses, which were in excess of one million dollars, were covered by insurance.

³⁴ They may, however, be asked to ignore the patient's quality of life when making decisions about life-sustaining care. See *infra* text accompanying notes 143-57.

³⁵ See, e.g., David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1457-58 (1992) (noting poorer outcomes commonly associated with de facto disabilities such as severe diabetes or cancer); David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308, 310 (1994) (noting that patients with pulmonary disease are poor candidates for coronary bypass surgery).

³⁶ Mary Crossley gives the example of an HIV-infected child with an unrelated perforated eardrum. Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1650 (1993). Because of this child's HIV status, she is more likely than other children to become infected if corrective surgery is performed on her eardrum. As a result, she may be better off with an alternative treatment.

³⁷ It is less controversial to examine quantitative factors than to assess a disabled person's quality of life because quantitative factors do not suggest that a disabled person's life is less valuable. As suggested in the text, however, their use can still potentially violate the disability rights laws. For a brief discussion of the issues in connection with decisions about the patient's best interests, see *infra* notes 140-41. For a brief introduction to the issues raised when quantitative factors are used to determine whether requested care is cost-effective, see *infra* note 238 and text accompanying notes 234-40.

requested by family members will be characterized by providers as cruel, pointless, or wasteful. Consequently, Robert Griss, the director of the Center on Disability and Health in Washington, D.C., contends that any decision not to treat based on patient quality of life violates the Americans with Disabilities Act of 1991 (ADA).³⁸ James Bopp, Jr. and Daniel Avila, counsel for the National Legal Center for the Disabled and Dependent, have reached the same conclusion.³⁹

To rule on this issue, the courts will have to resolve a conflict between two quite different philosophies. On one side are individuals, like Mr. Wanglie and Robert Griss, who believe that all life is worth living and that physicians who disagree are impermissibly discriminating on the basis of disability. On the other side are the physicians, ethicists, and state courts supervising termination of treatment cases who have concluded that quality of life is relevant and that it may be taken into account when deciding whether life-sustaining care is appropriate.

The stakes are substantial. A ruling that the antidiscrimination laws preclude any consideration of disability-impaired quality of life could restrict not only physicians and hospitals, but also other actors governed by the antidiscrimination laws, such as state courts, court-appointed guardians, and social service agencies.⁴⁰ All would be obliged to ignore the patient's quality of life, even if no family member were available to make the treatment decision, and even if the family's wishes appeared to be contrary to the patient's interests. Similarly, legislatures might be barred from taking disability-related quality of life into account when drafting advance directive legislation or standards for courts and guardians. This would work a substantial change in the substantive law of surrogate decision making. For some disability rights advocates, that is the objective.⁴¹

In addition, a prohibition on quality-of-life judgments would have crucial implications for health resource allocation and cost containment. Hospitals and insurers would be banned from taking quality of life into account when determining which life-extending treatments to fund. Heroic care, like dialysis and heart transplants, would have to be offered to anencephalic babies, severely demented adults, and veg-

³⁸ Jane Bryant Quinn, *Taking Back Their Health Care*, NEWSWEEK, June 27, 1994, at 36.

³⁹ James Bopp, Jr., & Daniel Avila, *When Worlds Collide: Disability Rights and Medical Prerogatives in Matters of Life and Death*, 7 HEC FORUM 132 (1995); accord Bopp & Coleson, *supra* note 29, at 835-37.

⁴⁰ See Bopp & Coleson, *supra* note 29, at 843 (stating that courts and guardians exercising power conferred by state courts or statutes are restricted); see also Bopp & Avila, *supra* note 39, at 146-47 (same); Crossley, *supra* note 36, at 1600-01 (noting that, as a practical matter, medical decisions for many children born with HIV infection are made by agents of the state). For a further discussion of these implications, see *infra* text accompanying notes 176-83.

⁴¹ See Bopp & Avila, *supra* note 39, at 146-47.

etative teenagers without regard to the quality of life that they are likely to enjoy as a result.

II. THE FEDERAL DISABILITY RIGHTS LAWS

A. *The Basic Statutory Framework*

Two federal statutes protect disabled individuals from improper discrimination. Section 504 of the Rehabilitation Act of 1973 ("Section 504") bars disability-based discrimination by any program receiving federal financial assistance.⁴² The more recent ADA⁴³ extends this prohibition against disability-based discrimination to employers, state and local governments, and public accommodations, including doctors' offices and hospitals.⁴⁴

Because the federal antidiscrimination laws define "disability" broadly to include any impairment "which substantially limits a major life activity,"⁴⁵ almost every serious health problem will qualify as a disability. Blindness, mental retardation, emotional illness, cancer, heart disease, and HIV infection are a few of the examples listed in the federal regulations.⁴⁶ As David Orentlicher notes, this definition is so broad that it is unlikely to be a serious hurdle for lawsuits over bedside rationing decisions,⁴⁷ especially those involving critically ill patients.⁴⁸

Although the specific terms of Section 504, the ADA, and their respective regulations are not identical in every respect,⁴⁹ the basic application of both statutes to medical treatment decisions that take

⁴² 29 U.S.C. § 794(a) (1994). Section 504 of the Rehabilitation Act, as amended, provides as follows: "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance"

⁴³ 42 U.S.C. §§ 12101-12213 (1994).

⁴⁴ *Id.* §§ 12112, 12131, 12181(7), 12182; 28 C.F.R. § 36.104 (1995) (establishing that public accommodations include the professional office of a health care provider, hospital or other similar service establishment); H.R. REP. No. 101-485, pt. 4, at 55-56 (1990), *reprinted in* 1990 U.S.C.C.A.N. 544-45. Public accommodations must also "affect commerce." 42 U.S.C. § 12181(7). Furthermore, in some situations individual providers may not qualify as public accommodations. *See Aikins v. St. Helena Hosp.*, 843 F. Supp. 1329 (N.D. Cal. 1994) (holding that failure to provide interpreter for patient's spouse did not give rise to action against physician who did not have any measure of control over the hospital providing the services).

⁴⁵ 42 U.S.C. § 12102(2) (1994); 29 U.S.C. § 706(8)(B) (1994).

⁴⁶ 28 C.F.R. § 36.104 (1995).

⁴⁷ Orentlicher, *supra* note 35, at 309.

⁴⁸ *See Crossley, supra* note 8, at 212-13 (noting that it is nearly impossible that someone who is denied life-sustaining treatment would not also qualify as "disabled").

⁴⁹ Section 504 is short and uses very general language. The regulations implementing it provide more detailed guidance. By contrast, the ADA is far more detailed than Section 504. The ADA has separate titles governing employment, government agencies, and public accommodations. Each has its own substantive prohibitions and, in some instances, each uses different terminology. In addition, each title has its own implementing regulations.

disability into account is the same.⁵⁰ Both statutes prohibit improper discrimination on the basis of disability.⁵¹ Under Section 504, such discrimination is only improper if an excluded person is “qualified” to receive the services he desires despite his disabilities.⁵² Title II of the ADA, which governs public services, including state or local hospitals and clinics, has a similar “qualifications” requirement.⁵³ Under both statutory provisions, a disabled person is “qualified” to receive services, and therefore is protected against disability-based discrimination, if he meets all “essential” or “necessary” eligibility requirements for

⁵⁰ Treatment decisions that do not expressly take disability into account, but which have a disproportionate impact on disabled persons (such as a limit on the length of insured hospital stays) are also prohibited under some circumstances by the antidiscrimination laws. However, the legal test governing these cases may be different under Section 504 than under the ADA.

The Supreme Court has assumed, without deciding, that Section 504 applies not only to facially disparate treatment but also to facially neutral conduct that has a disproportionate impact on disabled patients (such as a limit on insured hospital stays). *Alexander v. Choate*, 469 U.S. 287, 292-302 (1985); 28 C.F.R. § 35.130 (1995). The ADA appears to govern both kinds of discrimination explicitly. For example, Title III of the ADA prohibits the imposition of “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities . . . , unless such criteria can be shown to be necessary for the provision of the . . . services . . .” 42 U.S.C. § 12182(2)(a)(i) (1994) (emphasis added). But the Equal Employment Opportunity Commission has vacillated on the issue. *Compare* EQUAL EMPLOYMENT OPPORTUNITY COMM’N, INTERIM GUIDANCE ON DISABILITY-BASED DISTINCTIONS IN HEALTH CARE PLANS (June 6, 1993), reprinted in 2 Accommodating Disabilities (CCH) ¶¶ 140022 n.1, 140024 n.7 (assuming that the disparate impact theory is unavailable under the ADA or Section 504) *with* Facility Health Management, Health Law Focus (CCH) 2, at 2-3 (Dec. 21, 1993) (reporting that the EEOC’s director of ADA policy had indicated that the agency might change its position). The application of the antidiscrimination laws to facially neutral conduct is a fascinating and complex topic that justifies separate and extended discussion. For purposes of this Article, I have assumed that quality-of-life judgments based on a patient’s disability constitute facially discriminatory conduct. As a result, the analysis explored in the text of this Article applies to instances of disparate treatment but not necessarily to cases involving disparate impact. It would only apply to disparate impact cases if courts choose to apply the same test to these cases that they apply to disparate treatment cases. While the ADA text quoted above suggests that the same test may apply to disparate treatment and disparate impact cases which arise under the ADA, the Supreme Court has enunciated a distinct “meaningful access” test which applies to disparate impact cases which arise under Section 504. *Alexander*, 469 U.S. at 292-302. It has neither explored the full implications of this test nor determined whether this test applies in cases arising under the ADA. For an insightful analysis of meaningful access test as applied in the context of health care rationing, see David Orentlicher, *Deconstructing Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49, 79-86 (1996).

⁵¹ Although Section 504 and each title of the ADA prohibit discrimination based on disability, the operative language varies. See 42 U.S.C. § 12132 (1994) (barring discrimination in public services “by reason of” disability); *id.* § 12182(a) (barring discrimination in public accommodation “on the basis of disability”); *id.* § 12112(a) (barring discrimination in employment “because of the disability”); 29 U.S.C. § 794(a) (1994) (barring discrimination “by reason of” disability).

⁵² Section 504 prohibits discrimination against “otherwise qualified” persons. 29 U.S.C. § 794(a).

⁵³ 42 U.S.C. § 12132 (protecting “qualified” persons with disabilities).

the receipt of these services despite his disability.⁵⁴ Thus, an applicant's disability may be taken into account if it affects his qualifications.

Public accommodations, including private hospitals and physicians' offices, are governed by Title III of the ADA. On its surface, Title III lacks a "qualifications" requirement similar to those contained in Title II and Section 504.⁵⁵ Yet, Title III actually achieves the same result by permitting the exclusion of disabled persons who cannot meet "necessary" eligibility criteria.⁵⁶ Consequently, both the ADA and Section 504 protect only those disabled persons who are able to meet a program's "essential" or "necessary" eligibility requirements despite their disabilities.

By permitting disability to be taken into account when it affects a person's qualifications,⁵⁷ Congress has acknowledged that the presence of a disability will sometimes be a legitimate consideration.⁵⁸ This basic structure is quite different from civil rights legislation governing race, which assumes that race is irrelevant.⁵⁹ The qualifications

⁵⁴ Although Section 504 itself does not state when a person is "otherwise qualified" to receive services, the HHS regulations implementing the Rehabilitation Act define the term to mean "a handicapped person who meets the essential eligibility requirements for the receipt of such services . . ." 45 C.F.R. § 84.3(k)(4) (1995) (applying Section 504 to services other than employment or education). Under Title II of the ADA, which regulates government services, a person who is "qualified" to receive public services is someone who "meets the essential eligibility requirements" for receipt of the services "with or without reasonable modifications to rules, policies, or practices." 42 U.S.C. § 12131(2) (1994). The Justice Department regulations implementing Title II define essential eligibility requirements to be those "necessary for the provision of the service." 28 C.F.R. § 35.130(b)(8) (1995). In *Southeastern Community College v. Davis*, 442 U.S. 397 (1979), the Supreme Court held that an applicant's disability need not be ignored when deciding whether the applicant meets the eligibility requirements for the service.

⁵⁵ 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) (stating that the ADA, in contrast to the Rehabilitation Act, "does not require that a handicapped individual be 'otherwise qualified'").

⁵⁶ 42 U.S.C. § 12131(2); 28 C.F.R. § 36.301(a) (1994).

⁵⁷ See, e.g., *Davis*, 442 U.S. at 405; *United States v. University Hosp.*, 729 F.2d 144, 156 (2d Cir. 1984) (holding that consideration of disability is only improper when it "is unrelated to, and thus improper to consideration of, the services in question").

⁵⁸ See also U.S. COMM'N ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES 144 (1983) ("The goal is neither to exaggerate and stereotype nor to ignore handicapped people's functional limitations.").

⁵⁹ See *Davis*, 442 U.S. 397; *Doe v. New York Univ.*, 666 F.2d 761, 776 (2d Cir. 1981); U.S. COMM'N ON CIVIL RIGHTS, *supra* note 58, at 143; see also NATIONAL COUNCIL ON THE HANDICAPPED, TOWARD INDEPENDENCE app. A-37, A-38 (1986). The basic structure of the law governing disability rights is more like the treatment of gender, national origin, and religion. With respect to those classifications, employers are permitted to make a showing that discriminatory criteria are in fact bona fide occupational qualifications necessary to the business. NATIONAL COUNCIL ON THE HANDICAPPED, *supra* at app. A-37, A-38. When the civil rights laws were extended to disabled persons, it was widely recognized that the presumption of irrelevancy would also be inappropriate here. See *Davis*, 442 U.S. at 405; U.S. COMM'N ON CIVIL RIGHTS, *supra* at 143-44; NATIONAL COUNCIL ON THE HANDICAPPED, *supra* at app. A-37, A-38.

requirement is tempered materially, however, by the requirement that each program make "reasonable modifications" to its policies and practices in order to help disabled applicants qualify for the requested services.⁶⁰ As a result of this reasonable accommodation requirement, the disability rights laws confer something more than a bare right to equal access.⁶¹ The reasonable accommodation requirement does not, however, require a "fundamental alteration" of the program itself.⁶²

To summarize these statutory provisions, a disabled person is entitled to receive a desired service such as medical care if, with reasonable accommodations, she is able to meet all "essential" or "necessary" eligibility criteria. If she is so qualified, she may not be denied those benefits or services on the basis of her disability.⁶³ However, her disabilities may be taken into account when determining whether or not she is qualified.

B. *The Judicial History*

1. *Family Decisions To Withhold Life-Sustaining Care.*—Critics have long feared that the lives of disabled persons would be jeopard-

⁶⁰ Section 504 itself has no such requirement, but the HHS regulations implementing it expressly require reasonable accommodations by employers and educators. See 45 C.F.R. § 84.12(a) (1995) (regulating employment); *id.* § 84.44 (1995) (regulating accommodation in education). See also *Davis*, 442 U.S. at 407-13 (interpreting the education regulations). The ADA imposes a reasonable accommodation requirement as well. See 42 U.S.C. § 12182(b)(2)(A)(ii) (1994) (imposing a duty upon private entities providing public accommodations to make "reasonable modifications" to policies, practices, and procedures); 28 C.F.R. § 36.302(a) (1995) (requiring public accommodations to make "reasonable modifications in policies, practices or procedures").

⁶¹ See Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 *LAW MED. & HEALTH CARE* 331, 336 (1990) (describing the ADA as an entitlement program placed on the private sector); Peter M. Shane, *Structure, Relationship, Ideology, or, How Would We Know a "New Public Law" If We Saw It?*, 89 *MICH. L. REV.* 837, 862 (1991) (describing the ADA as "social welfare legislation," and not simply an "antidiscrimination" law).

⁶² See 29 U.S.C. § 794(a) (1994); 42 U.S.C. § 12182(b)(2)(A)(iii) (stating that public accommodations must make "reasonable modifications in policies, practice or procedures . . . unless the entity can demonstrate that making such modifications would fundamentally alter the nature of the . . . service"); *Davis*, 442 U.S. at 410; see also 28 C.F.R. § 35.130(b)(7) (1994) (excluding from the reasonable accommodation requirement for public services any changes that would "fundamentally alter the nature of the service").

⁶³ Whether a disabled applicant is "qualified" and whether that applicant has been discriminated against "on the basis of" a disability are two superficially distinct requirements that typically collapse into a single inquiry. As the U.S. Supreme Court observed in *Alexander v. Choate*, "the question of who is 'otherwise qualified' and what constitutes improper 'discrimination' . . . [are] two sides of a single coin." 469 U.S. 287, 299 n.19 (1985) (discussing the Court's interpretation of Section 504 in *Davis*, 442 U.S. 397); see also NATIONAL COUNCIL ON THE HANDICAPPED, *supra* note 59, at app. A-19, A-20 (the organization that initially proposed the Americans with Disabilities Act suggesting that the two requirements are redundant and unnecessarily confusing). A disabled person who lacks legitimate qualifications has not been impermissibly discriminated against. A disabled person who has them may not be treated unfavorably.

ized if decisions about their medical care could be based on their perceived quality of life. These concerns initially surfaced when *families*, rather than physicians, asked that life-sustaining care be discontinued. As the state law governing the withholding of life-sustaining care evolved, opponents of quality-of-life judgments asked state courts to use their common-law powers to bar families from taking disability or disability-impaired quality of life into account when making decisions to discontinue life-sustaining care. Most state courts refused this request, opting instead to allow surrogates to consider the quality of life that patients would enjoy if provided with life-sustaining care.⁶⁴

In response, opponents of quality-of-life decisions invoked the antidiscrimination protections of the Rehabilitation Act of 1974. The first of these cases arose in Bloomington, Indiana in April 1982, after parents of a child born with Down's Syndrome would not consent to a life-saving surgery that would have corrected a blocked esophagus.⁶⁵ The Indiana state courts refused to intervene, and the baby died six days later. In response to this case, the federal government made a major effort to police parental treatment decisions using its purported powers under Section 504.⁶⁶ These efforts were defeated in a series of lawsuits culminating in the Supreme Court's decision in *Bowen v. American Hospital Association*.⁶⁷ In a plurality opinion, the Court held that family decisions to withhold treatment fell outside the reach of Section 504 and that federal regulations enacted to force hospital surveillance of these parental decisions were invalid.

As the *Bowen* case worked its way to the U.S. Supreme Court, Congress enacted the Child Abuse Amendments of 1984.⁶⁸ That legislation requires states receiving federal child abuse assistance to treat parental failure to obtain medically indicated life-sustaining care as child abuse. That statute, along with the Supreme Court's decision in *Bowen*, temporarily put the issue to rest.

2. *Physician Resistance to Requested Care.*—In the futility disputes arising now, physicians and hospitals, rather than families, are resisting treatment. Under the antidiscrimination laws, the difference is crucial. Health care providers, unlike patients and their families,

⁶⁴ 1 ALAN MEISEL, *THE RIGHT TO DIE* 416-20 (1995); 2 *id.* at 337-39, 535-37.

⁶⁵ See *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 617 (1986). See also Crossley, *supra* note 36, at 1639-48; C. Everett Koop, *Life and Death and the Handicapped Newborn*, 5 *ISSUES L. & MED.* 101, 109-13 (1989). For a history of infant treatment cases including cases not addressing the antidiscrimination laws, see 2 MEISEL, *supra* note 64, at 306-14.

⁶⁶ The history is recounted in *Bowen*, 476 U.S. at 617-26; see also MEISEL, *supra* note 64.

⁶⁷ 476 U.S. 610 (1986).

⁶⁸ Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5107 (1994); 45 C.F.R. § 1340 (1995). These amendments were reportedly a compromise between those favoring and those opposing quality-of-life considerations. Capron, *supra* note 3, at 21.

are governed by the disability rights laws.⁶⁹ In addition, enactment of the ADA has expanded the reach of the disability rights laws beyond those providers receiving federal financial assistance to include all state agencies as well as private hospitals and doctors' offices.⁷⁰

So far, two different approaches to futility disputes involving life-sustaining care have been suggested by the courts. The first immunizes from judicial scrutiny all cases in which the disputed treatment is related to the patient's disability. The second approach rejects this exclusion and appears to prohibit physicians from taking disability into account when making end-of-life decisions.

a. The University Hospital line of cases.—The first important case to apply the antidiscrimination laws to individual medical decisions about life-sustaining care was *United States v. University Hospital*.⁷¹ Although the case arose out of a dispute between federal regulators and hospitals over the oversight of family (rather than physician) decisions to terminate life-sustaining care, its reasoning has obvious implications for the current futility cases. That reasoning suggested a distinction between treatment for a condition that is related to the patient's disability and treatment for a condition that is unrelated to the patient's disability. A physician's refusal to provide treatment for a condition unrelated to the patient's disability (such as an ear surgery for a patient with AIDS) would be subject to the antidiscrimination laws, but a refusal to provide treatment for a condition related to the patient's disability (such as corrective surgery for spina bifida) would not be.

In *University Hospital*, the parents of a child born with spina bifida, microcephaly, and hydrocephaly had decided to forego corrective surgery. Their hospital had honored that request. The Department of Health and Human Services (HHS) sought access to the hospital's records to determine whether improper discrimination had occurred. In the suit brought by HHS against the hospital, the Second Circuit stated that "[S]ection 504 prohibits discrimination against a handicapped individual *only* where the individual's handicap is *unrelated to*, and thus improper to consideration of, the services in question."⁷²

The court apparently based this conclusion on its reading of a previous Supreme Court decision requiring claimants under the disa-

⁶⁹ See *supra* note 44.

⁷⁰ 42 U.S.C. §§ 12112, 12131, 12181(7), 12182 (1994); 28 C.F.R. § 36.104 (1995) (defining public accommodations to include the "professional office of a health care provider, hospital, or other similar service establishment"); H.R. REP. No. 101-485, pt. 4, at 55-56 (1990), *reprinted in* 1990 U.S.C.A.N. 512, 544-45. The entity must also "affect commerce." 42 U.S.C. § 12181(7).

⁷¹ 729 F.2d 144 (2d Cir. 1984).

⁷² *Id.* at 156 (emphasis added).

bility rights law to prove that they are qualified despite their disabilities. As interpreted by the Second Circuit, that decision requires claimants to prove that their disabilities are irrelevant.⁷³ Because patients who allege that they have been denied a treatment that is related to their disabilities (like corrective surgery for spina bifida) cannot prove the irrelevance of their disability to the treatment decision, their cause of action fails.

In addition, the Second Circuit believed that proof of discrimination would be extremely difficult whenever the treatment in dispute arises out of the patient's disability. Although the court did not say so explicitly, it clearly recognized that plaintiffs in these cases would not be able to prove their discrimination claims in the classic style of civil rights litigation. That is, they could not prove that they had been denied a treatment that would have been offered to similarly situated patients who lack their disability.⁷⁴ They cannot make this showing because a patient without the same disability would not need the disputed treatment.⁷⁵

Furthermore, the court stated that "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.'"⁷⁶ Medical treatment claims would invariably require expert witnesses and lengthy litigation to determine if the medical treatment decision reflected "bona fide medical judgment."⁷⁷ The court declined to spawn this litigation without clearer proof of congressional intent.

Because the court assumed that most disputed treatment decisions would relate to the patient's disability,⁷⁸ and because it felt that the problems associated with this category of treatment disputes were substantial, it endorsed the defendant's contention that Section 504 could not be "meaningfully applied to a medical treatment decision."⁷⁹

⁷³ *Id.* The court was interpreting *Southeastern Community College v. Davis*, 442 U.S. 397 (1979) and a previous Second Circuit case interpreting *Davis, Doe v. New York University*, 666 F.2d 761 (2d Cir. 1981).

⁷⁴ See *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 655 (1986) (White, J., dissenting).

⁷⁵ See also *Johnson by Johnson v. Thompson*, 971 F.2d 1487, 1493 (10th Cir. 1992) ("[I]f such a person were not so handicapped, he or she would not need the medical treatment and thus would not 'otherwise qualify' for the treatment."), *cert. denied*, 113 S. Ct. 1255 (1993).

⁷⁶ 729 F.2d at 157.

⁷⁷ *Id.*

⁷⁸ *Id.* at 156 ("[I]t is typically the handicap itself that gives rise to, or at least contributes to, the need for services.")

⁷⁹ *Id.*

Although these concerns led the Second Circuit to exclude *all* medical treatment decisions from the scope of Section 504,⁸⁰ Justice White recognized in a later case that the Second Circuit's concerns would only apply when the condition requiring treatment is *related* to the patient's disability. These concerns would not justify immunity when a physician refuses to treat a condition which is *unrelated* to the patient's disability.⁸¹ In his dissenting opinion in *Bowen v. American Hospital Association*,⁸² a case decided on other grounds, Justice White pointed out that a patient who is denied treatment for a condition that is unrelated to his disability can compare his treatment to that of a similarly situated patient without his disability. To illustrate the point, he suggested that the antidiscrimination laws should apply when a physician fails to correct an esophageal defect in a baby with Down's Syndrome that would have been repaired in a baby without Down's Syndrome.⁸³

The plurality opinion in *Bowen* did not reach this issue.⁸⁴ Instead, it concluded that, absent parental consent, a hospital's withholding of treatment could not violate Section 504.⁸⁵ This effectively removed the disability rights laws from death and dying cases in which

⁸⁰ The Supreme Court has not yet ruled definitively on this issue. The plurality opinion in *Bowen* held only that a "hospital rule or state policy . . . would be subject to challenge under § 504." 476 U.S. at 624 (emphasis added). However, the better view today is that the antidiscrimination laws apply to at least some individual treatment decisions. See Crossley, *supra* note 36, at 1617, 1639-48. And the clear trend in the lower courts is in this direction. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994), *cert. denied*, 115 S. Ct. 91 (1994); *Miller v. Spicer*, 822 F. Supp. 158, 163-66 (D. Del. 1993) (patient denied tendon repair due to HIV status); *Glanz v. Vernick*, 750 F. Supp. 39, 46 (D. Mass. 1990) (patient denied ear surgery due to HIV status); see also *Johnson by Johnson v. Thompson*, 971 F.2d 1487, 1494 n.3 (10th Cir. 1992) (dictum), *cert. denied*, 113 S. Ct. 1255 (1993); *Gerben v. Holsclaw*, 692 F. Supp. 557, 562 (E.D. Pa. 1988); *State v. Clausen*, 491 N.W.2d 662, 665-68 (Minn. Ct. App. 1992) (applying Minnesota law to denial of tendon repair due to HIV status); cf. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402 (D.D.C. 1983) ("[I]t cannot be said that [S]ection 504 does not authorize some regulation of the provision of some types of medical care to handicapped newborns."). While a more lengthy defense of this conclusion is possible, I have refrained from making it here because the argument for complete immunity, especially under the ADA, has little current support.

⁸¹ *Bowen*, 476 U.S. at 655 (White, J., dissenting). For purposes of this point he assumed, but did not concede, that the reasoning of *University Hospital* was correct. Justice White hinted that the antidiscrimination laws should also cover denial of treatment for related conditions. *Id.* at 655 n.8 ("It could be argued, for example, that the [relevant] benefit provided by hospitals . . . is 'general medical care for whatever happens to need treating.' If this is the benefit, then a much broader application of the statute in this context is reasonable.").

⁸² 476 U.S. 610.

⁸³ *Id.* at 655.

⁸⁴ The Court noted the distinction made by Justice White between related and unrelated conditions, but saw no need to rule on the distinction based on the facts of the case at bar. *Id.* at 634 n.20.

⁸⁵ *Id.* at 630; see also *Johnson by Johnson*, 971 F.2d at 1492 (stating that actions by the providers which "rendered parental consent a sham" would be subject to challenge).

families requested the cessation of life-prolonging care. It left unresolved the law governing physicians who balk at family requests for life-sustaining care.

Since then, the Second Circuit's notion that all individual medical treatment decisions fall outside of the disability rights laws has gathered no additional support.⁸⁶ However, its distinction between related and unrelated conditions has been endorsed by the Tenth Circuit. In *Johnson by Johnson v. Thompson*, a group of Oklahoma families alleged that providers had improperly terminated life-sustaining care for their disabled babies.⁸⁷ The Tenth Circuit concluded that disputes about "related" care are non-justiciable,⁸⁸ but that this immunity need not extend to disputes about "unrelated" treatments.⁸⁹

Using this approach, a physician's refusal to provide HIV-infected patients with treatments for unrelated conditions such as dental care,⁹⁰ ear surgery,⁹¹ or tendon repair⁹² is actionable. So, too, is the refusal to offer a heart transplant to a patient whose prognosis is impaired by her diabetes.⁹³ Decisions like these would require a legally sufficient justification. On the other hand, the failure to close up the spinal column of a baby with spina bifida would not be actionable regardless of the provider's motivations, nor would the termination of resuscitative efforts for a patient with AIDS. The *University Hospital* line of cases, therefore, immunizes a broad class of bedside treatment decisions from judicial scrutiny.

b. In re Baby K.—A second approach to bedside treatment decisions was enunciated by the trial court in *In re Baby K*.⁹⁴ Baby K was born with anencephaly⁹⁵ and was discharged to a nursing home

⁸⁶ The better view now is that the federal disability rights laws do apply to individual medical treatment decisions. See *supra* note 80.

⁸⁷ *Johnson by Johnson*, 971 F.2d at 1493-94 & n.3.

⁸⁸ *Id.* at 1494. Thus, it limited the reach of Section 504 to "discrimination between the non-handicapped and the 'otherwise qualified' handicapped."

⁸⁹ *Id.* at 1494 n.3 ("[I]t would seem that the 'otherwise qualified' condition might be satisfied under such a scenario."); accord *Gerben v. Holsclaw*, 692 F. Supp. 557, 561-62 (E.D. Pa. 1988) (*dictum*).

⁹⁰ See *State v. Clausen*, 491 N.W.2d 662, 665-68 (Minn. Ct. App. 1982) (applying state law).

⁹¹ See *Glanz v. Vernick*, 750 F. Supp. 39 (D. Mass. 1990).

⁹² See *Miller v. Spicer*, 822 F. Supp. 158 (D. Del. 1993).

⁹³ See David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1457-58 (1992) (noting poorer outcomes associated with disabilities like severe diabetes and cancer).

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

⁹⁵ According to the court, "[a]nencephaly is a congenital defect in which the brain stem is present but the cerebral cortex is rudimentary or absent. There is no treatment that will cure, correct, or ameliorate anencephaly." *Id.* at 1025. The court described her condition as follows: "Baby K is permanently unconscious and cannot hear or see. Lacking a cerebral function, Baby K does not feel pain. Baby K has brain stem functions primarily limited to reflexive actions such

soon after her birth. In the ensuing weeks, she was readmitted to the hospital several times for treatment of her breathing problems. Her physicians repeatedly asked her mother to discontinue ventilator support, characterizing it as "futile and inhumane."⁹⁶ Her mother refused, because she believed that all life has value and that God would perform a miracle if it were His will.⁹⁷ As a result, the hospital took the issue to court.⁹⁸ The trial court ruled, *inter alia*, that failure to provide respiratory assistance and other aggressive care would violate the disability rights laws because Baby K would be denied care that would be provided to a patient who was not anencephalic.⁹⁹ The trial court opinion in *Baby K* rejected the related/unrelated condition distinction, thereby making all disability-based decisions subject to challenge.¹⁰⁰

The trial court then refused to examine the hospital's claim that further resuscitative efforts would be "futile" and "inhumane." Instead, the opinion appeared to prohibit any decisions based on patient quality of life. The court suggested that even a "dismal" prognosis must be ignored and that an anencephalic baby must be given the same treatment that would be given to babies without anencephaly.¹⁰¹ Unfortunately, the trial court overlooked the hospital's statutory authority to employ necessary or essential eligibility criteria, and thus, it did not consider whether the hospital's policies would meet that threshold. The Fourth Circuit did not review these conclusions when it affirmed the decision on other grounds.¹⁰²

The broad interpretation of the antidiscrimination laws espoused in *Baby K* stands alone for the moment. However, it is consistent with a prior interpretation of those laws by the Bush and Clinton Administrations. In 1991, Oregon attempted to rationalize its Medicaid spend-

as feeding reflexes (rooting, sucking, swallowing); respiratory reflexes (breathing, coughing) and reflexive responses to sound or touch." *Id.* The court concluded that anencephaly is a disability "because it affects the baby's neurological functioning, ability to walk, and ability to see or talk." *Id.* at 1028. The hospital conceded that its desire to withhold ventilation support was based on Baby K's anencephaly. *Id.* at 1027.

⁹⁶ *Id.* at 1025-27. Ms. K had previously rejected the suggestion of her obstetrician and neonatologist that she terminate her pregnancy with Baby K. *Id.* at 1025. Within days of the baby's birth, her physician unsuccessfully urged a "Do Not Resuscitate order." *Id.*

⁹⁷ *Id.* at 1026. God, she felt, not humans, should decide the moment of Baby K's death.

⁹⁸ Both the noncustodial father and the court-appointed guardian ad litem agreed with the hospital's position. *Id.* at 1026.

⁹⁹ *Id.* at 1029.

¹⁰⁰ *Id.* at 1028. The court rejected the distinction because, it concluded, the distinction would be impermissible in the context of racial discrimination. However, it did not address the concerns raised in *University Hospital* about the justiciability of these cases under the antidiscrimination laws.

¹⁰¹ *Id.* at 1027-29.

¹⁰² *In re Baby K*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994) (affirming the trial court ruling on the basis of the Emergency Medical Treatment and Active Labor Act).

ing by ranking treatments in order of priority.¹⁰³ The federal government objected to the ranking list because it was based, in part, on the expected quality of life of patients following treatment.¹⁰⁴ "[T]he premise that the value of life of a person with a disability is less than the value of the life of a person without a disability" was, HHS concluded, "inconsistent with the ADA."¹⁰⁵ Although Oregon denied that its methods impermissibly discriminated against disabled Oregonians, it modified its ranking procedures as requested in order to obtain federal approval of its plan.¹⁰⁶

c. Current status of the caselaw.—The caselaw suggests two quite different approaches to disputes about purportedly futile life-sustaining care. One approach would immunize from scrutiny a large fraction of the futility cases—all those in which the disputed treatment is related to the patient's disability. The second approach would subject all medical treatment decisions to the disability rights laws and apparently would oblige physicians to ignore the quality of life that therapeutic intervention would offer.

Each approach has serious problems. One insulates from challenge all treatment decisions that arise out of the patient's disability, no matter how patent the prejudice. The defensibility of this distinction between related and unrelated conditions is the subject of Part III. The other line of reasoning corrects that omission, but then prohibits providers from taking a patient's quality of life into account no matter how cruel or pointless the provider believes the treatment to be. A more balanced mechanism for handling cases in which the provider believes that treatment would be contrary to patient welfare is proposed in Part IV. In addition, neither of the two existing approaches to the disability rights laws accounts for the difference between decisions based on patient welfare and those based on cost-effectiveness. Yet, the shift in objectives has important implications for disability discrimination claims. They are explored in Part V.

¹⁰³ OREGON HEALTH SERV. COMM'N, PRIORITIZATION OF HEALTH SERVICES: A REPORT TO THE GOVERNOR AND LEGISLATURE (1991).

¹⁰⁴ Letter from Louis W. Sullivan, M.D., to Barbara Roberts, Governor of Oregon (Aug. 3, 1992), in 9 ISSUES L. & MED. 397, 409 (1994) [hereinafter Sullivan Letter].

¹⁰⁵ *Id.*

¹⁰⁶ OREGON HEALTH SERV. COMM'N, *supra* note 103, at 9. For a longer summary of the negotiations between Oregon and the federal government, see Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 503-05 (1995). On March 19, 1993, the government granted conditional approval to Oregon based on changes that Oregon had agreed to make and on the condition of further changes outlined in the government's response.

III. THE DISTINCTION BETWEEN RELATED AND UNRELATED CONDITIONS

Under the line of reasoning that distinguishes between related and unrelated conditions, patients with disabilities can only challenge medical decisions that deny them treatment for a condition that is unrelated to their disability. Thus, a patient with a disability, such as AIDS, can seek relief if he is improperly denied treatment for a medical condition that is unrelated to his AIDS, such as a torn tendon in his leg. But he would not be able to challenge a physician's decision to deny him a desired treatment for the AIDS itself. Likewise, a surgeon's reluctance to close the spine of a child born with myelomeningocele (a form of spina bifida) would not be actionable under the antidiscrimination laws because the need for treatment arises out of the patient's disability.

Yet, prejudicial treatment of persons with disabilities is not limited to circumstances in which they are denied treatment for unrelated conditions. Ignorance or prejudice can also cause inadequate treatment of the disability itself. Evidence suggests, for example, that physicians are likely to abandon life-saving efforts more quickly for patients with AIDS than for other patients with similar prognoses.¹⁰⁷ Similarly, the Baby Doe cases in the 1980s suggested that certain physicians were prejudiced against babies with Down's Syndrome. As Giles Scofield has noted, "there is evidence that health care providers do hold unwarranted beliefs about persons with disabilities, and that such beliefs do affect their recommendations with respect to life-sustaining treatment."¹⁰⁸

Why then would courts adopt a distinction that immunizes a huge class of potentially biased treatment decisions from scrutiny under the antidiscrimination laws? The Second Circuit expressed two related concerns. First, it believed that a disabled patient could only prove that she was "otherwise qualified" to receive medical services if she

¹⁰⁷ Robert M. Wachter et al., *Decisions About Resuscitation: Inequities Among Patients with Different Diseases, but Similar Prognoses*, 111 ANNALS INTERNAL MED. 525, 525 (1989) (noting that physicians wrote DNR orders more readily for AIDS and lung cancer patients than for cirrhosis and heart failure patients with similar prognoses); see also Betty W. Levin et al., *Treatment Choice for Infants in the Neonatal Intensive Care Unit at Risk for AIDS*, 265 JAMA 2976, 2976-80 (1991) (survey indicating that health professions at six New York hospitals would be less aggressive treating the life-threatening conditions of newborns infected with HIV than if the infant did not have HIV, or had other disabilities such as cystic fibrosis).

¹⁰⁸ Giles R. Scofield, *Medical Futility Judgments: Discriminating or Discriminatory?*, 25 SETON HALL L. REV. 927, 934 (1995) (citing Kenneth A. Gerhart et al., *Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS EMERGENCY MED. 807, 808 (1994); Lindsay Gething, *Judgments by Health Professionals of Personal Characteristics of People with a Visible Physical Disability*, 34 SOC. SCI. & MED. 809, 809 (1992); M.L. Paris, *Attitudes of Medical Students and Health-Care Professionals Towards People with Disabilities*, 74 ARCHIVES PHYSICAL MED. & REHABILITATION 818, 818 (1993)).

could prove that her disability was irrelevant to the treatment decision.¹⁰⁹ Patients complaining that they have been denied care for their disability cannot make that showing. Second, the Second Circuit believed that proof of discrimination would be too difficult if the condition to be treated were related to the patient's disability.¹¹⁰ In addition, the court may have been reluctant to supervise complex medical judgments. This Part examines these three concerns and concludes that they do not justify the immunization of an entire category of treatment decisions.¹¹¹

A. The Problem of Qualifications

Disabled patients who are denied treatment for medical problems arising out of their disability cannot show that their disability is irrelevant to the treatment decision. The Second Circuit believed that this inability constituted a fatal defect. The court appeared to base its conclusion on language from an earlier Supreme Court decision, *Southeastern Community College v. Davis*.¹¹² In *Davis*, the Supreme Court explained that an "otherwise qualified" disabled person under Section 504 must be able to meet all of the program's requirements *in spite of his handicap*. As a result, an institution need not disregard an individual's disability when it is relevant.¹¹³ Applying this rule to medical treatment decisions, the Second Circuit concluded that a patient's disability is relevant when the disability gives rise to the condition to be treated. Thus, it held that the patient's disability may permissibly be taken into account.

The court's reasoning is impeccable in all but one respect. The court overlooked the fact that a relevant criterion can be misused. Consider, for example, treatment decisions for patients with AIDS. The fact that they have AIDS is obviously relevant. It creates the need for treatment and influences the kinds of treatments that are most appropriate. But the presence of AIDS may also lead physicians to discriminate against these patients. Two separate studies indicate that physicians give up more readily on patients with AIDS or HIV-infection.¹¹⁴ The fact that a disability is in some respects relevant provides no guarantee that it will not be misused. Relevant information can be used in irrelevant, improper ways. Just as evidence admitted at trial for one purpose will sometimes be improperly considered by the

¹⁰⁹ *University Hosp.*, 729 F.2d 144, 155-56 2d Cir. 1984). Indeed, the court seemed to think that the very idea of "qualifications" could not be applied in the context of medical services.

¹¹⁰ *Id.*

¹¹¹ Several other scholars have also rejected the distinction. See Crossley, *supra* note 36, at 1648-50; Orentlicher, *supra* note 50, at 61; Scofield, *supra* note 108, at 927.

¹¹² 442 U.S. 397 (1979).

¹¹³ *Doe v. New York Univ.*, 666 F.2d 761, 775 (2d Cir. 1981).

¹¹⁴ See *supra* note 107.

jury for other purposes,¹¹⁵ so too a disability that legitimately bears on the treatment decision may be misused by biased physicians.

Assume that a newborn with Down's Syndrome needs life-sustaining care related to her disability. Assume further that her treating physician withholds the life-sustaining care because she believes that the quality of life of children with Down's Syndrome is tragic. The child's family is angered by this decision, believing that it reflects factually inaccurate assumptions and biases about life with Down's Syndrome. In their eyes, stereotypical judgments like these are precisely what Congress meant to eliminate with the ADA.

Should courts hear disputes like these on the merits? Under the *University Hospital* approach, they could do so only if the life-threatening condition were unrelated to the child's disability. In that event, a decision to deny life-sustaining care to a baby with Down's Syndrome might well violate the ADA. But if this child's life-threatening condition were related to her disability, the treatment decision would be immune from scrutiny under the antidiscrimination laws. This difference in outcomes is unwarranted. To the extent that quality-of-life judgments like this one are improper (a subject considered in Parts IV and V), they should be excised from all treatment decisions—not merely those in which the condition being treated is unrelated to the patient's disability. A patient who is denied access to a therapy necessitated by his disability should be permitted to prove that the decision was motivated by bias.

B. *The Problem of Proof*

The more serious problem created by suits arising out of "related" care is not conceptual, but practical. Identifying biased treatment decisions will be more difficult when the treatment is related to the patient's disability than when it is unrelated. When a patient with AIDS is denied treatment for an *unrelated* eardrum or dental problem, courts can easily ascertain whether the decision was based on the patient's disability by investigating whether the treatment is offered to similarly situated patients without AIDS. If differential treatment is proven, then the court can insist upon a legitimate justification.¹¹⁶ By contrast, when a disabled patient is denied treatment for a condition *related to* his disability, there may be no similarly situated non-disabled patient whose treatment can be compared. Instead, the patient will have to adduce other evidence to prove that the provider's decision was infected by bias.¹¹⁷

¹¹⁵ FED. R. EVID. 105 (requiring the trial judge to instruct the jury when evidence is admitted for one purpose but not others).

¹¹⁶ Parts IV and V consider when differential treatment might be justified.

¹¹⁷ In this respect, the government's suggestion in *University Hospital* that medical decisions must be "bona fide" was sound. 729 F.2d 144, 150 (2d Cir. 1984).

Admittedly, litigating and evaluating these claims will be difficult. Factfinders looking for evidence of bias will have to search for it within the complex matrix of factors influencing a physician's exercise of medical judgment. Nevertheless, five considerations justify this effort. First, no liability will arise unless the plaintiff can convince the court that impermissible discrimination has occurred. If the factfinder cannot determine whether disability improperly influenced the treatment decision, the claim will fail. That should provide substantial breathing room for complex medical judgments.

Second, it is easy to imagine cases in which proof of improper discrimination will be present. This proof might take a number of forms. It could, for example, include scientific studies or practice guidelines casting serious doubt on a physician's claim to have withheld a treatment because it would not have been effective.¹¹⁸ In other cases, a patient may be able to prove that the provider had made biased statements. Or plaintiffs may offer proof that patients with different illnesses, but similar prognoses, were offered treatments denied to the plaintiff.¹¹⁹ Finally, aggrieved patients may be able to prove

¹¹⁸ In the absence of resource constraints (considered in Part V), a patient should be able to establish his "qualifications" for treatment by proving his capacity to benefit from treatment. See *infra* note 174 (collecting authorities).

¹¹⁹ The courts have split on whether the antidiscrimination laws prohibit discrimination between disabilities. One line of cases suggests that the antidiscrimination laws are concerned only with "even-handed" treatment of the disabled vis-à-vis the non-disabled and not with discrimination among the disabled. See, e.g., *Turnage v. Turner*, 485 U.S. 535, 549 (1988) ("There is nothing in [Section 504] that requires that any benefit extended to one category of handicapped persons also be extended to all other categories of handicapped persons."); *Doe v. Colautti*, 592 F.2d 704, 708-10 (3d Cir. 1979); *Duquette v. Dupuis*, 582 F. Supp. 1365, 1370-72 (D.N.H. 1984); *Doe v. Devine*, 545 F. Supp. 576, 585 (D.D.C. 1982) (noting that equal benefits are not required, but in fact were provided), *aff'd*, 703 F.2d 1319 (D.C. Cir. 1983). Another line of cases suggests a contrary result. See *Henderson v. Bodine Aluminum, Inc.*, 70 F.3d 958 (8th Cir. 1995) (finding that a health plan that insured high dose chemotherapy for some cancers but not breast cancer violated the ADA); *McGuire v. Switzer*, 734 F. Supp. 99, 114-15 (S.D.N.Y. 1990) (holding that the plaintiff had established a cause of action under Section 504 based on the state's higher tuition and maintenance reimbursement to blind individuals as compared to reimbursement to other disabled individuals).

The issue is arguably further muddled by provisions in the regulations implementing both Section 504 and the ADA that expressly permit government programs to target, and thus favor, specific disabilities. 45 C.F.R. § 84.4(c) (1990) ("The exclusion of nonhandicapped persons from the benefits of a program limited by Federal statute or executive order to handicapped persons or the exclusions of a specific class of handicapped persons from a program limited by Federal statute or executive order to a different class of handicapped persons is not prohibited by this part."); 28 C.F.R. § 35.130(c) (1991) ("Nothing in this part prohibits a public entity from providing benefits . . . to individuals with disabilities, or to a particular class of individuals with disabilities beyond those required by this part."). In theory at least, this exception may also imply tolerance of private discrimination between disabilities. As noted above, some federal courts have given such latitude to health benefits plans. But nothing in the language of this narrowly targeted exception suggests that prejudicial discrimination against disfavored disabilities should be tolerated. To the contrary, the presence of this provision suggests a congressional assumption that differential treatment on the basis of disability would *ordinarily* violate the general prohibi-

that physicians used a controversial criterion, such as disability-impaired quality of life, in an improper manner.¹²⁰

Third, patients who can make the required showing deserve a remedy. As a corollary, the availability of a remedy will help to deter future discriminatory conduct.

Fourth, endorsing the distinction between related and unrelated conditions will not eliminate the need to make case-by-case evaluations of disputed medical treatment decisions. Even when the condition being treated is unrelated to the patient's disability, providers will sometimes offer justifications for differential treatment.¹²¹ Evaluating those justifications will require the same close scrutiny of the motivations of the provider that the Tenth and Second Circuits sought to avoid by endorsing the distinction between related and unrelated conditions. In *Glanz v. Vernick*,¹²² for example, the defendant claimed that his failure to perform ear surgery on an HIV-infected patient was necessitated by the risks associated with the patient's HIV infection. Before concluding that the patient had been improperly discriminated against, the trial court had to evaluate the genuineness of that defense. Consequently, endorsing the *University Hospital* approach will not eliminate the difficult task of supervising individual treatment decisions. It will merely reduce the number of cases in which supervision is undertaken.

tion on disability-based discrimination. Indeed, courts, litigants, and the Equal Employment Opportunity Commission have made this assumption in disputes over discriminatory limits on AIDS coverage by health benefits plans. See EQUAL EMPLOYMENT OPPORTUNITY COMM'N, *supra* note 50; EEOC v. Tarrant Distrib., No. H-94-3001 (S.D. Tex. Oct. 11, 1994), *abstracted in* CCH Accommodating Disabilities, No. 36, at 5 (Nov. 1994) (detailing a case in which an employer agreed to lift its \$10,000 lifetime cap on AIDS coverage); Mason Tenders Dist. Council Welfare Fund v. Donaghey, No. 93 Civ. 1154 (S.D.N.Y. Nov. 19, 1993) (trial court ruling permitting a cause of action alleging discriminatory failure to provide insurance coverage for HIV-related illness), *abstracted in* 91 HEALTH L. FOCUS, CCH, at 2 (Dec. 21, 1993); Laborers Dist. Council Bldg. & Constr. Health & Welfare Fund, EEOC, Charge No. 170930899 (Sept. 9, 1993), *abstracted in* 62 L.W. 2232 (Oct. 19, 1993) (finding that a lower cap for HIV-related illness violated the ADA); Estate of Kadinger v. International Bhd. of Elec. Workers Local 110, No. CIV 3-93-159 (D.C. Minn. Dec. 21, 1993) (consent decree removing discriminatory lifetime cap on health insurance benefits for AIDS), *abstracted in* 62 L.W. 2436 (Jan. 18, 1994). Ultimately, a line will have to be drawn between permitted "favorable" treatment and regulated "unfavorable" treatment. Thus far, neither the courts nor the regulators have attempted this task. For a thoughtful survey of the issue and citations to additional cases, see Crossley, *supra* note 8, at 227-31.

¹²⁰ Parts IV and V consider the circumstances in which qualify-of-life criteria may be employed.

¹²¹ See *infra* Parts IV and V.

¹²² 750 F. Supp. 39, 46 (D. Mass. 1990); see also *State v. Clausen*, 491 N.W.2d 662, 665-68 (Minn. Ct. App. 1992) (rejecting on the merits a dentist's claim that his referral of an HIV infected patient to a university center was intended to provide the patient with better protection from bacterial infection).

Fifth, the "related/unrelated" distinction presents line-drawing problems of its own that may offset the administrative advantages that it offers. Mary Crossley first made this point in her cogent examination of treatment decisions for HIV-infected newborns.¹²³ To illustrate, she asked whether an HIV-infected child's need for immunization was "related" to the child's HIV by virtue of the fact that the HIV-infected child needed the immunity more than the ordinary child.¹²⁴ Other difficult cases are easy to envision. Justice White, for example, assumed that a child born with both Down's Syndrome and an esophageal blockage presented the paradigmatic case of a patient needing a treatment unrelated to her disability.¹²⁵ But esophageal defects are 100 times more common in babies with Down's Syndrome than in other newborns.¹²⁶ Is this treatment, therefore, also related? And what if a disability, like AIDS, makes treatment of a purportedly unrelated condition more dangerous¹²⁷ or less effective?¹²⁸ Is the condition then sufficiently related to the disability?

The problem of classification was present, in fact, in *University Hospital*. In that case, the government argued that Baby Jane Doe would have received surgery to correct her spina bifida and hydrocephalus if she had not been born with microcephaly.¹²⁹ With this argument, the government hoped both to characterize the disputed care as unrelated to the disfavored disability (microcephaly) and also to show that similarly situated patients without her disfavored disability would have been treated differently. The court declined to accept this framing of the case, but it never explained why.

The same kind of debate could have occurred on the facts of *Baby K*.¹³⁰ The hospital's attorneys would have characterized Baby

¹²³ Crossley, *supra* note 36, at 1649-50. She also criticizes the distinction on the grounds that it will sometimes be overbroad, prohibiting dissimilar treatment for unrelated conditions even when it is defensible. *Id.* at 1650. While this is a reasonable reading of *University Hospital*, see *supra* text accompanying note 77, the question of which treatment decisions to supervise can be separated from the question of which dissimilar treatment to proscribe. In that event, endorsement of the distinction between related and unrelated conditions would not commit a court to ignoring possible justifications for nontreatment in cases involving unrelated conditions. Parts IV and V explore the circumstances in which dissimilar treatment may be defensible.

¹²⁴ *Id.* In my view, the intuitive answer is "yes" because the need arises out of the disability. See *University Hosp.*, 729 F.2d at 156. But that would leave providers free to exclude these children from immunization. Judicial unwillingness to live with this outcome would push them to a different conclusion.

¹²⁵ *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 655 (1986) (White, J. dissenting).

¹²⁶ Orentlicher, *supra* note 50, at 61.

¹²⁷ See *supra* note 35.

¹²⁸ See *supra* note 36.

¹²⁹ 729 F.2d at 150, 156.

¹³⁰ In fact, the majority and dissenting opinions engaged in this very debate in connection with a requirement of the Emergency Medical Treatment and Active Labor Act. 16 F.3d 590, 596 (4th Cir.) (concluding that breathing difficulty was the emergency medical problem at stake),

K's respiratory difficulties as "related" to her disfavored disability (anencephaly). But the family's attorneys would have characterized her respiratory difficulty as "unrelated" to her disfavored disability (retardation).

If the distinction between related and unrelated conditions is accepted, courts will devote substantial energies to the task of policing the border between related and unrelated conditions. They may be surprised to discover, as David Orentlicher notes, that the body is an integrated system and that disabling conditions can influence virtually all other medical needs.¹³¹ Because complete independence is rare, courts who insist on it will insulate a vast array of treatment decisions from any judicial scrutiny. But if they resist this approach, they will be forced to articulate some alternative boundary. Although it is conceivable that a coherent boundary would result,¹³² it is just as likely that the understandable desire to reach the underlying merits of these cases would lead courts to stretch this jurisdictional boundary in order to achieve substantive justice. It seems better to tackle the substantive issues directly and honestly.

C. Deference to Medical Judgments

Conceivably, a third rationale may be offered in defense of the *University Hospital* line of cases. As pointed out by a respected legal treatise, this line of cases may reflect judicial unwillingness to second-guess complex medical judgments about treatment effectiveness.¹³³ If so, the mechanism employed to provide breathing room for good faith medical judgments is overbroad and unwise. The distinction between related and unrelated conditions would insulate medical decisions based on bias, stereotype, and false assumption.¹³⁴ Furthermore,

cert. denied, 115 S. Ct. 91 (1994); *id.* at 599 (Sprouse, J., dissenting) (concluding that anencephaly was the relevant condition).

¹³¹ Orentlicher, *supra* note 50, at 61.

¹³² For example, the courts could treat multiple disability cases, like those in *University Hospital* and *Baby K*, as justiciable because treatment decisions in these cases can be readily compared to treatment decisions for patients who lack the allegedly disfavored disability.

¹³³ BARRY FURROW ET AL., HEALTH LAW 556 (1995) [hereinafter FURROW, HEALTH LAW]; see also Orentlicher, *supra* note 50, at 59 (suggesting that *University Hospital* "may reflect the court's view that medical decisions are objective and scientific"). The American Academy of Pediatrics made the point this way, in its brief to the Supreme Court in *Bowen*:

The pediatrician must assess, often without reliable medical data, the likelihood of successful treatment, the risk of damage to the infant from the therapy, the effect on the child of protracted artificial life-support care, and the pain and suffering of continued treatment. Treatment may be life-saving, but the result of the therapy could cause other damage.

Amicus Brief at 7-9, quoted in BARRY R. FURROW ET AL., BIOETHICS, HEALTH CARE LAW AND ETHICS 337 (1991) [hereinafter FURROW, BIOETHICS].

¹³⁴ See Orentlicher, *supra* note 35, at 311 (claiming that deference to medical judgments risks "condoning practices that are based on stereotypes or misleading data rather than real medical differences").

medical judgments about treatment effectiveness inevitably reflect crucial value judgments. Debate about the proper range of these value judgments lies at the heart of both the futility debate and the discrimination claims these judgments engender. Until these substantive questions about the proper range of physician value judgments have been decided, the range of desirable breathing room cannot be ascertained. After that task is undertaken, ample breathing room can be provided without offering physicians so broad an immunity. By placing the burden of proof on plaintiffs to prove bias and permitting physicians to consider all relevant criteria, courts can still confer substantial latitude on providers without also immunizing biased decision making.

D. Conclusions

The distinction between related and unrelated conditions arises out of legitimate judicial concerns about the difficulty of proving discrimination. Without question, proof of invidious discrimination will often be difficult. But endorsement of this distinction would immunize a whole class of discriminatory treatment decisions. In addition, the distinction presents line-drawing problems of its own. Furthermore, rejection of the distinction between related and unrelated conditions is consistent with the tradition of broadly construing the civil rights laws.¹³⁵ Ultimately, the arbitrariness of the distinction between related and unrelated conditions as a normative matter seems to justify acceptance of the practical difficulties.

IV. TAKING DISABILITY INTO ACCOUNT: QUALITY OF LIFE AS AN INDICATOR OF PATIENT WELFARE

Once courts have determined which medical treatment decisions they will scrutinize for compliance with the antidiscrimination laws, they must determine the extent to which a patient's disability may be taken into account. As explained above, the patient's disability will often be relevant to the treatment decision,¹³⁶ especially if courts are willing to supervise treatment decisions for related conditions.¹³⁷ Yet, decisions based on disability can also reflect bias or ignorance. The courts face the difficult task of distinguishing those circumstances in which a provider has permissibly taken the patient's disability into account from those in which the provider has behaved improperly. In the language of the disability rights laws, they must identify those instances (either individually or as a class) in which consideration of the

¹³⁵ See *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402 (D.D.C. 1983) (suggesting that this tradition applies to medical treatment cases).

¹³⁶ See *supra* text accompanying notes 34-36.

¹³⁷ See *supra* text accompanying notes 112-13.

patient's disability is "necessary" or "essential" to the clinic practice and those in which the patient's disability is either an irrelevant consideration or one that has been misused.

Disability-based discrimination can occur both when a provider relies on quantitative measures of treatment futility, such as the impact of disability on the odds or duration of success,¹³⁸ and when the provider acts on qualitative indicia of futility, such as the impact of a patient's disability on his quality of life.¹³⁹ However, quantitative factors are less controversial than quality-of-life judgments both because of their superficial objectivity and because providers who use them are not discounting the value of life with a disability.¹⁴⁰ Although quantitative criteria do pose serious disability rights issues,¹⁴¹ the most serious objections to physician futility judgments are raised when physicians take disability-impaired quality of life into account.¹⁴² For that reason, quality-of-life judgments will be used in this Article as the vehicle to test the application of the disability rights laws to physician futility decisions.

This Part examines the circumstances under which providers should be permitted to consider disability-impaired quality of life

¹³⁸ See *supra* text accompanying notes 34-36.

¹³⁹ See *supra* text accompanying notes 37-40.

¹⁴⁰ Quantitative factors are therefore more universally recognized to be relevant. See FURROW, HEALTH CARE LAW, *supra* note 133, at 94 (arguing that it is proper to base treatment decisions on medical effectiveness); Crossley, *supra* note 36, at 1646 (claiming "medical effects" of a disability should be a proper consideration); see also *infra* text accompanying notes 231-34 (noting greater scholarly acceptance of quantitative criteria, at least at the extremes).

¹⁴¹ For example, a physician presumably cannot rely on unfounded assumptions about poorer outcomes for disabled patients. In addition, physicians arguably have no business making futility decisions when the patient or the family is available to make the treatment decision. See *infra* text accompanying notes 158-64 (discussing the standing issue in connection with quality-of-life judgments) and *supra* notes 17-20 (pointing out that the desirability of a small chance for additional life is a value judgment arguably best made by the patient or the patient's family). In addition, the reasonable accommodation requirement may limit exclusions based on quantitative factors, such as the odds of success, to the most bleak cases. See Orentlicher, *supra* note 50, at 72. The disability rights issues raised by quantitative factors become even more complex when a physician bases his refusal to treat on the obligation to steward scarce health care resources, rather than on patient welfare. See *infra* note 238.

¹⁴² Quality-of-life judgments do not raise the same issue when the disputed treatment is quality-enhancing rather than life-extending. When the treatment is quality-enhancing only, such as surgery for hip discomfort, the impact of the treatment on patient quality of life can be assessed without placing a value on preservation of the patient's life. As a result, quality-of-life considerations do not threaten the principle of equal worth when the condition being treated is not life-threatening. To that extent, they are much less controversial. On the right set of facts, however, quality-of-life assessments could raise disability rights issues even in connection with noncritical care. Under a rationing system based on relative effectiveness or cost-effectiveness, for example, treatment of the disabled patients could conceivably receive a lower priority for funding than treatment of non-disabled patients if, because of co-morbidities, disabled patients showed less improvement from the therapy than non-disabled patients. For an examination of these issues, see Peters, *supra* note 106, at 543-46.

when deciding whether further life-extending care would advance a patient's welfare. Part V then explores the additional issues raised when poor quality of life influences a provider's conclusion that potentially beneficial life-extending care would, nevertheless, constitute a poor use of health care resources.

A. *Objections to Quality-of-Life Considerations*

1. *All Lives Have Equal Worth.*—To withhold life-sustaining care from a disabled patient because his quality of life is poor is to discount the value of that patient's life because of his disability. Critics believe that this discounting offends the ideal that each person's life has equal value, regardless of disability, and is entitled to equal protection.¹⁴³ From this perspective, quality of life is an irrelevant and discriminatory criterion that should not be used to make end-of-life treatment decisions.¹⁴⁴

In its strongest form, this is an argument against ever discounting the value of life. As the Association for Retarded Citizens wrote in an amicus brief to the U.S. Supreme Court ten years ago,

The *a priori* assumption [of physicians who resist treatment] . . . is not that the child cannot or will not live, but rather that because of his or her handicap the infant's life has such diminished value that the child *should* not live. . . . There is no more central civil rights issue than a life and death difference in treatment based on a different and lesser valuation of a human life attributable to membership in a particular group.¹⁴⁵

Under this argument, patients with severe disabilities should be given access to treatments like ventilators and artificial nutrition without regard to their quality of life. In the early days of the death and dying debates, this was called a "sanctity of life" argument.¹⁴⁶

In addition, opponents of quality-of-life judgments can argue that these judgments are so susceptible to abuse that they should be prohibited even if courts reject the argument that they are *per se* improper. Determining whether a patient's quality of life is so impaired that life-extending treatment is no longer worthwhile requires a very subjective value judgment. Because of this subjectivity, bedside treatment decisions by providers are susceptible not only to error and in-

¹⁴³ See, e.g., Amicus Brief of the Association for Retarded Citizens at 6-9, *Bowen v. American Hosp. Ass'n*, 476 U.S. 610 (1986), quoted in FURROW *BIOETHICS*, *supra* note 133, at 335-36; Robert A. Destro, *Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Rights and Equal Protection for the Disabled and Incompetent*, 2 J. CONTEMP. HEALTH L. & POL'Y 71, 96-99, 118 (1986).

¹⁴⁴ Bopp & Coleson, *supra* note 29, at 836-37, 843-44 (stating that quality-of-life considerations violate the disability rights laws); Bopp & Avila, *supra* note 39 (same).

¹⁴⁵ Amicus Brief of the Association for Retarded Citizens, *supra* note 143.

¹⁴⁶ See, e.g., Richard A. McCormick, *The Quality of Life, The Sanctity of Life*, HASTINGS CENTER REP., Feb. 1978, at 30, 35.

consistency, but also (and this is the discrimination concern) to unequal treatment based on prejudice against, or ignorance about, life with a disability.¹⁴⁷ This discretion is especially troubling in light of mounting pressures to contain costs that may increase the temptation to reduce care to disabled patients whose care is expensive and inconvenient, such as the demented elderly.¹⁴⁸ Yet, policing these judgments would require difficult line-drawing between quality-of-life judgments that are reasonable and unbiased and those which are objectionable. In addition, they present the danger of a slippery slope on which less and less severe disabilities might be deemed worse than death.

From this perspective, every disabled patient whose life can be extended with available medical technology should be considered "qualified" to receive that therapy no matter how poor her quality of life. Provider attempts to establish minimum thresholds of quality of life ought not be considered "necessary" or "essential." In addition, the reasonable accommodation requirement arguably obliges health care providers to accede to requests for life-extending care. Complying with these requests would not constitute the kind of "fundamental alteration" of medical practice that the statutes preclude.¹⁴⁹

Although neither the statutory texts nor the legislative histories provide any further guidance on this issue, the only court to address the issue directly has ruled that disability cannot be taken into account. In *Baby K*, a federal district court refused to examine the hospital's claim that further resuscitative efforts for an anencephalic baby would be "futile" and "inhumane."¹⁵⁰ Instead, it suggested that even a "dismal" prognosis must be ignored and insisted that an

¹⁴⁷ See, e.g., Crossley, *supra* note 8, at n.79; Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79 (1993); John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 253-55 (1975) (questioning quality-of-life arguments). While Field concedes that some babies may be better served by withholding care, she suggests that there are too few such cases to take the risk of permitting best interests decisions, even by families. Field, *supra*, at n.53.

¹⁴⁸ Rationing decisions could easily be disguised as decisions based on patient welfare. When physicians in Britain were forced to restrict access to health care because of rationing policies dictated by their national health plan, they reportedly rationalized them as in the best interests of the patient. Levinsky, *The Doctor's Master*, 311 NEW ENG. J. MED. 1573 (1984), reprinted in WILLIAM J. CURRAN ET AL., *HEALTH CARE LAW, FORENSIC SCIENCE, AND PUBLIC POLICY* 796-97 (4th ed. 1990).

¹⁴⁹ See *supra* text accompanying notes 57-62 (discussing reasonable accommodation requirement).

¹⁵⁰ 832 F. Supp. 1022, 1027 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). Although other cases have considered the relevance of a patient's disability to treatment decisions about noncritical care, none has addressed the question in the context of life-extending care.

anencephalic baby be given the same treatment that would be given to babies without anencephaly.¹⁵¹

The *Baby K* trial court's assumption that disability must be ignored may have been shared by the Second Circuit. In its *University Hospital* opinion, that court stated that "[S]ection 504 prohibits discrimination . . . where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question."¹⁵² This language gives the impression that it is presumptively improper to take disability into account when the treatment is unrelated to the disability.

The federal government took a similar view of end-of-life judgments about quality of life when it responded to the highly publicized Oregon Medicaid plan.¹⁵³ Oregon proposed to rank treatments in descending priority in order to determine which treatments would be funded by its Medicaid plan. The Department of Health and Human Services objected to the ranking scheme because the ranking methodology considered patient's quality of life.¹⁵⁴ Michael Astrue, who was the general counsel of the HHS at the time of Oregon's original application for Medicaid waivers, called Oregon's use of quality-of-life considerations "the most troubling element of the process."¹⁵⁵ "[T]he premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability," was, HHS concluded, "inconsistent with the ADA."¹⁵⁶

From this perspective, quality-of-life judgments are morally improper, susceptible to abuse, and prohibited outright by the antidiscrimination laws. Because quality of life is an improper consideration, its use should be barred not only by physicians and hospitals, but by all other actors governed by the antidiscrimination laws, including state courts, court-appointed guardians, state executive agencies, and state legislatures. Indeed, the most forceful critics of quality-of-life judgments would also bar families from taking quality of life into account.¹⁵⁷

¹⁵¹ *Id.* at 1028, 1029. The Fourth Circuit did not review the trial court's conclusions when it affirmed the decision on other grounds. See *In re Baby K*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994) (affirming the trial court ruling on the basis of the Emergency Medical Treatment and Active Labor Act).

¹⁵² 729 F.2d 144, 156 (2d Cir. 1984).

¹⁵³ For a brief summary of the disability rights issues raised by the Oregon plan, see Peters, *supra* note 106, at 502-05.

¹⁵⁴ Sullivan Letter, *supra* note 104, at 409. Oregon denied that it had violated the ADA, but nonetheless made the changes requested by the federal government. OREGON HEALTH SERVS. COMM'N, *PRIORITIZATION OF HEALTH SERVICES: A REPORT TO THE GOVERNOR AND LEGISLATURE* 9 (1993); Peters, *supra* note 106, at 504 (describing the negotiations).

¹⁵⁵ Michael J. Astrue, *Pseudoscience and the Law: The Case of the Oregon Medicaid Rationing Experiment*, 9 *ISSUES L. & MED.* 375, 381 (1994).

¹⁵⁶ Sullivan Letter, *supra* note 104, at 410.

¹⁵⁷ See *supra* text accompanying notes 64-68; cf. Bopp & Avila, *supra* note 39.

2. *Patients and Families, Rather than Physicians, Should Make These Judgments.*—In addition to a frontal attack on all quality-of-life judgments, patients and their families can also mount a more narrow challenge to physician futility judgments. Given the subjectivity of quality-of-life judgments, patients and families can reasonably argue that physicians should defer to them regarding the adequacy of the patient's quality of life. The argument is especially powerful when the patients themselves have concluded that aggressive treatment would be beneficial.

On first examination, this appears to be an argument for protecting patient and family autonomy, not one raising issues addressed by the antidiscrimination laws. In fact, however, the question of standing has a plausible place in antidiscrimination analysis. Under the disability rights laws, a patient's disability may only form the basis for an unfavorable treatment decision if taking the disability into account is necessary or essential to the program that does so. In the context of bedside futility disputes, the dispositive question, therefore, is whether quality-of-life judgments are necessary or essential for the practice of medicine. Physicians arguably have no need to make these judgments when patients or their families are available to do so.

An analogous issue arose under Title VII when employers argued that women could be excluded from dangerous jobs for their own safety. In *Dothard v. Rawlinson*, for example, a state had excluded women from certain jobs in a male maximum-security penitentiary.¹⁵⁸ The Court permitted this practice because the employment of females for this job would have presented a threat to prison security and to the safety of others. But the Court strongly suggested that this discrimination would not have been proper if the only people endangered were the female guards.¹⁵⁹ “[I]t is the purpose of Title VII,” the Court suggested, “to allow the individual woman to make that choice for herself.”¹⁶⁰ Later, in *International Union, UAW v. Johnson Controls, Inc.*¹⁶¹ the Court repeated this admonition, emphasizing that “danger to a woman herself does not justify discrimination.”¹⁶²

By analogy, critics of physician futility judgments can assert that patients with disabilities ought to be permitted to decide for themselves whether their quality of life justifies withholding life-sustaining care. Physicians, like employers, should accept their patients' decisions even if that means providing care that the physicians would not

¹⁵⁸ 433 U.S. 321, 335-36 (1977).

¹⁵⁹ *Id.* at 335 (“In the usual case, the argument that a particular job is too dangerous for women may appropriately be met by the rejoinder that it is the purpose of Title VII to allow the individual woman to make that choice for herself.”).

¹⁶⁰ *Id.*

¹⁶¹ 499 U.S. 187 (1991).

¹⁶² *Id.* at 202.

wish for themselves.¹⁶³ Title III of the ADA is consistent with this contention. It permits public accommodations to exclude disabled individuals who pose "a direct threat to the health or safety of others,"¹⁶⁴ but it says nothing about the exclusion of disabled persons for their *own* well-being. According to this reading of the antidiscrimination laws, patients, not physicians, should decide when life-sustaining treatment would advance their welfare.

B. *The Opposing View: Physicians Must Consider Quality of Life*

Juxtaposed against these arguments for barring quality-of-life judgments by health care providers is the viewpoint that quality of life matters and that physicians have an obligation, both as independent moral agents and as fiduciaries, to opt out of treatments that they reasonably perceive to be cruel or pointless.

1. *Quality of Life is a Proper Consideration.*—Medical ethicists widely agree that quality of life is relevant to end-of-life treatment decisions.¹⁶⁵ From this perspective, decisions about life-sustaining care would be tragically uninformed if a patient's quality of life were ignored. Patients in advanced, extremely painful stages of terminal cancer, in vegetative states, or with painful birth defects like Tay-Sachs disease will sometimes be better served by foregoing aggressive or invasive life-sustaining care. As Richard McCormick once explained, every person is of equal value, but not every life.¹⁶⁶ Competent patients prove this point on a daily basis through their decisions to decline life-sustaining care and their execution of advance directives. Because quality of life matters, ignoring it would leave an im-

¹⁶³ Physicians would remain free, of course, to differ with patients about nondiscriminatory matters, such as whether the treatment in fact works.

¹⁶⁴ 42 U.S.C. § 12182(b)(3) (1994) (emphasis added); *accord* 28 C.F.R. § 36.208 (1995). The rules governing employment discrimination are more unclear because the statute speaks only of harm to others, but the regulations include harm to the employee. *Compare* 42 U.S.C. § 12111(3) (1994) *with* 29 C.F.R. § 1630.2(f) (1995).

¹⁶⁵ *See, e.g.,* BEAUCHAMP & CHILDRESS, *supra* note 8, at 215-19; PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICAL AND BIOMEDICAL AND BEHAVIOR RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS* 218-19 (1983); James Drane & John Coulehan, *The Best-Interest Standard: Surrogate Decision Making and Quality of Life*, 6 J. CLINICAL ETHICS 20, 22-23 (1995); Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283 (1985). Even some conservative commentators appear to tolerate consideration of a patient's overall interests in the most compelling cases. *See, e.g.,* PAUL RAMSEY, *ETHICS AT THE EDGE OF LIFE* 191-93, 212-16 (1978) (discussing Tay-Sachs, Lesch-Nyhan disease, and anencephaly, respectively). For a review and critique of the ethical literature, see Crossley, *supra* note 36, at 1622-27; Philip G. Peters, Jr., *The State's Interest in the Preservation of Life: From Quinlan to Cruzan*, 50 OHIO ST. L.J. 891, 946-50 (1989).

¹⁶⁶ McCormick, *supra* note 146, at 35.

poverished and inaccurate assessment of a patient's genuine interests in further treatment.

For this reason, most states permit surrogates to take quality of life into account.¹⁶⁷ Others do so without admitting it.¹⁶⁸ For example, in *Brophy v. New England Sinai Hospital*, Judge Liacos disclaimed the use of quality-of-life considerations even as he relied on them in balancing the state's interests against Mr. Brophy's.¹⁶⁹ And in the New Jersey case *In re Jobses*, Judge Pollock, in a concurring opinion, objected to the use of quality-of-life considerations, but then disingenuously permitted the withholding of life-sustaining treatment from a woman in a persistent vegetative state on the ground that treatment was merely forestalling her inevitable death.¹⁷⁰ Patients, families, and judges take quality of life into account because it matters.¹⁷¹ Without question, current social norms permit consideration of quality of life, at least by patients, their surrogates, and the courts that supervise them.

Even critics of quality-of-life judgments have unwittingly acknowledged the relevance of quality of life. They have done so by acknowledging that the burden imposed by a treatment (rather than by a disability) is a relevant consideration.¹⁷² Yet, the burden imposed

¹⁶⁷ 1 MEISEL, *supra* note 64, at 383-88, 416-25. When evidence of patient preferences is inadequate to make a decision on that basis, most (but not all) courts permit the surrogate to base the decision on the patient's best interests. *Id.* at 402. Some courts reject best-interests decisions in name, but permit them in fact. *Id.* at 398-99. Only a few states insist that the patient have explicitly stated her preferences. *See, e.g., In re Mary O'Connor*, 531 N.E.2d 607 (N.Y. 1988).

¹⁶⁸ *See* 1 MEISEL, *supra* note 64, at 398-99.

¹⁶⁹ 497 N.E.2d 626 (Mass. 1986).

¹⁷⁰ 529 A.2d 434 (N.J. 1987) (Pollock, J., concurring).

¹⁷¹ In fact, the Missouri durable power of attorney statute, which specifically disavows discrimination on the basis of disability, specifically permits decisions based on the patient's prognosis and the burdens and benefits of treatment. MO. REV. STAT. §§ 404.870, 404.822 (1994).

¹⁷² Bopp & Coleson, *supra* note 29, at 840 ("In considering the best interests of a child with a severe disability the benefits and burdens of treatment must be weighed, not the quality of life of a patient."); Edward R. Grant, *Medical Futility: Legal and Ethical Aspects*, 20 LAW MED. & HEALTH CARE 330 (1992). In Grant's view, all life is presumed to be equally compelling, but in some cases the burden of treatment may outweigh the benefit of life. *Id.* at 333.

This distinction was initially suggested two decades ago by the noted ethicist, Paul Ramsey, as a way of limiting the instances in which families ought to be permitted to decline life-extending care. RAMSEY, *supra* note 165, at 180-81. It reappeared in the Missouri Supreme Court's decision in the case of Nancy Cruzan and in the well-known case of Joseph Saikewicz. *Cruzan v. Harmon*, 760 S.W.2d 408, 423-24 (Mo. 1988) (en banc), *aff'd*, 110 S. Ct. 2841 (1990); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 433 (Mass. 1977) (permitting consideration of the patient's retardation only to the extent that it exacerbated the pain and disorientation of chemotherapy). The distinction has rhetorical appeal under the disability rights laws because it segregates treatment decisions based on the burdens of disability (prohibited) from decisions based on the burdens of treatment (permitted). However, as indicated in the text, the distinction lacks a normative foundation. As a result, it has not influenced the mainstream legal and ethical debate about the withholding of life-extending care and should not be adopted as a part of disability rights analysis. Indeed, even Missouri and Massachusetts have

by a life-sustaining treatment, like the burden imposed by a disability, is relevant only because it reduces the quality of life that the patient will have if life-extending efforts are made. Whether the burden is imposed by treatment or by disability, the same ultimate judgment must be made: will the patient enjoy a minimally acceptable quality of life if life-sustaining care is offered? By conceding that this question is a proper one when evaluating a burdensome treatment, critics of quality-of-life judgments have implicitly conceded that quality of life is a relevant consideration.

For all of these reasons, a powerful case can be made that quality of life is an ethically permissible consideration. Advocates of this position also can make a reasonable argument that it is a legally proper consideration as well. Both the ADA and Section 504 permit consideration of a patient's disability when it affects the patient's ability to meet "necessary" or "essential" eligibility criteria.¹⁷³ These provisions reflect congressional recognition that disability, unlike race, is sometimes relevant to a person's qualifications. Presumably, a patient who will not benefit from a disputed treatment cannot demonstrate that he is qualified to receive it.¹⁷⁴ Yet, a patient's capacity to benefit from life-sustaining care cannot be accurately determined without taking into account the quality of life that the patient will enjoy if treatment is offered. The opinion in *Baby K* completely overlooked this fact

begun to retreat from it. See *Murphy v. Wheeler*, 858 S.W.2d 263 (Mo. Ct. App. 1993) (limiting *Cruzan* to vegetative patients in need of nutrition and hydration and permitting best interests assessments to be made for other patients); *Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626, 636 (Mass. 1986) (stating that it would ignore quality of life, but then permitting the withdrawal of tube feeding, a procedure that the trial court had determined was not highly invasive or painful, because the patient would have considered it "degrading and without human dignity").

¹⁷³ See *supra* text accompanying notes 49-56.

¹⁷⁴ Capacity to benefit is presumably a permissible eligibility criterion. See, e.g., *Majors v. Housing Auth.*, 652 F.2d 454, 457-58 (5th Cir. 1981) (holding that a woman with a mental disability who required a dog was capable of enjoying the full benefit of public housing); *Camenish v. University of Tex.*, 616 F.2d 127, 133 (5th Cir. 1980), *vacated as moot*, 451 U.S. 390 (1981) (finding that a deaf student could perform well, unlike the student in *Davis* who would not realize the principal benefits of nursing school); *Easley v. Easley v. Snider*, 841 F. Supp. 668, 673 (E.D. Pa. 1993) (requiring a state to show that persons excluded are "incapable of experiencing the benefit" targeted by a state program of attendant care), *rev'd*, 36 F.3d 297 (3d Cir. 1994); *Glanz v. Vernick*, 756 F. Supp. 632, 638 (D. Mass. 1991) (ruling that an HIV-infected patient's ability to benefit from ear surgery would determine his qualifications); U.S. COMM'N ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES 115 (1983) (noting that capability of benefitting is one standard used). See also *Douglas J. Besharov & Jessica D. Silver, Rationing Access to Advanced Medical Techniques*, 8 J. LEG. MED. 507, 529 (1987) ("A good argument can be made that anyone who can benefit from a heart transplant under purely medical criteria is otherwise qualified."); *Phillip G. Peters, Jr., Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 523 (1995) (discussing the notion of capacity to benefit and collecting cases); see also *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 655 (1986) (White, J., dissenting) (arguing that a patient who "would benefit from" treatment is "thus otherwise qualified").

and, as a result, mistakenly assumed that the disability rights laws precluded consideration of Baby K's anencephaly.¹⁷⁵

Furthermore, Congress gave no hint that the ADA was meant to exclude quality-of-life judgments from end-of-life treatment decisions. That omission is telling because critics of quality-of-life judgments have tried for decades to outlaw their use.¹⁷⁶ Initially, opponents of quality-of-life judgments unsuccessfully asked state courts to bar families from making quality-of-life judgments when deciding whether to authorize life-sustaining care for loved ones. Most states rejected this suggestion.¹⁷⁷ Then, opponents of quality-of-life decisions attempted to use the federal disability rights laws to prevent families from withholding care from seriously ill newborns.¹⁷⁸ These efforts were defeated in a series of lawsuits culminating in the Supreme Court's decision in *Bowen v. American Hospital Association*.¹⁷⁹

Congress responded to the Baby Doe cases by enacting the Child Abuse Amendments of 1984.¹⁸⁰ Those amendments require states receiving federal financial child abuse grants to treat the withholding of life-sustaining care from newborns as child abuse unless (1) the child is comatose, (2) the treatment would merely prolong dying or be futile in terms of survival, or (3) the treatment would be both virtually futile and inhumane.¹⁸¹ The first and third of these circumstances clearly reflect quality-of-life judgments and the second may as well.¹⁸² Passage of this legislation revealed Congress's willingness to permit some quality-of-life judgments, as well as its ability to draft specific restrictions when deemed necessary. Against that history, it is noteworthy that Congress did not choose to extend these restrictions to older children and adults by placing similar restrictions in Section 504. Nor did Congress include these restrictions when it enacted the ADA in 1991.

It is possible, of course, that Congress left these restrictions out of the disability rights laws because it assumed that Section 504 (and later the ADA) would bar quality-of-life judgments by physicians, state courts, state-appointed guardians, social service agencies, and

¹⁷⁵ 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

¹⁷⁶ See Grant, *supra* note 172, at 330-31 (noting that the underlying issue remains the same); see also Bopp & Avila, *supra* note 39 (acknowledging that the issue is not new and suggesting that the ADA changed the legal landscape).

¹⁷⁷ See *supra* note 64.

¹⁷⁸ See *supra* text accompanying notes 65-67.

¹⁷⁹ 476 U.S. 610 (1986).

¹⁸⁰ These amendments were reportedly a compromise between those favoring and those opposing quality-of-life considerations. Capron, *supra* note 3, at 21.

¹⁸¹ Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-07 (1994); 45 C.F.R. § 1340 (1995).

¹⁸² See Weir, *Pediatric Ethics Committees: Ethical Advisers or Legal Watchdogs?*, 15 LAW MED. & HEALTH CARE 99, 103 (1987); see also NORMAN CANTOR, LEGAL FRONTIERS OF DEATH AND DYING 178-79 (1987).

other entities governed by the antidiscrimination laws. But this reading is inconsistent with a committee report on a predecessor of the ADA stating that "nothing in this legislation is intended to prohibit a physician from providing the most appropriate medical treatment in the physician's judgment."¹⁸³ More importantly, this reading is inconsistent with the historical setting against which the ADA was enacted in 1991—a setting in which state law commonly permitted anticipated quality of life to be taken into account at least by patients, surrogates, and the trial courts supervising them. Congress would surely have signaled its intention to bar state courts from taking quality of life into account. Yet, it did not.

From the perspective of those who favor quality-of-life judgments, the difficult question is not whether quality of life is a permissible consideration, but whether treating physicians are among the persons permitted to take it into account.

2. *Physicians as Moral Agents.*—In addition to the argument that quality of life is a relevant and legally proper consideration, physicians can also make a reasonable argument that they, like patients and families, should be permitted to consider it. Otherwise, they could be forced to render care that they perceive to be cruel or pointless. Advocates of granting physicians the autonomy to opt out of futile care correctly point out that physicians are independent moral agents.¹⁸⁴ Their consciences matter. Otherwise, as Judith Daar notes, they would be treated as mere "medical vending machines."¹⁸⁵ Forcing physicians to provide treatments that they perceive to be cruel or pointless would constitute a fundamental alteration in their practice of medicine. It would violate their ethical obligation to do no harm,¹⁸⁶ and it would default on their social responsibility to steward health care resources. For these reasons, physicians can argue that they have an independent responsibility to act and make recommendations consistent with patient welfare.

¹⁸³ S. REP. NO. 101-116, at 63 (1989) (Committee on Labor and Human Resources Report accompanying The Americans with Disabilities Act of 1989).

¹⁸⁴ See Daar, *supra* note 8, at 1245; John C. Fletcher, *The Baby K Case: Ethical and Legal Considerations of Disputes About Futility*, II BIOLAW S:219, S:227 (1994) (recognizing the moral agency of both physician and family); E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33, 37.

¹⁸⁵ Daar, *supra* note 8, at 1245 (quoting Lawrence J. Nelson & Robert M. Nelson, *Ethics and the Provision of Futile, Harmful, or Burdensome Treatment to Children*, 20 CRITICAL CARE MED. 427 (1992)).

¹⁸⁶ See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 8, at 214 (stating that it is unjustified for clinicians to treat against a patient's best interests); FURROW, *HEALTH LAW*, *supra* note 133, at 767 (noting ethical obligation to treat patients with dignity); Miles, *supra* note 16, at 311.

Furthermore, a prohibition on quality-of-life considerations could interfere with communications between providers and patients.¹⁸⁷ If, as some have suggested,¹⁸⁸ advice to patients that takes the extent of their disability into account could constitute a violation of the antidiscrimination laws, then physicians would no longer be able to reveal their honest opinions about future treatment to families without fear of potential civil rights liability. Yet, open communication between patient (or family) and provider is a necessary and essential component of this fiduciary relationship.

This argument does not suggest that physicians have greater standing than patients or their families to decide whether a patient would benefit from aggressive care. However, it insists that physicians have a moral stake as well. From this perspective, obliging physicians to provide treatment that they believe to be cruel or pointless would fundamentally alter their role and, thus, is not required even as a reasonable accommodation to their disabled patients. Otherwise, the disability rights laws would force physicians to provide life-sustaining care to suffering patients like Baby Rena (an eighteen-month-old dying of AIDS),¹⁸⁹ Baby L (a blind, deaf and quadriplegic two-year-old in pain),¹⁹⁰ and Jane Doe (a thirteen-year-old Georgia girl with an irreversible degenerative neurological disorder).¹⁹¹

C. Critique

When dissecting these competing viewpoints about physician quality-of-life judgments, several related questions must be kept in separate focus. The first is whether quality of life is a *per se* improper consideration. If so, all actors governed by the antidiscrimination laws would be prohibited from taking it into account. Such a prohibition would limit the discretion not only of physicians and hospitals, but also of state courts and court-appointed guardians. If quality of life is not a presumptively prohibited consideration, the next question is whether health care providers (as distinguished from families, guardians, or state courts) may permissively take quality of life into account. In effect, this is a standing question. The third question is what restrictions to place on health care providers who do have standing to consider patient quality of life. Such restrictions might include an obligation to defer to clearly proven patient wishes, an obligation to cooperate with the transfer of the patient to a provider who is sympathetic to the family's wishes, and a requirement that the physi-

¹⁸⁷ Cf. Daar, *supra* note 8, at 1245.

¹⁸⁸ Mary Crossley, *Infants with Anencephaly, the ADA, and the Child Abuse Amendments*, 11 ISSUES L. & MED. 379, 402-03 (1995-96).

¹⁸⁹ See *supra* text accompanying notes 26-28.

¹⁹⁰ See *supra* text accompanying note 33.

¹⁹¹ See *supra* text accompanying note 32.

cian's asserted beliefs about patient welfare be genuine and reasonable. In the pages that follow, each of these issues will be discussed.

1. *The Fundamental Value Conflict.*—Disputes between families of disabled patients who view life in any condition as a benefit and physicians who believe that life-extending care is not always a blessing arise out of a fundamental disagreement about the meaning and value of life. As medical ethicist Haavi Morreim observes, rational discourse cannot resolve this dispute.¹⁹² Yet, as she points out, choosing between these two viewpoints means compelling one side to abide by the moral choices of the other.¹⁹³

What role should the disability rights laws play in this conflict? On the one hand, Congress has chosen to limit physician freedom of action whenever exercising that freedom would produce improper disability-based discrimination. In this respect, the value choice has already been made. On the other hand, Congress has given remarkably little guidance for determining whether quality-of-life judgments result in the kind of discrimination that Congress meant to prohibit. Given the generality of the governing texts and the absence of legislative history to aid in interpreting the antidiscrimination laws, the courts have substantial discretion to apply them to futility cases as they see fit.

Reasonable people disagree about the relevance of quality of life. Given the difference of sincere and reasonable opinion over this fundamental matter and the absence of legislative guidance, courts should be reluctant to conclude that one of these two conflicting viewpoints violates public policy.¹⁹⁴ This caution is especially appropriate in light of the widespread judicial and social acceptance of quality-of-life judgments by surrogates making end-of-life treatment decisions. As a matter of legislative interpretation, therefore, there is insufficient basis for reading a total prohibition on quality-of-life judgments into the antidiscrimination laws. Indeed, it would be inconsistent with the Child Abuse Amendments of 1984, which contemplate some quality-of-life judgments.

Furthermore, as a matter of ethics and public policy, this resolution of the dispute would be too one-sided. Most obviously, it would draft reluctant physicians into the service of families who disagree with them. Physicians could not refuse to render treatments that they

¹⁹² Morreim, *supra* note 184, at 34.

¹⁹³ *Id.* at 33-36.

¹⁹⁴ My willingness to tolerate quality-of-life judgments may be influenced by my own belief that quality of life matters. In addition, I believe that the argument for prohibiting quality-of-life considerations altogether is weakened by disability rights advocates' acknowledgement that quality of life is relevant when a *treatment* (rather than a *disability*) imposes a burden on the patient. See *supra* text accompanying note 172.

believed to be cruel. Furthermore, if state courts are also barred from taking quality of life into account, providers could not seek a judicial ruling that the requested treatment is abusive. They could not even ask that the patient be transferred to another physician.¹⁹⁵ They might also be barred from letting quality of life play a role in their recommendations to families.¹⁹⁶ One can sympathize with the hopes of Baby K's mother for a miracle without believing that the disability rights laws permit her to conscript her physicians in this fashion.

Less obviously, but even more disturbingly, a blanket prohibition of quality-of-life considerations would apply to other actors, such as state courts, court-appointed guardians, and social service agencies, who routinely must make decisions about patient welfare.¹⁹⁷ When these individuals and agencies make decisions about a patient's best interests, they too would be obliged to ignore the patient's quality of life, even if there were no family member willing or available to make the decision¹⁹⁸ or if the family's wishes appeared to be contrary to the patient's interests.¹⁹⁹ Legislatures might be similarly barred from taking disability-related quality of life into account when drafting legislation to regulate death and dying. This would work a substantial and probably unintended change in the substantive law of surrogate decision making.

Given the absence of legislative guidance about quality-of-life judgments, the presence of reasonable disagreement on the issue, and the broad implications of a total prohibition, courts should not interpret the antidiscrimination laws to make disability-impaired quality of life a forbidden consideration. A blanket prohibition would be both too wide-reaching and too blunt. It would be too wide-reaching because it would not merely privilege families over physicians in futility disputes, but it would also prohibit courts, guardians and others from taking quality of life into account. It would be too blunt because it would ignore the consciences of physicians who believe that they are being asked to administer cruel or pointless treatments.

A more subtle solution to the futility disputes would be preferable, one which focuses more discretely on the dispute between physicians and families and which respects each party's values to the

¹⁹⁵ At least one medical commentator has erroneously assumed that transferability would moot the legal issues. Miles, *supra* note 16, at 312. While it may preclude a tort abandonment claim under some circumstances, a transfer motivated by antisdisability bias would be actionable under the ADA. See Glanz v. Vernick, 750 F. Supp. 39 (D. Mass. 1990).

¹⁹⁶ See *supra* note 188.

¹⁹⁷ If, as seems likely, state courts constitute an "instrumentality of a State," then Title II of the ADA applies to them. See 42 U.S.C. § 12131(1) (1994); see also *supra* note 40.

¹⁹⁸ See, e.g., Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); Crossley, *supra* note 8, at 186.

¹⁹⁹ See Bopp & Coleson, *supra* note 29, at 825-27 (describing the case of Baby Terry).

maximum extent possible.²⁰⁰ Such a solution should respect physicians' consciences while, at the same time, preserving for families the opportunity to seek the help of physicians who share their views about aggressive life support.²⁰¹

Before the contours of a compromise of this kind can be mapped, however, a preliminary question must be answered. Do physicians have standing under the antidiscrimination laws to take disability-impaired quality of life into account when patients or their families are available to make the treatment decision themselves?

2. *Standing to Consider Quality of Life.*—Before physicians may permissibly take a patient's disability into account, they must demonstrate that doing so is "necessary" or "essential" to their practice. Physicians will probably be able to make this showing when they genuinely believe that life-extending treatments requested by family members would be contrary to patient welfare. They will have far more difficulty doing so when the patient has personally requested the disputed life-sustaining treatment. In both circumstances, the physicians will have a more powerful claim for freedom of conscience when the treatment is reasonably perceived to be cruel than when it is merely believed to be pointless or wasteful.

a. *Conflicts with patients.*—Physicians will have difficulty establishing the requisite necessity when the patient has personally requested life-sustaining care. That is the lesson of the Title VII cases forbidding employers from excluding female employees from dangerous jobs. This interpretation of the antidiscrimination laws is also consistent with the provisions of the ADA, which specifically authorize consideration of any threat that a disabled patient poses to the safety of others, but do not specifically authorize efforts to protect a disabled person from dangers to himself. Furthermore, deference to the patient's assessment of his own interests would seem to constitute the kind of reasonable accommodation required by the antidiscrimination laws.

Still, a plausible argument can be made for respecting physician consciences. Physicians can point out that their position is different from that of employers who are barred from making paternalistic judgments on behalf of their female employees. Physicians, unlike those employers, could be forced to personally provide care that they believe to be cruel or harmful.²⁰² From their perspective, the more

²⁰⁰ Morreim, *supra* note 184, at 33.

²⁰¹ Daar, *supra* note 8; Morreim, *supra* note 184, at 38.

²⁰² The Supreme Court's Title VII analysis may also be distinguishable on other grounds. Most obviously, the Supreme Court's observations were made in the context of BFOQ analysis. Proving a BFOQ is harder than showing a business necessity. In addition, the Court was inter-

appropriate analogy is to the living will statutes²⁰³ and abortion legislation²⁰⁴ that permit physicians to opt out when patients demand care that would violate their moral convictions. Physicians can argue that the antidiscrimination laws should similarly respect their independent moral agency.²⁰⁵

Furthermore, protection of physicians' consciences would be consistent with state tort law. Under typical state common law, physicians need not honor requests for non-customary care.²⁰⁶ Indeed, on proper notice they may end their relationship with patients whose preferences regarding even customary care differ from their own.²⁰⁷ If patient and physician disagree about a course of treatment, each view is partially respected. Physicians can opt out, but may not make a unilateral decision to terminate care. Instead, the patient must be given reasonable notice and an opportunity to locate a provider who shares her views. In this way, tort law respects the views and consciences of both parties. Arguably, the antidiscrimination laws should strike a similar compromise when physicians resist treatments that they believe are contrary to patient interests.

In the context of the disability rights laws, however, the argument for freedom of conscience has a serious weakness when the patient has personally requested the disputed care. Although it is true that physicians will be more intimately affected than employers are if they are obliged to defer to patient wishes, it will be extraordinarily rare when a life-sustaining treatment personally requested by the patient will present a threat to the physician's moral compass on par with a request to perform an abortion or to let the patient die. In each of those other settings, physicians seek the freedom to opt out of conduct that they believe constitutes the killing of another human being. On the right set of facts, perhaps, a compelling case for freedom of conscience might be presented when a patient requests life-sustaining care, but these cases are likely to be too rare to dictate the shape of the antidiscrimination laws.

More typically, a physician's desire to opt out of life-sustaining treatments personally requested by the patient will be motivated by the belief that the requested treatment will confer little or no material

preting a statutory text requiring that eligibility criteria be related to ability to work. By contrast, the language governing eligibility criteria for medical services (necessary and essential) is more general and potentially places fewer restrictions on consideration of disability.

²⁰³ See *infra* note 213.

²⁰⁴ See Daar, *supra* note 8, at 1241-45 (collecting and discussing authorities).

²⁰⁵ If they adopt this view, courts interpreting the disability rights laws would have to conclude that it is necessary and essential for physicians to opt out of care that they do not believe will advance the welfare of their patients, even when the patient disagrees.

²⁰⁶ W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 32, at 189 (5th ed. 1984).

²⁰⁷ JOSEPH H. KING, JR., THE LAW OF MEDICAL MALPRACTICE 23 (2d ed. 1986).

benefit upon the patient and is, therefore, wasteful. The physician's conscience objection in these cases is more likely to arise out of concerns about the wise use of scarce resources than out of allegiance to the patient's welfare. As discussed later in Part V, decisions based on resource allocation concerns will sometimes be justified. But they raise additional issues that deserve separate consideration. To the extent that a physician's objection to "pointless" care is based solely on qualms about patient welfare, however, the argument for freedom of conscience is relatively weak.

b. Conflicts with families.—By contrast, the argument for physician standing is much stronger when the family, rather than the patient, has made the determination that aggressive life support is warranted. Assume, for example, that Mr. Wanglie had not known his wife's wishes. In that event, his own views about her welfare would be pitted against the views of her providers. Or assume that a parent insists on unrestricted treatment for her newborn. Unlike disputes between patients and providers, these conflicts are not about paternalism, but about the allocation of power between third parties who disagree about the patient's welfare. Under these circumstances, a stronger case can be made that a physician's freedom to challenge family decisions is a necessary and essential part of her fiduciary obligation to her patient, especially when the physician reasonably believes the requested treatment to be cruel, rather than merely pointless or wasteful. Although the physician's standing may not be equal in stature to that of the family and would not justify unilateral cessation of treatment without a court order, it seems sufficient to justify the physician's recusal from the case when she believes that the requested care would be cruel. In the language of disability rights laws, an obligation to render cruel treatment would fundamentally alter medical practice. As a result, it exceeds the requirement of reasonable accommodation.

The distinction proposed here between decisions made by patients and those made by families is consistent with the language of the regulations implementing the ADA. Those regulations authorize disabled patients to decline services that would otherwise be mandated by the ADA, but expressly refuse to authorize guardians or representatives of disabled persons to decline medical treatment.²⁰⁸ Although the regulations make this distinction in the context of family objections to life-sustaining care, rather than family requests for such care, they support the principle that patient preferences are entitled to greater deference than family wishes.

²⁰⁸ 28 C.F.R. § 35.130(e) (1995).

3. *Seeking a Better Accommodation.*—If physicians sometimes have standing to take quality of life into account, how is their use of this discretion to be monitored? Just as a complete prohibition on quality-of-life considerations would be too blunt a solution to the ethical dispute between families and physicians, so too is unfettered physician discretion. As Haavi Morreim has noted, this resolution would simply transfer the power to coerce from families to physicians.²⁰⁹ Without some further restriction on their conduct, physicians would be free under the antidiscrimination laws to protect their own consciences while ignoring the values of families who disagree. Not only would a family be unable to insist on aggressive treatment, but a physician would be free to cease treatment without giving advance notice to the family or offering them the opportunity to transfer the patient to another physician. Furthermore, physicians could not be challenged even if their judgments appeared to reflect patent bias, such as an unwillingness to treat patients with Down's Syndrome or AIDS as aggressively as other patients with similar prognoses.

Two kinds of limits on physician discretion are necessary. First, physicians should be obliged to cooperate with the transfer of the patient to a physician who shares the family's views. Second, even opting out of treatment should be prohibited when families can prove that this decision was not a good-faith medical judgment, but instead was motivated by improper bias.

a. *Notification of the family and cooperation with transfer.*—Because futility disputes arise out of a fundamental values conflict, Morreim suggests that an ideal solution would respect each actor's values to the maximum extent possible.²¹⁰ Using this reasoning, physicians should be permitted to opt out when families request treatments that physicians genuinely and reasonably perceive to be contrary to patient welfare, but they should not be permitted to force their own views on patients and their families. The same moral pluralism that supports the freedom of physicians to take quality of life into account, supports the family's freedom to seek like-minded health care providers. As a result, both Morreim and Judith Daar have recommended that physicians be permitted to opt out of the physician-patient relationship when futility conflicts of this kind arise, but not to unilaterally terminate care.²¹¹ Under this compromise, the family would remain free to seek the services of a physician or hospital that shares their evaluation of the patient's interests. In this way, the values of each disputant are protected without privileging one view entirely over the other. Morreim would also impose a duty upon

²⁰⁹ Morreim, *supra* note 184, at 33, 35.

²¹⁰ *Id.* at 33.

²¹¹ *Id.* at 38; Daar, *supra* note 8.

providers to give early notice to families of their personal convictions so that patients are not left stranded.²¹² As a matter of policy, this compromise has considerable intuitive appeal. By encouraging communication between physician and family it would also help ensure that any misunderstandings are cured and that, if possible, a mutually agreeable treatment plan is designed.

In addition, this "opting out" solution has some precedent in the state law doctrines governing the withholding of life-sustaining care and medical malpractice. State statutes governing living wills and health care surrogates, for example, commonly provide some protection for physicians or hospitals who have moral objections to the termination of life-sustaining care.²¹³ However, patients and their families remain free to transfer to other providers. Physicians who exercise their right to opt out are commonly required to cooperate or assist in transfer of the patient.²¹⁴

There is even some authority for this compromise when physicians, rather than families, believe that life-sustaining care should cease. Several states, as well as the U.S. Department of Veterans Affairs, have recently enacted statutes or regulations explicitly rejecting any obligation to render medically ineffective care.²¹⁵ In addition, under traditional tort law, physicians who disagree with a family's demands need only provide customary care. They are not obliged to offer every intervention that a family or patient demands.²¹⁶ Even that duty ends if the provider terminates the relationship with reason-

²¹² Morreim, *supra* note 184, at 38. Judith Daar later made the same suggestion about early notice. Judith F. Daar, *Medical Futility and Implications for Physician Autonomy*, 21 AM. J.L. & MED. 221, 239 (1995).

²¹³ See CHOICE IN DYING, INC., 1995 RIGHT-TO-DIE LAW DIGEST (Noncompliance Provisions in Living Will Statutes; Noncompliance Provisions in Statutes Authorizing Health Care Agents). When the question is not governed by a statute, the courts have split. Compare, e.g., Brophy v. New England Sinai Hosp., 497 N.E.2d 26 (Mass. 1986) (holding that a hospital does not have to participate in removing life-sustaining measures, but that it must assist in transferring a patient to a doctor who will) with Bouvia v. Superior Court, 225 Cal. Rptr. 297, 306 (Cal. Ct. App. 1986) (holding that hospital must follow patient's wishes to have life-sustaining measures discontinued).

²¹⁴ Daar, *supra* note 8, at 1277-80.

²¹⁵ Minnesota Living Will Act, MINN. STAT. § 145B.05 (1996) (stating that physicians are bound to comply with living will "within the limits of reasonable medical practice"); Health Care Decisions Act, VA. CODE ANN. § 54.1-2990 (Michie 1992) (declaring treatment not required if "medically or ethically inappropriate"). The Veterans Administration also concluded that treatments which "would not accord with prevailing medical practice . . . need not be presented for patient consideration." DEPARTMENT OF VETERANS AFFAIRS, VETERANS HEALTH ADMINISTRATION, 1993, MANUAL M-2, Clinical Affairs, pt. I, ch. 31, "Withholding and Withdrawal of Life-Sustaining Treatment," quoted in Bethany Spielman, *Futility and Bargaining Power*, 6 J. CLINICAL ETHICS 44, 49 (1995).

²¹⁶ See KEETON ET AL., *supra* note 206, § 32, at 185-89; KING, *supra* note 207, at 39-43 (discussing standard of care).

able notice.²¹⁷ As a result, allowing physicians to “opt out” of family requests for morally objectionable care has respectable precedent.

It is not entirely clear, however, that this compromise can be imposed using the disability rights. The most promising doctrinal vehicle for achieving this objective is the statutory requirement of reasonable accommodations. Under the ADA and Section 504, physicians who wish to take disability-impaired quality of life into account must make reasonable modifications of their policies and practices before concluding that a patient is ineligible for treatment. Conceivably, this reasonable modification requirement could be construed to require both notification of the patient’s family of the provider’s unwillingness to offer life-sustaining care and also cooperation with transfer of the patient.

This approach would require the courts to apply the reasonable accommodation requirement in a novel way. Ordinarily, reasonable accommodations must be offered to determine whether a disabled person can, with such accommodations, meet a program’s eligibility requirements.²¹⁸ If a disabled person cannot qualify for requested benefits, even with reasonable accommodations, then denial of those benefits (and of the accompanying accommodations) does not violate the antidiscrimination laws. In the futility cases, by contrast, notice and transfer would not qualify the disabled patient for treatment by the recalcitrant physician. Instead, this accommodation would enable the patient to receive treatment from another physician who shares the patient’s values. Viewed this way, a notice and transfer requirement seems analogous to requiring an employer to help an unqualified job applicant find a job elsewhere. To the extent that this analogy is fair, a notice and transfer requirement would make new law.

But the analogy is only superficially correct. The circumstances of futility disputes are quite different from those of employment discrimination disputes and of the other typical contexts in which disability discrimination issues arise. In disputes over life-sustaining care, the treating health care provider has control over the patient’s body and life. Given the physician’s control over the catastrophically ill patient and the finality of a unilateral cessation of treatment, the patient is far more dependent on the physician than a job applicant is on a potential employer. The rejected job applicant can look for another job; the patient whose life support is unilaterally withheld cannot look for another physician. Because of this difference, the reasonable accommodation requirement must be interpreted creatively in order to treat all parties fairly. Only with notice and the opportunity to trans-

²¹⁷ See, e.g., *Payton v. Weaver*, 182 Cal. Rptr. 225 (Cal. Ct. App. 1982) (holding that a doctor who gave sufficient notice could relinquish obligation to continue treatment of a woman with renal disease); KING, *supra* note 207, at 23-29.

²¹⁸ 42 U.S.C. § 12182(b)(2)(A)(ii) (1994) (“necessary to afford such . . . services”).

fer can the "rejected" patient look elsewhere for a provider whose criteria he can meet.

Courts should, therefore, require that physicians who wish to opt out of life-sustaining care cooperate with transfer of the patient,²¹⁹ unless they have obtained a judicial determination that the requested care would be abusive. This requirement will protect the patient's future options while only temporarily interfering with the physician's freedom. If courts are unwilling to employ the reasonable accommodations requirement in this novel way, then a statutory amendment will be needed to strike this compromise, unless state law is used to fill the gap.²²⁰

b. Placing a limit on biased decisions.—Patients should be permitted to prove that physician recalcitrance, ostensibly based on patient welfare, is actually explained by another, less defensible motive, such as an aversion to persons with the patient's disability. A refusal to provide CPR to a patient with advanced AIDS or one with a drug dependency might fall into this category. A recent study showing that AIDS patients are treated less aggressively than other patients with similar prognoses may reflect this kind of bias.²²¹ As a result, some judicial scrutiny of physician actions must be retained, even when the physician requests only to be replaced by another physician. Indeed, transfer of patients is one way that providers are alleged to act on their bias against patients with AIDS.²²²

²¹⁹ It is not clear whether the antidiscrimination laws could support an obligation to treat the patient if transfer were impossible. Arguably, the reasonable accommodation requirement mandates as much. On the other hand, the reasonable accommodation requirement has already been stretched quite far to encompass an obligation to assist in transfer of a patient whose anticipated treatment the provider believes to be cruel. Requiring treatment when transfer efforts fail seems to go beyond accommodation and effectively trumps the physician's claim of conscience. Indeed, the patient's inability to locate a physician who will provide life-sustaining care goes a long way to establishing the reasonableness of the recalcitrant physician's views. However, no firm conclusions can be drawn until we have some clinical experience with an "opt out" compromise and have a better sense of its actual consequences.

²²⁰ The hornbook law of malpractice is already nearly sufficient to play that role. Because reasonable notice is already required before a physician terminates her relationship with a patient, *see supra* text accompanying note 207, the only troubling shortcoming in traditional state law is the possibility that physicians would be permitted to forego life-extending care within an existing relationship if the treatment is not customary. *See supra* note 206. As yet, no reported decision has addressed this issue. As a result, state court imposition of a duty to offer non-customary life-sustaining care pending transfer is uncertain. Because the policy reasons behind a duty to cooperate with transfer are powerful, however, it is quite possible that state courts will impose it. However, because the question is currently unanswered as a matter of state law, federal courts can ensure a suitable balance between the rights of patients and physicians by imposing this obligation using the reasonable accommodations requirement.

²²¹ *See supra* note 107.

²²² *See, e.g., Glanz v. Vernick*, 750 F. Supp. 39 (D. Mass. 1990).

The difficult task, of course, will be to determine whether a physician's refusal to treat is based on beliefs that can be confidently characterized as biased or whether, instead, the refusal arises out of a genuine and reasonable disagreement with the family about the patient's welfare. Whenever the physician's views fall outside the range of reasonable disagreement about the harmfulness or cruelty of a requested treatment, a strong suspicion will arise that the decision was not motivated by a good faith belief about harm to the patient and instead reflects prejudice or ignorance. Searching for impermissible bias in these cases will require fact-finders to make hard decisions about provider motives.²²³

Applying this approach to medical treatment decisions, we might expect fact-finders to excuse a request to opt out of further resuscitative efforts for a suffering child like Baby Rena, but not to tolerate a refusal to perform an esophageal repair on a patient with Down's Syndrome. A refusal to repair this condition on a baby with Down's Syndrome appears to reflect distorted factual assumptions about the quality of life of persons with Down's Syndrome.²²⁴ For this reason, a court is likely to conclude that the decision to let the patient die falls outside of the range of reasonable disagreement about the harmfulness of treatment and, therefore, reflects impermissible bias. While judicial scrutiny of these cases will be difficult, some supervision seems necessary in order to avoid abuse of the latitude given to providers to opt out of treatment.

D. Synthesis

Courts should rule that quality of life is not a *per se* improper criterion for end-of-life decisions. However, physicians should be required to defer to clearly proven patient preferences. When the patient's actual wishes are unknown, as with newborns, physicians should be permitted to opt out of treatments they genuinely and reasonably believe to be cruel, even if they have based this conclusion on the anticipated quality of life. However, physicians should be required to inform families of their objections to further treatment and to cooperate with the transfer of the patient to a physician who shares

²²³ If this task proves too difficult, Congress will need to specify statutorily the permissible range of physician discretion, much as it has done with the Child Abuse Amendments. *See infra* text accompanying notes 258-59 (discussing the advantages and disadvantages of this approach). In the absence of such legislation, however, the courts could fashion a default rule similar to the one proposed in the text.

²²⁴ *See* BEAUCHAMP & CHILDRESS, *supra* note 8, at 218; E. Haavi Morreim, *Futilitarianism, Exoticare, and Coerced Altruism: The ADA Meets Its Limits*, 25 SETON HALL L. REV. 883, 897 (1995). Requiring that the physician's views fall within the range of reasonable disagreement is conceptually similar to the "respectable minority" rule of malpractice doctrine that exonerates physicians so long as they "pursue one of several recognized courses of treatment." Downer v. Veilleux, 322 A.2d 82, 87 (Me. 1974); KING, *supra* note 207, at 65-66.

the family's views. Furthermore, physicians should be denied the power to opt out of treatment when their decision reflects demonstrable bias on the basis of disability.

When physicians resist providing care because it would be pointless or wasteful, however, and not because they reasonably believe it will be harmful, they are asserting a justification more firmly rooted in concerns about the wise use of finite health care resources than in protection of patient welfare. Treatment decisions based on allocation concerns raise additional issues that are discussed in Part V.

V. ALLOCATING HEALTH CARE RESOURCES

At present, none of the litigated futility cases has produced an explicit claim that a requested treatment would simply not be a wise use of scarce resources. Yet, concerns about prudent resource allocation are surely part of the landscape against which these disputes arise. A recent study by Mildred Solomon revealed that physicians often use medical language like "futility" and "medically indicated" to mask value judgments about the adequacy of benefits provided by treatment.²²⁵ Also, Mark Hall has noted that futility decisions about CPR increasingly incorporate cost-effectiveness calculations.²²⁶

Indeed, the current climate of intense cost-consciousness surely helps to explain why futility cases are surfacing with increasing frequency.²²⁷ The national public debate in anticipation of the Clinton health plan reminded us all of the excessive costs and inadequate access that characterize our health care delivery system. In addition to this heightened consciousness about responsible stewardship of health care resources, the emergence of managed care organizations has given an increasing number of providers concrete financial incentives to reduce health care costs. Not surprisingly, providers are no longer as receptive to family requests for medical treatments of dubious benefit. Over time, these concerns can only become both more prevalent and more patent.

Allocation decisions based on the relative effectiveness of a requested treatment present potential disability rights issues whenever the treatment's ineffectiveness is associated with the patient's disability. A physician, for example, may feel that aggressive treatment for

²²⁵ Mildred Z. Solomon, *How Physicians Talk About Futility: Making Words Mean Too Many Things*, 21 J.L. MED. & ETHICS 231 (1993); see also S. Van McCrary et al., *Physicians' Quantitative Assessments of Medical Futility*, 5 J. CLINICAL ETHICS 100, 102 (1994) (noting that physicians consider lifesaving treatment to be futile if the odds of success fall below a cutoff point).

²²⁶ Hall, *supra* note 4, at 723-25 (collecting medical authorities).

²²⁷ See, e.g., John D. Lantos, *Futility Assessment and the Doctor-Patient Relationship*, 42 J. AM. GERIATRICS SOC'Y 868, 869 (1994) (linking prospective payment systems with the futility debate); Miles, *supra* note 22, at 514 (noting that Helga Wanglie received roughly \$700,000 in care "paid for by people who had not consented to underwrite [this] level of medical care").

premature babies is wasteful whenever the patient's disabilities are so severe that any extension of life, even if arguably beneficial, will be brief and unpleasant. For the same reason, a transplantation team might refuse to allocate organs to patients with disabilities like pulmonary disease, cancer, or retardation because these conditions significantly reduce the odds that the transplant will succeed.²²⁸

In one respect, the disability rights issues raised by these rationing practices are similar to those raised by the treatment decisions discussed in Part IV. In each context, a disabled patient is denied life-sustaining care because her physicians believe that her disability makes the extension of her life either less likely or less beneficial than it would otherwise be. In each context, courts must determine whether the disability rights laws permit health care providers to consider the impact of patient disability on treatment effectiveness. However, a number of additional considerations surface when access to life-sustaining medical care is resisted, not because it would be contrary to patient welfare, but because it would be a poor use of resources. Most obviously, the underlying justification for opting out is different and requires its own defense. In addition, the range of cases in which patients might be disfavored by their disability is far broader. It is broader because the rationing of relatively ineffective care could mean the denial of access not only to treatments that are perceived to be positively harmful, but also to treatments that the provider perceives to be pointless and even to treatments that are admittedly beneficial, as evidenced by the example of organ transplantation in the preceding paragraph. Finally, the shift in objectives has implications for the allocation of decision-making authority. Neither patients nor physicians have so obvious a claim to protection of their personal values when the underlying goal is stewardship of collective resources, rather than protection of patient welfare.

Thus far, no court has considered the additional issues raised when a provider resists giving life-sustaining care because it would be a poor use of resources.²²⁹ However, the Bush and Clinton Adminis-

²²⁸ See *supra* text accompanying note 35.

²²⁹ In none of the reported bedside futility cases litigated in the U.S. thus far has the provider or insurer explicitly raised the question of wise resource allocation in court. The judicial focus has been upon the competency of surrogate decision makers and the interests of the patient. See *supra* notes 2-4; *supra* text accompanying notes 26-33. However, a court in the United Kingdom reportedly ruled in 1992 that a London hospital could withhold life support from a severely brain-damaged eighteen-month-old child on the ground that it had "too few resources to treat all the patients whom they would like to treat." *Re J [A Minor][Medical Treatment]* (C.A. 10 June 1992), quoted in Ross Kessel, *British Judges Cannot Order Doctors to Treat*, HASTINGS CENTER REP., July-Aug. 1992, at 3-4.

Although American courts have not addressed the disability rights implications of bedside treatment decisions, they have sometimes relied on resource limits as a basis for permitting private and governmental benefits plans to selectively assist specific disabilities. See *supra* note 119

trations objected when Oregon proposed an experimental Medicaid plan that considered patient quality of life.²³⁰ Although Oregon denied that the plan discriminated improperly against patients with disabilities, it modified the plan as requested to obtain prompt federal approval of its novel Medicaid plan. As a result, no judicial analysis of the additional issues raised by allocation decisions has yet been undertaken.

This Part first considers the circumstances in which rationers should be permitted to consider the impact of disability on treatment effectiveness. After concluding that quality of life is a permissible consideration, but only if confined within narrow limits, the text then considers the circumstances in which physicians have sufficient standing to make bedside allocation decisions that take disability into account.

A. Efficiency and the Disability Rights Laws

As Mark Hall notes, rationing decisions involve a "fundamental and unresolved tension" between allocating resources to those with the most to gain and distributing resources without regard to disability.²³¹ On one side of the debate are those who believe that scarce health care resources should be allocated where they will do the most good. Health economist David Hadorn, for example, emphasizes the wisdom of minimizing human suffering as much as available resources permit.²³² He and many other commentators have concluded that society legally can and ethically should consider the effectiveness of medical treatment, even when disability-based classifications result.²³³ Allocations that fail to take the effectiveness of a treatment into account would, under this view, grossly misallocate resources toward life-extending care of dubious benefit. Irrational and unaffordable health care would result.

(collecting cases). However, unlike the bedside futility disputes, none of the plans at issue in those cases denied access to life-sustaining care based on quality of life.

²³⁰ See Sullivan Letter, *supra* note 104; Peters, *supra* note 106, at 502-03 (describing the negotiations between Oregon and the federal government).

²³¹ Hall, *supra* note 4, at 711.

²³² Hadorn, *supra* note 93, at 2225; see also Alan Williams, *Economics of Coronary Artery Bypass Grafting*, 291 BRIT. MED. J. 326, 328-29 (1985) (arguing for redeployment of resources such that benefits "are high in relation to costs").

²³³ LARRY R. CHURCHILL, RATIONING HEALTH CARE IN AMERICA 95, 121-25 (1987); Hadorn, *supra* note 93, at 1454, 1547; Paul T. Menzel, *Some Ethical Costs of Rationing*, 20 LAW MED. & HEALTH CARE 57 (1992); Karen J. Merrikin & Thomas D. Overcast, *Patient Selection for Heart Transplantation: When Is a Discriminating Choice Discrimination?*, 10 J. HEALTH POL. POL'Y & L. 7, 15-18 (1985) (concluding that disabled candidates may be excluded if they are "unable to benefit" or have "[no] reasonable chance of a successful clinical outcome"); Orentlicher, *supra* note 35, at 312 (endorsing likelihood, duration, and degree of benefit); Steven A. Toms, *Outcome Predictors in the Early Withdrawal of Life Support: Issues of Justice and Allocation for the Severely Brain Injured*, 4 J. CLINICAL ETHICS 206, 210 (1993).

On the other side of the debate are egalitarians who contend that relative medical effectiveness is not a morally sufficient basis for treating one patient differently from another.²³⁴ For them, the susceptibility of a patient's condition to successful therapy simply does not reflect the patient's virtue, merit, or worth.²³⁵ That a person's disability deprives her of an equally promising prognosis is tragic enough without compounding that misfortune by denying equal access to potentially beneficial medical care. Containing costs by singling out these patients is, therefore, improper.²³⁶

The tension between these two views is illustrated in the third edition of Beauchamp and Childress' classic treatise on bioethics. The text first endorses a "fair opportunity" principle requiring equal distribution of social benefits unless the differences are ones for which the affected persons are responsible. Yet, it later accepts as an "unargued premise" that it is "morally imperative" to take medical utility into account in an effort to "save as many lives as possible through the available resources."²³⁷

This conflict between efficiency and equality colors all efficiency-based rationing decisions, but it is much less pronounced when quantitative, rather than qualitative, measures of treatment effectiveness are used.²³⁸ Like Beauchamp and Childress, other scholars who object in

²³⁴ See, e.g., ROBERT M. VEATCH, *THE FOUNDATIONS OF JUSTICE* 138-45 (1986) (arguing for equality in resource allocation); Jerry Avorn, *Benefit and Cost Analysis in Geriatric Care: Turning Age Discrimination into Health Policy*, 310 *NEW ENG. J. MED.* 1294 (1984); John Harris, *QALYfying the Value of Life*, 13 *J. MED. ETHICS* 117, 120, 122 (1987) (arguing that life expectancy is irrelevant); John Harris, *Unprincipled QALYs: A Response to Cubbon*, 17 *J. MED. ETHICS* 185 (1991) (objecting to both life expectancy and quality of life considerations); Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 *AM. J.L. & MED.* 15, 29 (1992); see also Dan W. Brock, *Ethical Issues in Recipient Selection for Organ Transplantation*, in *ORGAN SUBSTITUTION TECHNOLOGY: ETHICAL, LEGAL, AND PUBLIC POLICY ISSUES* 86, 93 (Deborah Mathieu ed., 1988) (describing the arguments for an equal chance or lottery to ration scarce organs).

²³⁵ See Harris, *QALYfying the Value of Life*, *supra* note 234, at 121.

²³⁶ See Morreim, *supra* note 224, at 887 (describing this view).

²³⁷ BEAUCHAMP & CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 270-72, 296-97 (3d ed. 1989).

²³⁸ Quantitative measures of treatment effectiveness are less controversial than quality-of-life assessments because they do not treat the lives of disabled persons as less valuable. As with patient welfare decisions, however, rationing based on quantitative factors can raise discrimination issues of its own. From a strong egalitarian perspective, factors like the odds of success should not be used when the result is to disfavor persons with disabilities. That could occur, for example, when a patient with schizophrenia is excluded from a heart transplantation program. See Orentlicher, *supra* note 50, at 57. Egalitarians dislike exclusions of this kind because the patient's poor odds do not reflect the person's worth, merit, or need. Harris, *QALYfying the Value of Life*, *supra* note 234, at 117, 121. David Orentlicher cogently argues that poor outcomes may be the product of a biased allocation of research funding and interest. Orentlicher, *supra* note 50, at 66-71. Nevertheless, even egalitarian scholars seem to have conceded that a point can be reached when the odds of success are too low to justify the cost. See *infra* text accompanying notes 239-40. And the federal government has apparently permitted Oregon to take odds into

principle to allocations based upon efficiency have, nonetheless, conceded that treatments which rarely work²³⁹ or provide only brief relief at high cost need not be provided, even if the result is to disfavor some patients on the basis of their disabilities.²⁴⁰ Otherwise, potentially limitless resources would have to be committed to nearly hopeless care. To this extent, these egalitarian critics of utilitarian rationing schemes have conceded that efficient use of available resources is, at least at the extremes, a legitimate objective. This concession disappears, however, when qualitative, rather than quantitative, measurements are used to allocate life-sustaining care.²⁴¹

The objection to qualitative rationing of life-sustaining care is that it devalues the lives of patients with severe disabilities.²⁴² This, of course, is the same objection raised against qualitative futility judgments purportedly based on patient welfare (discussed above in Part IV). On one level, therefore, qualitative rationing decisions present the same substantive issue. When the treatment decision is based on resource allocation considerations, however, rather than protecting patient welfare, a number of additional considerations deserve attention as well.

account in its Medicaid plan. See Peters, *supra* note 106, at 522-23. As a legal matter, however, the issue remains unresolved. For a more extended discussion of the issue, see Orentlicher, *supra* note 50, at 58, 71-74; Peters, *supra* note 106, at 517-33.

Even if quantitative considerations are deemed permissible, other disability rights issues will remain. For example, the rationing decision must not be based on unfounded, stereotypical assumptions about the outcomes of patients with disabilities. Less obviously, David Orentlicher has suggested that the reasonable accommodations requirement restricts the use of effectiveness data to situations where the expected benefit is "minimal" and the cost of the treatment would be "high." Orentlicher, *supra* note 50, at 72-73. His proposal is a logical corollary of the idea, noted above, that discrimination should be tolerated only at the extremes. Although most futility cases are likely to lie at this extreme, a discrimination claim may lie in the case that does not.

²³⁹ See Robert M. Veatch, *Justice and Outcomes Research: The Ethical Limits*, 4 J. CLINICAL ETHICS 258 (1993) (concluding that rationing of marginally effective care is inevitable).

²⁴⁰ See Orentlicher, *supra* note 50, at 72 (stating that it is appropriate to ration care that fails to provide a reasonable minimum benefit and incurs a high "monetary" or "financial" cost).

²⁴¹ See, e.g., Letter from Timothy B. Flanagan, Assistant Attorney General, Office of Legal Counsel, U.S. Department of Justice, to Susan K. Zagame, Acting General Counsel, U.S. Department of Health and Human Services (Jan. 19, 1993), in 9 ISSUES L. & MED. 418 (1994); Attachment to Sullivan Letter, *supra* note 104, at 409, 410-12; James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?*, 68 NOTRE DAME L. REV. 581, 583-84, 615 (1993); Nancy K. Stade, Note, *The Use of Quality of Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV. 2010, 2017-20 (1993) (suggesting that quality of life considerations violate the ADA, but recommending that the statute be amended to permit their use). This was one basis of the Federal Government's objection to the Oregon rationing plan. Sullivan Letter, *supra* note 104, at 409; see also Peters, *supra* note 106, at 503-04.

²⁴² It is important to note, however, that no threat to the principle of equal worth arises when quality-enhancing, rather than life-saving care is rationed because no value needs to be placed on the patient's life. For a lengthier discussion of the distinction between quality-enhancing and life-sustaining care, see Peters, *supra* note 106, at 543-46.

First, rationing decisions do not purport to advance the affected patient's current interests. At most, they advance the patient's *ex ante* (and hypothetical) interests in affordable medical care. More concretely, these decisions advance the interests of other taxpayers and insurance subscribers in affordable and more rational medical care. The change in justifications is highly material. While I personally endorse the use of quality-of-life considerations to maximize the benefits obtained from finite health care resources, there is no societal consensus on this issue similar to that which supports the use of quality-of-life judgments to advance patient welfare. Although there is no legislative history to indicate that the efficient allocation of finite resources is an illegitimate goal,²⁴³ there is also none to suggest that Congress either endorsed health care allocations based upon treatment effectiveness or contemplated quality-of-life criteria as a means of allocating health care efficiently. Furthermore, the debate about rationing criteria is so fresh that we lack a robust body of ethical literature and popular experience from which to extrapolate sound legal doctrines.

Second, the use of quality-of-life considerations to make rationing decisions would greatly expand the circumstances in which disabled patients could be disfavored. Rationing decisions deny access not only to treatments believed to be contrary to patient welfare, but also to treatments believed by the provider (but not the patient) to be pointless and even to treatments likely to be beneficial. Beneficial treatments could be rationed, for example, because the benefit is small, the odds are long, or the cost is relatively high. As a result, patients who would probably benefit from a treatment could be denied access to it if the marginal benefit is believed to be exceeded by the cost. Likewise, naturally scarce resources like transplantable organs could be denied to severely disabled patients who stand to benefit from them on the theory that other patients would benefit more. Consequently, a quadriplegic patient with heart disease could be assigned a lower priority for organ transplantation than a heart patient without paralysis on the theory that treatment of the quadriplegic patient would produce less benefit.²⁴⁴ Because allocation decisions are

²⁴³ Programs that seek to allocate their available resources in a way that will maximize health outcomes can presumably prove that consideration of effectiveness is "necessary" or "essential" to achieve their objective. *See id.* at 517-20. The harder question is whether the objective of maximizing outcomes is itself sufficiently essential to justify disability-based classifications. *See id.* at 520-46. The uncertainties about this question explored in the text make judicial caution appropriate. For a more extended discussion of the issue in the context of health benefits plans, *see id.*

²⁴⁴ A corollary of this shift from protecting patient welfare to maximizing health benefits is that the value of saving one life must be *compared* with the value of saving another life. To say that one patient's life is less worth saving than another's seems different from saying that a particular life-sustaining therapy should be foregone because the patient will not benefit. Rationing pits life-saving care for one patient against life-saving care for another.

not limited to circumstances in which physicians and families disagree about the likelihood that the patient would benefit from treatment, they greatly expand the number of cases in which a disabled patient could be disfavored because of a poor quality of life.

Third, the financial savings likely to be obtained by supplementing quantitative measures of treatment effectiveness with qualitative ones are currently unknown.²⁴⁵ It is possible that most of the cases in which rationing based on quality of life could be successfully advocated already warrant rationing on some other basis that does not threaten the principle of equal worth (such as previously expressed patient preferences or low odds of success). If so, the cases that turn on qualitative criteria may not produce sufficient savings to justify the ethical and symbolic costs. Furthermore, there is no guarantee that the cost savings will be used to fund more cost-effective care or to make health care more affordable. As a result, reasonable accommodations might require that qualitative criteria be reserved for the clearest cases.²⁴⁶

Finally, the standing of physicians to act on their own values (and, thus, to take disability into account) is less obvious when the decision turns on the wastefulness of the expenditure rather than harm to the patient. When, for example, a patient or her insurer is willing to fund a requested treatment that the provider believes to be wasteful, the physician's claim of conscience lacks the power that it has when the provider seeks to opt out of personal participation in a life-extending treatment that she sincerely believes to be cruel.

Cumulatively, these concerns justify great caution when considering whether health care providers should be permitted to make full use of the greatly expanded range of quality-of-life judgments that rationing decisions could entail. However, these concerns must be balanced against the arguments that quality of life is relevant. Advocates of rationing based on quality-of-life considerations, including ethicist Paul Menzel and health economist David Hadorn, support the use of quality-of-life rankings to prioritize health decisions.²⁴⁷ From their

²⁴⁵ Although none of the existing medical studies examine the impact of quality of life considerations, several recent studies have found that cost savings from the rationing of borderline care would be less than might be expected. See, e.g., Alexander M. Capron, *Medical Futility: Strike Two*, HASTINGS CENTER REP., Sept.-Oct. 1994, at 42, 43 (reporting on a study of care offering a less than 1% chance of two-month survival); Ezekiel J. Emanuel & Linda L. Emanuel, *The Economics of Dying: The Illusion of Cost Savings at the End of Life*, 330 NEW ENG. J. MED. 540, 540-43 (1994).

²⁴⁶ Just as an employer must accept some lost economic benefit to result from its obligation to make reasonable accommodations, so too must a provider or health plan. See Orentlicher, *supra* note 50, at 75.

²⁴⁷ See, e.g., Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449, 1510 (1994) (suggesting that most people would want it to play more than a supplemental role); David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy*, HASTINGS

perspective, maximizing the health benefits obtained from available health care resources is a legitimate policy objective.²⁴⁸ Advancement of that objective requires consideration of the relative effectiveness of requested treatments. In the language of the disability rights laws, the effectiveness of a requested treatment is an "essential" or "necessary" eligibility criterion.

From this perspective, the effectiveness of a treatment can and should be measured not only by quantitative factors, such as the odds or duration of relief, but also by the magnitude of the benefit conferred. For example, the value to Barney Clark of Jarvik's artificial heart would be greatly exaggerated if his quality of life were ignored. Surely, a life-sustaining treatment that offers a month of pleasurable life is preferable to one that promises months of debilitating side effects.

The strongest evidence of this assumption is provided by the daily decisions of patients and their families to discontinue life-sustaining care. And if some life-extending care is reasonably perceived as contrary to patient interests, then surely some other life-extending treatments are nonbeneficial or barely beneficial. These treatments should receive lower priority than treatments that offer a better prognosis. Plausible candidates for the rationing axe might, therefore, include dialysis requests for vegetative patients,²⁴⁹ respirators for anencephalic babies like Baby K,²⁵⁰ or organ transplants for severely demented patients with multiple organ failure. If health care resources must be allocated to these treatments, then our money, organs, and other health care resources will be poorly used. At least at the extremes, there ought to be limits on the demands that patients and families can make to use collective resources. In this respect, genuine efforts to allocate health resources efficiently provide an even stronger justification for the denial of "pointless" or "nonbeneficial" care than concerns about patient welfare.²⁵¹

CENTER REP., May-June 1991, at Supp. 11; Hadorn, *supra* note 35, at 1455; Paul T. Menzel, *Oregon's Denial: Disabilities and Quality of Life*, HASTINGS CENTER REP., Nov.-Dec. 1992, at 21; see also Alexander M. Capron, *Oregon's Disability: Principles or Politics?*, HASTINGS CENTER REP., Nov.-Dec. 1992, at 18, 20 (suggesting that ranking on the basis of disability is permitted, but that exclusions based on disability are not).

²⁴⁸ For an elaboration of this point, see Peters, *supra* note 106, at 517-33.

²⁴⁹ Judith W. Ross, *The Puzzle of the Permanently Unconscious*, HASTINGS CENTER REP., May-June 1992, at 2, 3.

²⁵⁰ Her care reportedly cost \$246,000 between her birth on Oct. 13, 1992, and mid-June of 1993 for hospital care alone. She resided in a nursing home when not hospitalized. Jane B. Quinn, *Taking Back Health Care*, NEWSWEEK, June 27, 1994, at 36. Ellen Wright Clayton thoughtfully asks what we would do if Baby K had needed a heart transplant or dialysis. See Ellen W. Clayton, *Breathing for Baby K*, ASLME BRIEFINGS, No. 10, Summer 1994 at 1, 2. Baby K died in the spring of 1996 despite aggressive care.

²⁵¹ See *supra* text following note 207.

How are these two views to be reconciled? Given the serious concerns raised when quality of life is used to make end-of-life rationing decisions and the absence of either public consensus or congressional guidance, courts should not permit unrestricted consideration of patient quality of life. At the same time, the reasonability of arguments for taking quality of life into account in the most extreme cases suggests the need for some limited freedom to take quality of life into account. In those cases in which the benefits to be derived from treatment are most doubtful and the costs to be saved are substantial, the presumption that all life has equal value should yield to the goal of maximizing the health care benefits derived from finite resources. So limited, the use of qualitative rationing criteria can be squared with the statutory requirements that exclusionary eligibility criteria be essential and that reasonable accommodations be offered. In addition, the freedom to take quality of life into account in these limited circumstances should be limited to those physicians with a legitimate role as rationers, a subject considered further below,²⁵² and to opting out of treatment, rather than unilaterally withholding it.²⁵³

A number of different approaches could be used to define the most defensible cases for taking quality of life into account. Haavi Morreim, for example, has proposed a relatively narrow definition. She recommends adoption of the limits imposed by the Child Abuse Amendments of 1984 on treatment decisions for newborns.²⁵⁴ Under those rules, life support can only be withheld when a patient is chronically and irreversibly comatose, the treatment would be futile in terms of survival, or treatment would be virtually futile and inhumane.²⁵⁵

A slightly different definition would permit actors with legitimate rationing responsibility²⁵⁶ to opt out of all treatments which meet a test that I have previously suggested for rationing by health benefits plans. Under that limit, quality-of-life rationing would be permitted only when the patient's quality of life is so poor that doubt exists about the patient's interest in life-sustaining care, the patient's cognitive function is so severely impaired that the conscious benefits of living are unlikely to be significant, and finally, the anticipated costs of life-extending care are extraordinary.²⁵⁷ Applying this standard, courts and juries could conclude that refusal to provide dialysis to a

²⁵² See *infra* text accompanying notes 262-71.

²⁵³ Patients would, therefore, be free to fund the disputed care with their own resources, to appeal the rationing decision to their insurer, to seek other sources of financing, or to seek gratuitous services.

²⁵⁴ Morreim, *supra* note 224, at 924-25.

²⁵⁵ *Id.*

²⁵⁶ The extent to which physicians have a role as rationers is considered in subpart V.B.

²⁵⁷ Peters, *supra* note 106, at 541.

comatose patient is defensible, but that denying a quadriplegic or retarded patient access to organ transplantation is not.

Significantly, each of these approaches shares one important similarity. Each would allow the rationing of life-sustaining care only when the existence of any net benefit to the patient is seriously in doubt.²⁵⁸ Under these circumstances, the case for allowing quality-of-life judgments does not depend exclusively on the arguments in favor of efficiency. Instead, it overlaps and reinforces the arguments for permitting providers to opt out of treatments that they doubt will advance patient welfare.

As an alternative to these two relatively narrow exceptions to the prohibition on quality-of-life judgments, courts could conceivably endorse a more general and somewhat more permissive exception for all potentially life-sustaining treatments that providers genuinely and reasonably believe will confer no benefit upon the patient. As a matter of statutory interpretation, this more general restriction may be easier to defend as an interpretation of the existing antidiscrimination statutes than the approaches described above, which probably require congressional action.

Each of these approaches has its own advantages. Mimicking the Child Abuse Amendments would offer greater specificity and therefore more guidance to physicians, families, and courts than a rule which permits rationers to opt out of care they reasonably and genuinely believe to be non-beneficial. It would also coordinate the requirements imposed by the antidiscrimination statutes with those of the federal child abuse statute. On the other hand, the price of that specificity is a narrowness that focuses principally on easily identified categories of patients such as those who will die soon and those in a vegetative state. Such an approach inescapably excludes many cases in which providers may reasonably believe that aggressive life-support would be nonbeneficial.

A more general standard does, however, accentuate one risk. Physicians might claim that a treatment is non-beneficial when their true conviction is that the treatment is not worth the cost. The experience of the British with their National Health system suggests that physicians often convert even obvious rationing criteria, such as arbitrary age limits, into decisions about medical appropriateness.²⁵⁹ Hence, a physician's reluctance to treat Baby K or Baby Rena may be

²⁵⁸ See e.g., Elhauge, *supra* note 247, at 1540 (arguing that risk-adjusted premiums ought not reflect costs of "heroic measures that do no more than postpone death in an unconscious, painful, or temporary state near the end of life"); Ronald Dworkin, *Will Clinton's Plan Be Fair?*, N.Y. REV. BOOKS, Jan. 13, 1994, at 20, 23 (concluding that individuals would not desire insurance coverage for vegetative or demented states or care for the elderly that would extend life only a few months).

²⁵⁹ Levinsky, *supra* note 147, at 797.

more likely to be experienced by the physician as a decision based on patient welfare than one based entirely or even principally on cost-effectiveness.

Several factors could help to reduce this risk. First, the burden placed on physicians to prove the genuineness and reasonableness of their beliefs that the treatment is nonbeneficial should serve as a barrier against treatment decisions that are unduly based on inappropriate quality of life judgments.²⁶⁰ Second, the physician's obligation to provide patients and their families with notice and an opportunity to transfer to another physician will temper the dangers of overzealous rationing by subjecting provider decisions to public scrutiny.²⁶¹

Nevertheless, courts will understandably be reluctant to permit rationing decisions based on quality of life without clearer statutory authority. In addition to their concerns about administrability, they may reasonably conclude that any exceptions to the general prohibition on rationing decision based on quality-of-life judgments should be products of public and democratic processes. As a result, they are likely to wait for congressional guidance before permitting quality of life to be considered in those extreme cases in which the benefits are most dubious and the costs are substantive.

B. *Physician Standing to Ration*

Even if quality of life is a permissible rationing criterion, an individual physician should not be permitted to act on her own beliefs about wasteful care unless she occupies a legitimate role as rationer. If she does, however, she need not defer to patient views about an acceptable quality of life.

1. *The Physician's Role as Rationer.*—Absent responsibility to ration, health care providers cannot demonstrate that disability-based allocation decisions are necessary or essential to their practice.²⁶² The

²⁶⁰ Especially skeptical courts could even impose a clear and convincing evidence standard.

²⁶¹ See *supra* text accompanying notes 210-20. In addition, reasonable accommodations might include a right to appeal an adverse decision to others in the health insurance plan to assure fairness and consistency across the plan. Courts might even require that physicians demonstrate that an obligation to render treatments like the one in dispute would have a significant impact on patient access to more effective care or on health insurance premiums and thus would constitute an undue burden on the provider or plan. See Orentlicher, *supra* note 50, at 72 (suggesting that reasonable accommodations preclude disability-based decisions in health care unless the treatment would be very expensive and would not be minimally beneficial); see also EQUAL EMPLOYMENT OPPORTUNITY COMM'N, *supra* note 50.

²⁶² In addition, defensible rationing decisions will often require reliable data about the cost-effectiveness of the disputed treatment and an understanding of either the cost-effectiveness threshold established by available resources or the cost-effectiveness of other competing marginally effective treatments. But if, as proposed here, quality-of-life criteria can only be used to determine whether the treatment confers any benefit at all, the data problem is obviated considerably. Instead, the provider must show that his beliefs about minimal quality of life are genuine

wisdom of assigning rationing responsibilities to treating physicians is a complex, controversial, and evolving topic that cannot be thoroughly revisited here.²⁶³ But a few preliminary observations will suggest the contours of the dispute as it relates to the antidiscrimination laws. Physicians will most readily establish that it is “necessary” for them to make rationing decisions under the following circumstances: (1) when they have been expressly delegated the task of apportioning scarce resources by the benefits plans whose resources must be allocated, (2)

and fall with the range of reasonable disagreement. Survey or research data that examine disabled patients’ perceptions about their quality of life would be relevant in determining whether the physician’s beliefs are reasonable. See Peters, *supra* note 106, at nn.200-02.

²⁶³ As a general normative matter, physician rationing raises fundamental questions about the nature of the physician-patient relationship and the extent to which it can or should survive the “dual agency” that arises when physicians act as rationers. See, e.g., Marcia Angell, *The Doctor as Double Agent*, 3 KENNEDY INST. ETHICS J. 279 (1993); Paul T. Menzel, *Double Agency and the Ethics of Rationing Health Care: A Response to Marcia Angell*, 3 KENNEDY INST. ETHICS J. 287 (1993). See also COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AM. MED. ASS’N, *Ethical Issues in Managed Care*, 273 JAMA 330, 332, 334 (1995) (rejecting bedside rationing, but then fudging by limiting the objection to cost-benefit judgments that “go beyond” those made “as part of their normal professional responsibilities”); Hall, *supra* note 4. The conflict is especially acute when physicians are given financial incentives to contain costs by reducing utilization. See MARC A. RODWIN, *MEDICINE, MONEY AND MORALS: PHYSICIANS’ CONFLICTS OF INTEREST* (1993); Hall, *supra* note 4, at 758-76.

Yet, clinicians can individualize their allocation decision to the circumstances of individual patients far better than insurers can. As a result, they will have to play an important role in the rational allocation of health resources. See, e.g., Susan D. Goold & Howard Brody, *Rationing Decisions in Managed Care Settings: An Ethical Analysis*, in HEALTH CARE CRISIS? THE SEARCH FOR ANSWERS 135, 139 (Robert I. Misbin et al. eds., 1995); Hall, *supra* note 4, at 701-02; Miles, *supra* note 16, at 313; David Orentlicher, *Paying Physicians to Do Less: Financial Incentives to Limit Care*, 30 U. RICH. L. REV. 155 (1996). Indeed, physicians have always played a stewardship role to some extent. They routinely make unarticulated cost-benefit decisions when making determinations such as whether to order diagnostic tests, preventive screenings, referral to specialists, or hospitalization. If every treatment of conceivable benefit were ordered, as Mark Hall notes, we would all have whole body MRI scans regularly. Hall, *supra* note 4, at 723. Tort law recognizes this stewardship role by delegating determination of the standard of care to medical custom. KEETON ET AL., *supra* note 206, § 32, at 189 & nn.51-57. In fact, a few states have recently enacted legislation explicitly protecting physicians from liability for withholding “ethically inappropriate” or “medically ineffective” care. See *supra* note 215. On the other hand, there is much less reason to believe that an unstated consensus in favor of physician rationing in general supports physician decisions about a minimally adequate quality of life in particular.

Ultimately, a marriage between payors and providers may yield the most ideal rationing process. Insurers and government assistance plans not only have a better sense of current budget constraints than clinicians, but they may also be better positioned to consider customer or taxpayer preferences about the role that bedside rationing should play vis-à-vis other methods of controlling costs, including categorical exclusions of some kinds of coverage (such as dental, mental, or infertility care) and random allocations (such as first-come-first-served). They may also be better situated than practitioners to screen the many medical specialties in search of the most wasteful practices and to impose a relatively uniform threshold of cost-effectiveness across diverse areas of practice. In the long term, the respective strength of payors and providers could be combined. Clinicians could be given discretion to individualize within parameters set by public policy, government agencies, and organizations with access to defensible comparative data and public input.

when they themselves are the stakeholders, or (3) when they have the responsibility of allocating a naturally scarce commodity such as transplantable organs. By contrast, the physician's claim of standing is much weaker when the patient or her insurers are willing to pay for an available treatment and the physician, nonetheless, insists that the treatment is wasteful.

Under some circumstances, health plans will expressly delegate to physicians the task of bedside rationing. This is most likely to occur in a managed care setting where physicians may be expected to implement either specific guidelines or more general efficiency goals. When this occurs, the physician shares the standing of the benefits plan to use whatever eligibility criteria the plan is legally permitted to employ, even if the patient disagrees.²⁶⁴ Even traditional indemnity insurers delegate some of their coverage decisions to physicians when they limit their reimbursement obligations to "medically necessary" or "medically appropriate" care. Likewise, physicians responsible for the allocation of a naturally occurring shortage, such as transplantable organs or intensive care beds, should have standing to take effectiveness into account in legally permissible ways. For these groups of physicians, the difficult question is whether courts should insist that any delegation of decision-making authority specifically include authority to consider quality of life. Without it, courts may doubt that quality-of-life judgments are essential to the clinician's rationing responsibilities.

In other instances, physicians will be stakeholders themselves. Physicians paid by capitation, for example, must ration their own time and resources among their pool of patients;²⁶⁵ so, too, must clinicians who provide unreimbursed care for indigent patients. Under those circumstances, a physician seeking to maximize the health of her patient pool will take into account the probable effectiveness of treatment. She should be permitted to take disability into account to the extent otherwise permitted by the antidiscrimination laws.

The standing of physicians to make rationing decisions is far more tenuous when they are not allocating their own assets and have not been assigned such a role by the groups whose assets are being allocated. Imagine, for example, that the patient's insurer is willing to fund the requested life-sustaining care, as apparently occurred in the cases of Helga Wanglie and Baby K.²⁶⁶ In such cases, the plan has

²⁶⁴ For a discussion of the limits that the disability rights law impose on health benefits plans, see Crossley, *supra* note 8, Orentlicher, *supra* note 50, and Peters, *supra* note 106.

²⁶⁵ See Crossley, *supra* note 8, at 245-48 (noting that the captivated provider has a stronger case for arguing that a futility policy is necessary). As a stakeholder, providers would also have a plausible claim to qualify for the statutory provision which explicitly authorizes consideration of underwriting risks. 42 U.S.C § 12201(c)(2) (1994).

²⁶⁶ See *supra* text accompanying notes 22-25, 94-102.

already chosen the criteria it will employ to allocate its available resources and has determined that the disputed care meets those criteria. Under these circumstances, the physician's effort to trump the insurer's decision does not seem "essential" to his practice of medicine.²⁶⁷ In this setting, physicians who refuse to offer care that they perceive to be wasteful are actually attempting to conserve the resources of insurance plans that do not agree that their resources are being spent inappropriately. This is a far less powerful claim of conscience than providers can assert when they are asked to provide care that they genuinely and reasonably believe to be harmful.

Although physicians can still make plausible arguments for freedom to opt out, these arguments are not likely to be sufficient. For example, an individual physician can argue that she is an autonomous agent with her own conscience and sense of social responsibility.²⁶⁸ She can contend that she has a responsibility directly to other patients or subscribers to use her knowledge to identify especially cost-ineffective care on their behalf. She may, in some instances, be acting consistently with customs of her peers and, thus, drawing on the accumulated experience of her profession. If not, she may feel an obligation to help establish new and more responsible medical customs. From her perspective, she should be permitted to opt out of treatments that she reasonably and genuinely believes would not benefit her patient, even if her patient disagrees. However, courts are unlikely to accept these arguments in favor of physician autonomy. Under the antidiscrimination laws, a patient's disability cannot be considered unfavorably unless doing so is essential to achieving a program's objectives. When a health benefits plan is willing or contractually obliged to pay for a requested treatment and the patient believes it would be beneficial, the individual physician's rationing input is not essential.

²⁶⁷ *Accord* Crossley, *supra* note 8, at 245. Although there is neither legislative history nor caselaw applying this requirement to the identity of the rationer, it seems reasonable to postulate that a physician seeking to meet that burden will have to demonstrate not merely that rationing would advance a broad societal interest in maximizing the impact of health dollars, but further that bedside rationing by physicians of ineffective care is essential either to their role as treating physicians or to some other specific health care program of which they are an integral part.

This issue can also be couched as a failure to make reasonable modifications because elimination of disability-based decisions to ration under these circumstances arguably would not require a "fundamental" alteration of medical practice. *See* Southeastern Community College v. Davis, 442 U.S. 397, 407-14 (1979) (interpreting Section 504); *see also* 42 U.S.C. § 12131(2) (1994) (public services must make "reasonable modifications to rules, policies or practices"); 42 U.S.C. § 12182(b)(2)(A)(ii) (1994) (public accommodations must make reasonable modifications unless doing so would "fundamentally alter the nature of such services"); 28 C.F.R. § 35.130(b)(7) (1994) (excluding from the reasonable accommodation requirement changes that would "fundamentally alter the nature of the service").

²⁶⁸ *See supra* text accompanying notes 184-86.

2. *Deference to Patient Wishes.*—As discussed in Part IV, physicians who are motivated exclusively by concerns about their patient's well-being should ordinarily defer to the views of their patient regarding an acceptable quality of life. But when the physician making a determination of the patient's interests in further life-sustaining care is motivated by concerns about efficient resource allocation, the argument for deference to patient preferences is much less compelling.

When rationing decisions are being made, deference to patient wishes may not be warranted for two reasons. First, the disability rights laws permit government and private health benefits plans to determine the criteria by which they will allocate their available resources as long as those criteria do not violate the disability rights laws. As discussed earlier in this Part, a provider's refusal to fund treatments that are reasonably characterized as non-beneficial comports with those laws. Must a plan, nevertheless, defer to patients who disagree? Not if the plan is motivated by concerns about efficient resource use in addition to doubts about patient well-being. If protecting patient welfare were the only objective, deference to the patient's values would be appropriate. If, however, the plan is attempting to distribute pooled assets in a way that maximizes the benefits achieved, patients have a less powerful claim that their own subjective evaluation of benefits should trump those of the plan and its subscribers. Although patients should be free to use their own assets to purchase the treatments they desire, there are limits on the obligation of health care plans, their subscribers, and clinicians to fund every treatment that patients or their families desire. Those plans may reasonably decide not to fund life-sustaining treatments that their members do not believe are beneficial, even if individual subscribers disagree.

Second, patients who desire unlimited life-extending care have a patent conflict of interest. Patients and their families have an obvious incentive to disregard relative cost and effectiveness in favor of unrestricted access to resources, as evidenced by the families who have sought continued treatment for brain dead patients²⁶⁹ and dialysis for vegetative patients.²⁷⁰

Does this mean that physicians can ignore a patient's views about the value of additional life as long as they are genuinely motivated by concerns about wise resource use and their conclusions are reasonable? Yes, but only if the treating physician has a legitimate role as a rationer of health care resources and applies the rationing criteria even-handedly.²⁷¹

²⁶⁹ See Miles, *supra* note 22, at 512-19.

²⁷⁰ Ross, *supra* note 249, at 2, 3.

²⁷¹ Crossley, *supra* note 8, at 246 n.285 (stating that inconsistent application of effectiveness criteria may indicate bias).

To summarize, physicians who disagree with a patient's own assessment of the value of life-sustaining care will need to establish their standing to make rationing decisions before they may make rationing decisions that take disability into account. Physicians who are stakeholders or are assigned a rationing role by stakeholders may be able to make this showing. In the context of bedside rationing of life-sustaining care, these physicians would, therefore, be permitted to consider quality of life in those situations in which it is otherwise permissible, even if the patient disagrees. But the standing of individual physicians to act on their own consciences is far more doubtful.

VI. CONCLUSION

Application of the federal disability rights laws to medical treatment decisions is complex. On the one hand, a patient's disability will often seem a relevant and proper consideration. On the other hand, consideration of a patient's disability can put a disabled patient at a disadvantage whenever the patient's disability reduces the effectiveness of the requested treatment. Under these circumstances, the courts face the unenviable task of determining when disability may permissibly be taken into account.

This Article has examined this tension in the context of bedside futility judgments about life-sustaining care. It has focused exclusively on the use of quality-of-life judgments to make these treatment decisions. Although quantitative measures of treatment effectiveness, such as the odds of success, also raise serious disability rights issues, quality-of-life judgments are especially controversial because they implicitly assume that the value of life is reduced when the patient has a severe disability.

In order to determine when physician judgments about patient quality of life violate the disability rights laws, courts must first identify the medical treatment decisions to which the federal disability rights laws apply. They should extend the reach of these laws to all medical treatment decisions regardless of whether the treatment in question is related to the patient's disability. Although the distinction between related and unrelated conditions responds to legitimate judicial concerns about the difficulty of establishing unequal treatment, it would exclude a whole class of patients from redress. In addition, it presents line-drawing problems of its own. Ultimately, the arbitrariness of the distinction as a normative matter justifies acceptance of the practical difficulties which accompany its rejection.

Once the reach of the antidiscrimination laws has been decided, the courts will have to determine the circumstances in which a patient's disability may permissibly be taken into account. A patient's disability is arguably relevant whenever it is likely to influence the effectiveness of the treatment and, thus, the patient's ability to benefit

from it. From this perspective, the value of life-sustaining care cannot be determined without considering the quality of life that the treatment offers. Patients and their families confirm this judgment on a daily basis through their decisions to decline life-sustaining care. To critics of quality-of-life judgments, however, all life is equally valuable regardless of disability or quality of life. Quality-of-life judgments raise the disturbing specter of decisions that would, for example, exclude quadriplegic or retarded patients from the receipt of organ transplants or other life-prolonging care because the treatment would do more good if offered to others. From this perspective, quality-of-life judgments threaten the principle of equal worth and violate the antidiscrimination laws.

Congress has given no guidance on how the disability rights laws should apply to cases posing this conflict in fundamental values. As a result, the courts will have to decide whether quality-of-life judgments are among the "necessary" or "essential" criteria that may be employed when making a decision about life-sustaining care. Because reasonable people disagree about the relevance of quality of life to end-of-life treatment decisions and because Congress has given no guidance on the issue, the courts ought not interpret the antidiscrimination laws to prohibit all quality-of-life judgments. A complete prohibition would preclude not just physicians, but also courts, guardians, and others governed by the disability rights laws from taking quality of life into account when making or regulating treatment decisions. In addition, a complete prohibition would ignore the consciences of physicians who genuinely and reasonably feel that a treatment requested by the patient's family would be cruel. Furthermore, a prohibition would have crucial implications for the allocation of health care resources. Providers and insurers would be barred from taking quality of life into account when determining, for example, whether to fund organ transplants or dialysis for patients in a vegetative state.

Instead, a more subtle reconciliation of the competing interests of patients, families, and physicians should be crafted. In limited circumstances, providers can make a legally and ethically powerful claim for freedom to take the quality of life of their patients into account. When they can, courts ought to permit them to opt out of requested treatments, but oblige them to cooperate in transfer of the patient to another provider. In this way, the conscience of the provider can be accommodated without sacrificing the family's opportunity to find a provider who shares their values.

Physicians should be permitted to opt out of requested life-sustaining care when they genuinely and reasonably believe that a treatment requested by the patient's family would be harmful to the patient. They will be able to meet this test of reasonableness only

when their conclusions about patient welfare fall within the range of reasonable disagreement and there is no proof of invidious bias or factual error. In addition, a request to opt out of purportedly cruel treatment is not persuasive when the patient has personally requested the disputed treatment.

Physicians may also wish to opt out of life-sustaining care because they believe it to be an unwise use of scarce health care resources. Once again, quality of life will seem a relevant consideration to some and improper to others. However, rationing decisions such as these would greatly expand the circumstances in which disabled patients could be disfavored by consideration of quality of life. In addition, there is less societal consensus about the propriety of using quality of life to make rationing decisions than there is supporting consideration of quality of life when deciding whether life-sustaining care would be best for the patient. Furthermore, the financial savings that would accrue are uncertain. As a result, quality-of-life judgments should not be permitted except in the most extreme cases, i.e., those instances where the value of treatment to the patient is most dubious and the costs are significant. Dialysis treatments for a vegetative patient might qualify for such an exception. Courts could conceivably craft this exception to the general prohibition on quality-of-life judgments as a matter of statutory interpretation, but are more likely to await guidance from Congress.

When the physician's request to opt out of requested care appears to be based on concerns about waste, rather than cruelty, the physician's role as rationer will also need to be examined. The propriety of that role is most likely to be established when the physicians are rationing their own resources or when the stakeholder has expressly delegated rationing authority to her. When the physicians act on their own conscience, however, their demand for freedom of conscience is much less powerful than it is when they seek to opt out of a treatment that they genuinely and reasonably believe to be cruel.

These are the restrictions that the disability rights laws ought to place on futility judgments about life-sustaining care. Each can be squared with the existing federal statutes, although some will require novel interpretations of the statutory text. If, however, courts are unwilling to interpret the statutory requirements in this fashion or if they feel that the tests proposed here are too difficult to administer, then specific statutory modifications to strike a similar balance would be preferable to either a blanket prohibition on quality-of-life judgments or unfettered discretion to take disability-impaired quality of life into account.