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Medical Futility and Disability Discrimination

Mary A. Crossley*

I. INTRODUCTION

In Washington D.C. in July 1990, about 3000 persons with disabilities crowded the South Lawn of the White House and cheered as President George Bush signed the Americans with Disabilities Act of 1990 (ADA).1 "Every man, woman and child with a disability can now pass through a once-closed door to a bright new era of equality, independence and freedom," the President proclaimed before signing the bill into law. Likening the landmark legislation to the recent dismantling of the Berlin Wall, he declared: "Let the shameful wall of exclusion finally come tumbling down."2

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Less than a year later, in Minneapolis, Helga Wanglie lay in her hospital bed attached to a respirator, the center of a dispute between her family and physicians at the hospital. The elderly woman was in a persistent vegetative state, unconscious, and unable to interact with her environment or other persons. Because they judged her condition to be irreversible, her physicians believed that keeping her on the respirator offered her no benefit and recommended that she be removed from the machine. Her family, by contrast, insisted that all forms of treatment be continued. When the hospital failed to persuade the family to discontinue treatment, it took the family to court, but Helga Wanglie died before any new law was made.3

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In 1993 in Denver, physicians from local hospitals sat down in

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committees to begin the task of drafting guidelines to identify types of patients for whom continued treatment or specific interventions would be pointless, or "futile." Their purpose, in seeking a consensus regarding what cases involve futile care, was to allow Denver hospitals to act collectively in refusing to provide treatments deemed futile, regardless of the desires or demands of patients or their families. One goal of such collective action was cost control.  

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These three stories encapsulate the themes this Article braids together. Of the three stories, the first two already are emblematic of significant developments in American society in this last decade of the twentieth century. And, though it is too soon to be certain, the third story foretells a nascent development.

The first story's events represent the crowning glory of decades of efforts by disability rights advocates: Recognition and support from the highest levels of government, indeed from the bully pulpit of the Presidency itself, that Americans with disabilities should no longer be segregated and excluded from the richness of life in our society. The ADA trumpets the message that persons with disabilities should be accorded equal opportunities and integrated into society. No longer would disability be a cause for isolation or shame.

The story of Helga Wanglie has come to symbolize a debate within the medical community that emerged in the late 1980s and blossomed in the early 1990s: Whether a patient or her family has the right to demand medical treatment that her physician deems futile and accordingly seeks to withhold. This controversy over how "medical futility" affects the balance of decisional authority between doctor and patient has spilled into the legal literature and has drawn into question the very goals of medicine.

Finally, the account of Denver physicians meeting to determine collectively what types of medical conditions render treatment futile and to implement a policy of withholding treatment for those conditions represents a budding offshoot of the futility debate—an eminently logical offshoot in a society concerned about uncontrolled medical spending. These physicians, along with others, have seized on a plausible idea: If one can identify medical care that is futile and thus provides no benefit to a patient, wouldn't that be a good place to start limiting or "rationing" care to control costs?


6. For the meaning of "rationing," see infra note 82.
Of course, whether limiting the provision of futile care is a good place to start rationing health care resources is essentially a policy question. To address that question we might consider, among other questions, whether a futility-based rationing scheme would comport with whatever theory of distributive justice we espouse; whether it would be administratively feasible; and whether costs saved by the scheme would outweigh the costs—both symbolic and financial—it would impose. These are questions well worth asking, but they are not the focus of this Article.

Instead, this Article focuses on a narrower question raised by the attempt of Denver hospitals to craft a cost-conscious futility policy for limiting care: Is this a legal way to ration health care? More specifically, how compelling is the claim likely to be raised by disability rights advocates that a cost-conscious futility policy violates the ADA? Just such a contention scuttled Oregon's original plan for rationing medical care, and a similar challenge likely will be launched against any rationing scheme that directly or indirectly limits the medical benefits available to persons with disabilities.

The proper judicial response to an ADA challenge to a futility-based rationing scheme is far from clear. The ADA is still in its relative infancy as a civil rights statute, and the courts have yet to flesh out the statute's impact either in the health care area generally or, more specifically, in the context of health care allocation decisions. While cases decided under Section 504 of the Rehabilitation Act of 1973, the ADA's statutory precursor, supply some guidance, those cases are easily distinguished factually and thus provide no steady compass. Consequently, a court called on to decide the validity of a futility-based rationing scheme will forge a new trail.

The purpose of this Article is to peer down that trail, which likely lies in our future. The method chosen is one that, as a law professor, I appear to have drilled not only into my students, but into myself as well—examining both sides of every question. Accordingly, after first examining the debate in the medical literature over the concept of futility, this Article proceeds by attempting to develop the best arguments both for and against the legitimacy of a cost-conscious futility policy under the ADA.

Beyond fleshing out the various doctrinal points pertinent to an ADA analysis of a health care rationing scheme, however, this approach serves a further purpose: It highlights how powerfully the characterization of dying, disability, and the goals of medicine can influence legal understanding.

After elaborating and evaluating arguments likely to be raised in litigation challenging a futility-based rationing scheme, this Article

7. For a discussion of Oregon's rationing plan, see infra part III.B.2 (discussing the nature of Oregon's plan).
ultimately concedes those arguments' inconclusiveness. Legal argument, by itself, is not an adequate tool for determining whether cost-conscious futility policies are an intolerable form of disability discrimination. To answer that question, something more profound than citations to precedent and fine and persuasive legal advocacy is needed. We, as a society, need instead a deeper understanding of several questions: When and why is discrimination based on disability wrongful? How should we balance the individual interests of persons with disabilities in being free from such discrimination against society's communal interests in seeking to allocate resources in ways judged desirable? What does it mean to be near the end of life and profoundly compromised in our physical, and perhaps mental, selves? What do we want medicine to do for us?

The ADA does not attempt to answer the latter two questions, nor does the statute truly or clearly comprehend the former two. Thus, I will argue that the ADA is an inadequate and even inept tool for resolving whether we should tolerate cost-conscious futility policies. It will be difficult for a court hearing an ADA-based challenge to a futility policy to reach a conclusion on the case's merits. It may be even harder, however, for our society to acknowledge and respond to the critical need to develop ways of addressing the questions that legal analysis under the ADA leaves unanswered.

Part II of this Article examines the flowering of the debate over medical futility in the medical literature, elucidates its primary points of contention, and highlights the linkages made between futility-based limitations on treatment and cost control. Part III then considers, by articulating opposing arguments on the question, whether a policy using futility as a criterion for rationing medical care would run afoul of the ADA. Finally, Part IV discusses whether disability discrimination law, as we currently understand it, is by itself up to the task of resolving the issues raised by the implementation of cost-conscious futility policies.

II. THE DEBATE OVER MEDICAL FUTILITY

A. Origins of the Debate: The Medical Literature

By the late 1980s, the right of a competent patient to refuse life-sustaining medical treatment appeared well established. At the same time, however, a fresh debate regarding the nature of and limitations on a patient's right of medical self-determination was brewing in the medical literature. The subject of this debate, dubbed "medical futility," was a physician's authority to refuse to provide a patient with treatment that the

10. At this point, I use the term "discrimination" in its pure sense of making a distinction, without intending its negative connotation of a distinction based on some illegitimate prejudice.

physician deemed medically nonbeneficial, or futile.\textsuperscript{12}

The debate ostensibly sprang from the concern that many physicians were inappropriately using medical technology in situations where the technology offered a patient no real benefit.\textsuperscript{13} The "overuse" of cardiopulmonary resuscitation (CPR)\textsuperscript{14} emerges from the literature as the prime example of an unthinking proliferation of a technology resulting in inappropriate treatment.\textsuperscript{15} CPR was originally developed in the late 1960s to permit the resuscitation of persons who had experienced a cessation of spontaneous heartbeat and respiration as the result of suffering some acute trauma, such as near drowning, electrical shock, or heart attack.\textsuperscript{16} Over the decades, however, physicians have come to provide CPR routinely to all hospital patients experiencing such a cessation, regardless of its cause or the patients’ underlying health status.\textsuperscript{17} This presumptive use of CPR prompted some physicians to decry the indiscriminate application of an invasive therapy\textsuperscript{18} to patients who had not consented to it and for many of

\textsuperscript{12} See John D. Lantos, The Illusion of Futility in Clinical Practice, 87 Am. J. Med. 81 (1989) (arguing that clinical judgments and evaluation of a patient’s goals for therapy should be used to make futility judgments); Tom Tomlinson & Howard Brody, Ethics and Communication in Do Not Resuscitate Orders, 318 New Eng. J. Med. 43 (1988); Tom Tomlinson & Howard Brody, Futility and the Ethics of Resuscitation, 264 JAMA 1276 (1990) (arguing that physicians can make futility judgments on nonpaternalistic grounds and that a failure to make such judgments undermines autonomous choices by patients and surrogates) [hereinafter Tomlinson & Brody, Futility and Ethics]; Stuart J. Youngner, Who Defines Futility?, 260 JAMA 2094 (1988).

\textsuperscript{13} I say “ostensibly” because at least one commentator has suggested that the futility debate developed as a response to specific political and economic developments in medical care. See John D. Lantos, Futility Assessments and the Doctor-Patient Relationship, 42 J. Am. Geriatrics Soc’y 868, 868 (1994).

\textsuperscript{14} CPR is used to treat cardiac arrest by seeking to maintain the flow of oxygenated blood to the patient’s organs in order to prevent damage and to restore spontaneous cardiopulmonary function. CPR may include manual massage of the chest, application of electrical jolts to the chest, artificial ventilation of the lungs, and intravenous medications. See James T. Niemann, M.D., Cardiopulmonary Resuscitation, 327 New Eng. J. Med. 1075, 1075-77 (1992) (explaining methods of artificial circulation, artificial ventilation, and artificial defibrillation); Paul C. Sorum, Limiting Cardiopulmonary Resuscitation, 57 Alb. L. Rev. 617 (1994).


\textsuperscript{16} Blackhall, supra note 15, at 1281; Sorum, supra note 14, at 617.

\textsuperscript{17} See Boozang, supra note 15, at 25; Kathy Faber-Langendoen, Resuscitation of Patients with Metastatic Cancer: Is Transient Benefit Still Futile?, 151 Archives Internal Med. 235, 236 (1991). Hospitals classify CPR as an emergency procedure and, as a result, can provide it without obtaining the patient’s express informed consent. Both statutory and common law recognize an emergency exception to the doctrine of informed consent so that when an emergency exists, consent to treatment will be presumed. See Boozang, supra note 15, at 52-53. For a description of how the use of CPR became a standard protocol in hospitals, see Blackhall, supra note 15, at 1282.

\textsuperscript{18} Cf Rebecca Dresser & Peter J. Whitehouse, The Incompetent Patient on the Slippery
whom the intervention held little, if any, potential benefit.

From this criticism of CPR's routine use followed a more daring proposition: In cases in which CPR would be futile, physicians should have the unilateral authority to determine prospectively that CPR should be withheld from a patient in the event of cardiac arrest. In other words, some commentators argued that when a physician believes CPR will not benefit a patient, the physician can enter a "do not resuscitate" (DNR) order in the patient's chart without first consulting with the patient or the patient's surrogate. It is worth noting that in some of these cases, the patient will not have expressly requested CPR, and therefore, the physician's action will represent a failure to consult with and obtain consent from the patient, but not an overriding of the patient's express wishes. In those cases, the clash between the physician's action and respect for patient autonomy may seem less stark than in cases in which a physician flouts the patient's express request.

Slope, 24 Hastings Center Rep., July-Aug. 1994, at 10 (noting that the chest compression necessary to perform CPR is likely to inflict severe pain on frail patients).

19. The literature suggests a number of examples of cases in which CPR should be deemed futile. These cases include bedfast patients with metastatic cancer, persons with multiple organ failure, and persons with HIV infection who have experienced two or more episodes of pneumocystis carinii pneumonia. See Faber-Langendoen, supra note 17, at 238-39; Donald J. Murphy & Thomas E. Finucane, New Do Not Resuscitate Policies: A First Step in Cost Control, 153 Archives Internal Med. 1641, 1642-43 (1993). But cf. Robert D. Truog et al., The Problem with Futility, 326 New Eng. J. Med. 1560 (1992) (arguing that only a small number of cases involving CPR lend themselves to determinations of strict physiologic futility).

20. By "patient's surrogate," I mean a person who has the authority to make medical treatment decisions for an incompetent patient. A person can attain the status of surrogate decisionmaker in a number of ways: (1) appointment by the patient, when previously competent, pursuant to a durable power of attorney for health care; (2) legislative designation as a surrogate; (3) judicial appointment as the patient's conservator or guardian; or (4) de facto deference accorded by the patient's physicians or the courts. Usually, but by no means always, the surrogate will be a member of the patient's family. See generally Alison Patrucco Barnes, Beyond Guardianship Reform: A Reevaluation of Autonomy and Beneficence for a System of Principled Decision-Making in Long Term Care, 41 Emory L.J. 633, 636-38 (1992); Charles P. Sabatino, Death in the Legislature: Inventing Legal Tools for Autonomy, 19 N.Y.U. Rev. L. & Soc. Change 309, 310-11 (1991/1992).

In making medical treatment decisions for a patient, the surrogate is supposed to choose the treatment option that the surrogate believes, based on previous statements by the patient when competent and the patient's beliefs and values, that the patient would choose if she were competent. This process of attempting to replicate the patient's autonomous choice is called "substituted judgment." If the patient has never been competent or if the patient's previous competent statements or beliefs provide no basis for predicting what treatment option the patient would have preferred in a given situation, the surrogate is supposed to base its decisions on the "best interests" of the patient. Some studies suggest that surrogates' decisions often may not accurately reflect what the patient, if competent, would desire for herself. See D.T. Watts, The Family's Will or the Living Will: Patient Self-Determination In Doubt, 40 J. Am. Geriatric Soc'y 533 (1992).

Throughout this Article, a reference to "the patient's" decisions or desires should be read as including those of an incompetent patient's surrogate unless otherwise indicated.
Expanding beyond discussions of CPR, however, the futility debate evolved to address issues raised when a patient or his surrogate requests a specific therapy that the treating physician deems futile. The prime example of this conflict occurs when the family of a patient in a persistent vegetative state (PVS) demands that the patient continue to receive life-sustaining therapies that the physician considers pointless. The situation poses the question pointedly: Can the physician unilaterally override the express choices of the patient's surrogate and refuse to provide, or even physically withdraw, the futile treatment?

While these questions provoked heated debate in the medical

21. "The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with [some level of] preservation of hypothalamic and brain-stem autonomic functions." As such, a person in a vegetative state is totally unable to interact with his environment or others. A vegetative state that lasts longer than a few weeks is referred to as a persistent vegetative state. When the patient's condition is deemed irreversible, as a matter of clinical probability, the patient's prognosis is for a permanent vegetative state. The Multi-Society Task Force on PVS, Medical Aspects of the Persistent Vegetative State (First of Two Parts), 330 New Eng. J. Med. 1499, 1500-01 (1994). See also Kenneth R. Mitchell et al., Medical Futility, Treatment Withdrawal and the Persistent Vegetative State, 19 J. Med. Ethics 71 (1993).

22. See Mitchell et al., supra note 21, at 73-75; Truog et al., supra note 19, at 1560. For a patient in a PVS, life-sustaining therapies may range from high-technology "rescue" interventions, such as mechanical ventilation, dialysis, and CPR, to more basic treatments such as antibiotics, nutrition, and hydration. For such a patient, however, there is commonly believed to be no therapy that can return the patient to consciousness. See The Multi-Society Task Force on PVS, Medical Aspects of the Persistent Vegetative State (Second of Two Parts), 330 New Eng. J. Med. 1572, 1577 (1994). But see Nancy L. Childs & Walt N. Mercer, Brief Report: Late Improvement in Consciousness After Post-traumatic Vegetative State, 334 New Eng. J. Med. 24 (1996) (reporting a case of emergence from a permanent vegetative state).

A condition analogous to PVS is anencephaly, a condition in which an infant is born lacking a major portion of the brain, skull and cap. Although anencephalic infants are permanently unconscious because they lack a functional cerebral cortex, they may display some brainstem functions in varying degrees. See The Medical Task Force on Anencephaly, The Infant with Anencephaly, 322 New Eng. J. Med. 669, 671 (1990). For discussion of a case involving treatment decisions for an anencephalic infant, see infra text accompanying notes 47-53. One commentator has described the class of patients whose ongoing treatment may raise futility issues more broadly as patients with "profoundly diminished life," and includes in that class both persons who are permanently unconscious and those who are deeply demented. E. Haavi Morreim, Profoundly Diminished Life: The Casualties of Coercion, 24 Hastings Center Rep., Jan.-Feb. 1994, at 33.

Another therapy that has been described as futile in some cases is extracorporeal membrane oxygenation (ECMO). See John J. Paris et al., Beyond Autonomy—Physicians' Refusal to Use Life-Prolonging Extracorporeal Membrane Oxygenation, 329 New Eng. J. Med. 354 (1993); Truog et al., supra note 19, at 1560.

23. Situations may also arise when the wishes of an incompetent patient, expressed when the patient was competent, may be overridden by physicians on grounds of futility. For example, the question arises when a competent patient who expresses his desire that his caregivers "do everything possible" later becomes incompetent and his physicians advise against the continuation of aggressive life-sustaining treatment that they deem futile. See Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics 213-14 (4th ed. 1994); Jay A. Gold et al., Is There a Right to Futile Treatment? The Case of a Dying Patient with AIDS, 1 J. Clinical Ethics 19 (1990).
literature, several cases in the early 1990s alerted the legal community to the question of medical futility. The most celebrated of these was the case of Helga Wanglie, an elderly woman who lapsed into a PVS after extended respiratory failure and a cardiopulmonary arrest. Mrs. Wanglie's husband and family refused to consent to the recommendations of the medical staff at Hennepin County Medical Center that Mrs. Wanglie be removed from respiratory life support. In response, the Medical Center filed suit seeking the appointment of a conservator to make medical decisions for Mrs. Wanglie.

Ultimately, the court that heard this case made no law directly addressing medical providers' obligation to provide care deemed futile, for it appointed Mr. Wanglie as his wife's conservator, and several days later Mrs. Wanglie died without being disconnected from her respirator. Nonetheless, the Wanglie case thrust the futility debate into a broader realm and has stimulated further discussion of physicians' legal and moral authority to make unilateral decisions refusing treatment judged futile.


25. In re Helga Wanglie, No. PX-91-283 (Hennepin County, Minn., 4th Dist. Ct., P. Ct. Div. July 1, 1991). Because the Wanglie case generated no written opinion, the following account is derived from the reports of persons involved in the case. See Cranford, supra note 3; Miles, supra note 3.


Another dispute between family and physician went to court, but produced no judicial resolution of the legal aspects of the futility debate. In re Baby Girl L, 576 A.2d 1142 (Pa. Super. Ct. 1990), involved a dispute between the mother of a profoundly retarded child, who requested maximal treatment for her child, and hospital personnel, who sought to discontinue treatment on the grounds that to do so would be in the child's best interests. The case became moot when a physician retained as a consultant by the mother's attorney agreed to provide continuing care for the child. See John J. Paris et al., Physicians' Refusal of Requested Treatment—The Case of Baby L, 322 New Eng. J. Med. 1012, 1014 (1990).


Despite increased attention to the questions central to the futility debate and a growing recognition of its implications, however, the debate remains far from resolved.

B. A Foundational Question: What is “Futility”?

A major obstacle to achieving any consensus regarding physicians’ moral and legal authority to make decisions about futile treatment is the absence of consensus on how to define the term “futility.” While several different conceptions of the term have been advanced, no single meaning has been widely accepted as definitive.

Some commentators view futility narrowly, as existing only when a proposed treatment is incapable of producing the desired physiologic effect in a patient. Under this view, therapeutic interventions are


28. Cf. Ronald Cranford & Lawrence Gostin, Futility: A Concept in Search of a Definition, 20 Law Med. & Health Care 307 (1992) (discussing the “relatively new, extremely important, but also highly dangerous, concept of medical futility”); Marshall B. Kapp, Futile Medical Treatment: A Review of the Ethical Arguments and Legal Holdings, 9 J. Gen. Internal Med. 170, 170 (1994) (“[O]ne of the most controversial and important questions emerging presently—a question with significant ethical, legal, and psychological/interpersonal ramifications.”); Steven H. Miles, Medical Futility, 20 Law Med. & Health Care 310, 310 (1992) (“The current debate about medical futility is one of the most important and contentious in medical ethics. . . . [I]t is leading to a reexamination of the nature of a patient’s entitlement to health care . . . .”). Although the futility debate is far from resolved, one commentator suggests that the aggressive stance adopted in the medical literature towards futility determinations is filtering into clinical practice. See Troyen A. Brennan, Physicians and Futile Care: Using Ethics Committees to Slow the Momentum, 20 Law Med. & Health Care 336, 336 (1992).

29. See Beauchamp & Childress, supra note 23, at 213 (“This situation of equivocation and ambiguity suggests that the term futility generally should be avoided in favor of more precise language.”); Cranford & Gostin, supra note 28, at 307 (noting lack of consensus regarding definition of concept); Daar, supra note 24, at 1254-55 (summarizing different definitional approaches to futility); Lantos, supra note 12, at 82 (“Futility, a nonquantitative expression of probability, means different things to different doctors.”); Truog et al., supra note 19, at 1580 (“A clear understanding of futility has proved to be elusive.”); Youngner, supra note 12, at 2094 (describing five varying conceptions of futility); cf. Paris et al., supra note 22, at 354 (describing the debate over futility as a “relapse into nominalism”).

30. See e.g., Sorum, supra note 14, at 621-23 (agreeing with American Heart Association guidelines allowing the withholding of CPR in cases where the patient is already dead or about to die, but disagreeing that CPR can properly be deemed futile for patients who are unlikely to survive to discharge); Truog et al., supra note 19, at 1561; cf. Beauchamp & Childress, supra note 23, at 213 (stating that “futile” refers to situations in which irreversibly dying patients reach a point at which further treatment provides no physiological benefit or is hopeless); Veatch & Spicer, supra note 27, at 16-17 (accepting label of “medical futility” for care that produces no demonstrable effect at a chosen level of probability, but rejecting label for care that, even though it produces an effect, is believed by the speaker to be of no net benefit to the patient).
properly deemed futile in only a very limited number of cases, for example, when CPR is considered for a patient who suffered a cardiac arrest more than ten minutes earlier. Proponents of this narrow definition of futility assert that its invocation can properly be viewed as an exercise of professional medical judgment, rather than as a subjective value judgment, only when the concept is so limited.

Other commentators, by contrast, propose a far broader conception of futility. For example, Lawrence Schneiderman and Nancy Jecker put forward an understanding of futility that involves both qualitative and quantitative components. As a qualitative matter, Schneiderman and Jecker frame the question as whether a proposed treatment offers any benefit to the patient as a whole person, not simply whether the treatment will produce discrete physiological effects. Put simply, will the patient as a person achieve and appreciate a benefit from the treatment? By way of example, the authors describe using a gastrostomy tube for an elderly and severely demented woman as futile. Although the tube would prolong the woman’s survival, it would not provide any benefits that she seems capable of appreciating.

In addition, as a quantitative matter, Schneiderman and Jecker assert the relevance of the probability that any benefit will be achieved. In other words, even if a treatment offers a possible benefit, the probability of achieving that benefit may be so slight that the treatment is properly deemed futile. For example, if studies reveal that, among patients with

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31. See Sorum, supra note 14, at 621; see also Ann Alpers & Bernard Lo, When is CPR Futile?, 273 JAMA 156 (1995) (suggesting, as example of physiologic futility, CPR for a 72-year-old man with progressive septic shock, renal failure, obtundation, and respiratory failure despite seven days of intensive care).

32. See infra notes 71-73 and accompanying text.


34. “[P]hysicians should distinguish between an effect, which is limited to some part of the patient’s body, and a benefit, which the patient has the capacity to appreciate and which improves the patient as a whole. Treatment that fails to provide the latter, . . . whether or not it achieves the former, is “futile.”” Schneiderman & Jecker, Futility in Practice, supra note 27, at 437.

35. Id. at 439.

36. The authors specifically suggest that, “when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empirical data) that in the last 100 cases, a medical treatment has been useless,” it should be
metastatic cancer, none has survived to hospital discharge after receiving CPR, then resuscitating patients with metastatic cancer should be considered futile. Consequently, Schneiderman and Jecker's conception of futility's qualitative and quantitative aspects yields a far broader, more inclusive definition of the term than a definition that focuses solely on the physiologic effects of treatment.

The danger of articulating these two opposing visions of what futility means is that it may create the oversimplified and inaccurate impression that the disagreement over the meaning of futility boils down to a debate between these two visions. Instead, numerous other definitions have been advanced in the literature, and dissension exists even among those advocating a single approach. Moreover, the debate is not simply academic. In the real world, different physicians use the term to mean different things. Thus, significant agreement as to the meaning of futility deemed futile as a quantitative matter. Schneiderman & Jecker, Ethical Implications, supra note 33, at 949. They are presumably referring to previous similar cases. Cf. Stell, supra note 15, at 490 (questioning what level of evidence is sufficient for a responsible decisionmaker to conclude that an intervention will be futile); Truog et al., supra note 19, at 1562-63 (highlighting need to account for differences between patients). But see Edmund D. Pellegrino, Ethics, 270 JAMA 202 (1993) (expressing concern regarding quantitative approach to futility based on the potential shortcomings of objective criteria, such as errors in diagnosis, prognosis, and medical information).

37. Cf. Faber-Langendoen, supra note 17, at 236 (questioning the validity of studies regarding the survival of patients with metastatic cancer after receiving CPR).


39. See, e.g., Daar, supra note 24, at 1255 (suggesting that a particular treatment should be deemed futile only if it will not produce the benefit sought by the patient); Miles, supra note 28, at 510 (suggesting four clinical usages of "futility"); Stell, supra note 15, at 490 (citing dictionary definition of "futile effort" and applying to medical interventions). For an enlightening account of the mythical origins of the concept of futility and an interpretation of the present day concept in light of those origins, see Thomas J. Prendergast, Futility and the Common Cold: How Requests for Antibiotics Can Illuminate Care at the End of Life, 107 Chest 836, 836-39 (1995). Dr. Prendergast suggests that the current debate's focus on the outcomes of treatment is inappropriate and that greater emphasis should be placed on the process of providing care. According to Prendergast, "it is primarily a sense of disproportion [in providing treatment] that gives rise to the sense of futility [among physicians]." Id. at 837.

40. See, e.g., Mark A. Ebell, When Everything is Too Much: Quantitative Approaches to the Issue of Futility, 4 Archives Fam. Med. 352, 352 (1995) (suggesting two alternative quantitative approaches); Loewy & Carlson, supra note 27 (endorsing Jecker and Schneiderman's patient-centered definition of futility, but suggesting that approach may define benefit too narrowly by focusing only on the medical benefit received by the patient); Murphy & Finucane, supra note 19, at 1641 (supporting the quantitative approach, but suggesting that individual communities should define their own threshold levels for the likelihood of benefit).

41. See Mildred Z. Solomon, How Physicians Talk About Futility: Making Words Mean Too Many Things, 21 J.L. Med. & Ethics 231, 232-33 (1993) (describing survey results showing that physicians used the concept and the word itself in multiple and contradictory ways); see also J.
seems far away.  

C. The Heart of the Matter: Patient Autonomy Versus Physician Authority

While the definitional questions just discussed may have important implications for the legitimacy of using "futility" as a standard in policy making, the real heart of the debate over medical futility has been whether, and on what basis, a physician enjoys the moral and legal authority to make unilateral decisions limiting medical treatment deemed futile. In both legal and ethical discussions, an assertion of the physician's authority to make such decisions typically meets a counterassertion of the patient's right of self-determination, or autonomy, regarding medical treatments. Thus, while other interests and factors figure into the debate, the fundamental conflict concerns who—patient or physician—ultimately exercises decisional authority with respect to treatment that the patient desires, but the physician judges to be nonbeneficial.

The law has not yet clearly vested decisional authority in either party. Although the concept of futility has been legislatively recognized in different policy contexts as a legitimate basis for terminating or withholding life-sustaining treatment, no statutory or case law squarely...
addresses the balance of authority between patient (or patient’s surrogate) and physician with respect to treatment demanded by the patient (or surrogate), but deemed futile by the physician. The only reported case in which a court has dealt with a health care provider’s claim that the futility of requested treatment excused the provider’s obligation to execute treatment chosen by a patient’s surrogate involved a hospital seeking to avoid treating an infant with anencephaly.46

In In the Matter of Baby X,47 a hospital sought a declaratory judgment that its refusal to provide ventilator treatment to an anencephalic infant whose mother requested the treatment48 would not violate certain federal or state laws, including Section 504 of the Rehabilitation Act, the ADA, and the federal Emergency Medical Treatment and Active Labor Act (EMTALA).49 The hospital argued that none of these statutes should be

coverage provided by the Amendments).

New York’s legislation regarding “do not resuscitate” (DNR) orders attaches legal significance to a finding that CPR is “medically futile” in two instances. A surrogate, acting on behalf of an adult patient lacking capacity, may consent to a DNR order for the patient only if two doctors concur that the patient is terminally ill or permanently unconscious, or that resuscitation would be medically futile or would impose an extraordinary burden on the patient in light of his condition and expected outcome. N.Y. Pub. Health Law § 2965(3)(c) (Lawyers Cooperative Publishing 1993). When an adult patient lacks capacity and a surrogate is not reasonably available, a doctor may issue a DNR order only if two doctors agree that CPR would be medically futile or upon court order. Id. § 2966(1). Even if a patient lacks capacity, he must be notified of a surrogate’s consent or a physician’s decision to issue a DNR order “when there is any indication of the patient’s ability to comprehend such notice.” In these cases, if the patient objects, the DNR order shall not be issued. Id. §§ 2965(5), 2966(3). The New York statute provides the following definition: “Medically futile means that cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs.” Id. § 2961(12).

46. For a description of anencephaly, see supra note 22.
48. Baby K was born in the hospital in October 1992 and was diagnosed with anencephaly. Immediately following her birth, hospital physicians provided her with mechanical ventilation to assist her with breathing, but shortly thereafter, both the physicians and the hospital’s Ethics Committee recommended to Baby K’s mother that she permit a DNR order which would discontinue the ventilator treatment. The mother rejected these recommendations and insisted on continued ventilator treatment. Eventually, Baby K was transferred from the hospital to a nursing home during a period when she was not experiencing respiratory distress, but the transfer was conditioned on the hospital’s agreement to readmit Baby K for ventilator treatment if she again developed respiratory distress. The hospital in fact readmitted Baby K twice to treat respiratory distress and in each instance subsequently retransferred her to the nursing home. After the second readmission and retransfer, the hospital filed suit for a declaratory judgment to determine its legal obligations regarding the likely future requests for readmission and ventilator treatment. See id. at 1024-26.
49. The Emergency Medical Treatment and Active Labor Act (EMTALA) was enacted as part of the Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA). The Act requires that hospitals provide “any individual ... an appropriate medical screening examination” to determine whether the patient has “an emergency medical condition” as
interpreted to require it to provide ventilator treatment that its physicians deemed futile. The district court held that withholding requested ventilator support would violate each of the statutes. With respect to the ADA, the court reasoned that because life-sustaining ventilator support would be provided to an infant without disabilities at its parents' request, the hospital's allegation regarding the futility of such treatment for Baby K would not allow the hospital to evade the ADA's nondiscrimination mandate. Likewise, relying on the plain, unqualified language of the statute, the court rejected the hospital's argument that EMTALA should be read as not requiring a hospital to provide stabilizing treatment that its physicians consider futile or inhumane: "The statute does not admit of any 'futility' or 'inhumanity' exceptions." The Fourth Circuit affirmed the district court, but relied solely on the obligations imposed by EMTALA in doing so.

Thus, in Baby K, the courts rejected a hospital's claim that the alleged futility of requested treatment would shield the hospital from liability for

defined by the statute. 42 U.S.C. § 1395dd(a) (1994). If a medical emergency exists, the Act mandates the hospital to provide treatment to stabilize the patient or transfer the patient to another medical facility, unless the patient refuses such treatment after being informed of the risks and benefits of treatment. Id. § 1395dd(b) (1990). EMTALA forbids the hospital from transferring the patient until the patient is stabilized, unless the patient requests a transfer in writing after being informed of the hospital's duty under the Act and the risks of transfer, and a physician signs the request, finding that treatment benefits at a different facility outweigh the risks of transfer. Id. § 1395dd(c) (1990). Violations of EMTALA subject both the hospital and the individual physician responsible for the patient's treatment to heavy civil penalties (up to $50,000). Id. § 1395dd(d) (1990). The Act expressly authorizes individuals injured as a direct result of a hospital's violation of the Act to bring a personal injury action. Id. § 1395dd(2) (1990). See generally Helene Hoffman, Does COBRA Work? The Problem of Patient Dumping and Possible Solutions, 25 J. Health Hosp. L. 1 (1992); Thomas L Stricker, Jr., Note, The Emergency Medical Treatment and Active Labor Act Denial of Emergency Medical Care Because of Improper Economic Motives, 67 Notre Dame L. Rev. 1121 (1992).

The hospital also sought declarations that its withholding of requested ventilator treatment would not violate the Child Abuse Amendments of 1984, 42 U.S.C. §§ 5101-107 (1988 and Supp. III 1991), and the Virginia Medical Malpractice Act, Va. Code Ann. §§ 8.01-581.1 to 8.01-581.20 (Michie 1992). The court did not issue a declaration with respect to either of these statutes.

50. The district court's analysis under § 504 varied from its ADA analysis by focusing on whether Baby K was "otherwise qualified" to receive ventilator services and distinguishing the case from precedent finding § 504 inapplicable to cases in which parents had refused to consent to the provision of life-sustaining treatment for disabled infants. The district court concluded that Baby K was "otherwise qualified" for ventilator support and that the hospital's withholding that support over the mother's objection would violate § 504. Baby K, 832 F. Supp. at 1028.

51. "[T]he plain language of the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request." Id. at 1029.

52. Id. at 1027.

53. "Because we conclude that the hospital has a duty to render stabilizing treatment under EMTALA, we need not address its obligations under the remaining federal statutes...." In re Baby K, 16 F.3d 590, 592 n.2 (4th Cir. 1994).
refusing to provide the treatment. In doing so, however, the courts focused on the dual status of Baby K—as both an individual with a disability and a patient experiencing an emergency medical condition—in finding the hospital’s obligation to provide the treatment. Neither court addressed the more general question posed by the futility debate in the medical literature: Can a patient or his surrogate compel a physician to provide the patient with treatment that the physician deems futile? 54

As a result of this legal vacuum, opponents in the debate are left relying on case law that does not address the crux of the futility debate. Advocates of patient authority quote judicial language regarding the patient’s (or surrogate’s) right to make medical decisions, but this language comes from cases in which the issue was the patient’s authority to refuse recommended medical treatment. 55 As such, the language deals only with the patient’s ability to avoid unwanted bodily invasion—not his ability to commande medical treatment from an unwilling provider. 56 By

54. Admittedly, if all cases of alleged futility in fact involve patients who either have a disability or are requesting treatment to stabilize an emergency medical condition, then the district court’s opinion in Baby K would obliquely but effectively answer the question posed in the text. Indeed, a review of the medical literature on futility reveals that the medical commentators tend to focus on instances of demands for “futile” treatment that would fall into this category. As discussed below in part III.C.1, however, cases could conceivably arise in which the patient requesting treatment is not disabled and the treatment requested is not necessary to stabilize an emergency medical condition. For example, imagine a patient diagnosed with viral pneumonia who becomes frustrated with how long it takes him to feel better and demands a prescription of antibiotics. Here, the pneumonia, while a serious health concern, neither creates an emergency medical condition nor rises to the level of disability. The treating physician may refuse to prescribe the requested antibiotics and could justify her refusal on the grounds that prescribing antibiotics to treat viral pneumonia is futile.


56. Cf. Bernard Gert et al., Distinguishing Between Patients’ Refusals and Requests, Hastings Center Rep., July-Aug. 1994, at 13 (examining the distinction between the obligation of physicians to respond to patients’ treatment refusals and the obligation of physicians to respond to patients’ requests for treatment and other actions). Patients’ rights regarding medical treatment choices have typically been recognized in negative contexts, i.e., where the patient essentially claims a right to be left alone. By contrast, proponents of patient authority in the futility context must argue that the patient’s right of medical self-determination is also positive in nature, i.e, the patient must be provided with the treatment that she autonomously chooses. See Stell, supra note 15, at 483-84 (arguing that a patient’s right to participate in making medical decisions does not include right of terminally ill patient to demand specific life-sustaining treatment when there is no medical willingness to offer it); cf. Brennan, supra note 28, at 338 (noting distinction between an individual’s negative right to terminate care and the positive right of a patient to health care); Cranford & Gostin, supra note 28, at 309 (rejecting idea that patients have an affirmative right to insist on receiving any and all services they may desire). This distinction between positive and negative rights in the area of end-of-life decisionmaking also surfaces in analyses of a patient’s right to receive assistance in committing suicide. Compare Compassion in Dying v. State of Washington, 850 F. Supp. 1455 (W.D. Wash. 1994), aff’d, 1996 WL 94848 (9th Cir. 1996) (en banc) with Quill v. Koppel, 870 F. Supp. 78 (S.D.N.Y. 1994) (finding that physician-assisted suicide was not protectable as “there was no fundamental right on the part of [a] terminally ill patient to end his or her
contrast, defenders of a physician's authority to refuse treatment point to judicial language assuming that futility is a medical determination. This language, however, comes from cases in which a patient or surrogate requested the discontinuation of treatment based on medical advice. Because none of these cases involved a conflict between physician and patient over the advisability of treatment, they provide scant authority for how to resolve that conflict when it does arise.

Similarly unresolved is the moral authority of either physicians or patients to make unilateral medical decisions in the face of asserted futility. A number of commentators, citing Hippocrates and others, invoke the ancient principle that physicians are not morally obligated to continue to provide care that offers a patient no benefit. They point to the ethical principle of beneficence as the underlying foundation and argue that

57. See Stell, supra note 15, at 494.
59. One recent case involved providers' claims of futility, but failed to provide clear legal resolution of the issues discussed in the text. In Gilgunn v. Massachusetts Gen. Hosp., Super. Ct. Civ. Action No. 92-4820 (Suffolk County, Mass., Apr. 21, 1995), a woman sued the hospital and two of its physicians for withdrawing lifesupport from her comatose mother over the plaintiff daughter's objections. The hospital and doctors defended on the ground that they were not obligated to provide futile treatment. The jury absolved the defendants of liability. Although the media reported the case as "ruling that a hospital and its doctors need not provide care deemed futile, even if the patient has asked for it," Gina Kolata, Court Ruling Limits Rights of Patients, N. Y. Times, Apr. 22, 1995, at 6, Alexander Capron has argued convincingly that the jury's verdict in itself has little legal significance. Alexander M. Capron, Abandoning a Waning Life, 25 Hastings Center Rep., July-Aug. 1995, at 24. Capron attributes this insignificance to a combination of several factors, including (1) the current lack of appellate review of the verdict; (2) testimony at trial suggesting that other family members may have consented to the withdrawal of life support; and (3) confusion over the definition of futility employed by the defendants.
60. See, e.g., Faber-Langendoen, supra note 17, at 238; Lantos, supra note 12, at 81-82 (citing classical Greek medicine and Jewish and Christian moral law); Mitchell et al., supra note 21, at 73 (citing Hippocrates and Plato). Commentators also frequently find a more modern ethical basis for the futility doctrine in the conclusion of the President's Commission for the Study of Ethical Problems in Medicine, which found that "informed consent does not mean that patients can insist upon anything they might want. Rather, it is a choice among medically accepted and available options, all of which are believed to have some possibility of promoting the patient's welfare . . . ." President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship 42-44 (1982).
61. The principle of beneficence requires that a moral agent act to promote good or to minimize or prevent harm. See Beauchamp & Childress, supra note 23, at 194-95 (relating that "the obligation to confer benefits and actively to prevent and remove harm is important"); cf. Edward R. Grant, Medical Futility: Legal and Ethical Aspects, 20 Law Med. & Health Care 330 (1992) (asserting that futility decisions can be more properly characterized as being based on
agreeing to provide futile treatment would require a physician to harm her patient either by creating false hopes regarding the treatment's efficacy or by subjecting the patient to the risks and harms of treatment without any realistic prospect of a counterbalancing benefit.

More often, however, advocates of a physician's authority to refuse futile treatment argue that a physician, no less than a patient, is a moral agent entitled to make autonomous decisions consistent with his values. Accordingly, it would violate the ethical principle of autonomy to force a physician to provide treatment that he believes is inappropriate, inhumane, or wasteful. Some commentators bolster this concept of physician autonomy by invoking the autonomy of the medical profession. They argue that, not only is it wrong to compel a physician to provide treatment that is inconsistent with his own ethical values, but that likewise it is wrong

beneficence concerns, in terms of the welfare of the patient, as socially defined).

62. Tomlinson and Brody go so far as to argue that by offering a treatment deemed to be futile, a physician may compromise the patient's ability to exercise autonomous choice. Tomlinson & Brody, Futility and Ethics, supra note 12, at 1276; cf. Murphy & Finucane, supra note 19, at 1645 ("Raising the issue of CPR as an option is fundamentally misleading in many situations."). But see Brennan, supra note 28, at 337-38 (arguing that physicians can no longer rely on "false hopes" argument).

63. See Tomlinson & Brody, Futility and Ethics, supra note 12, at 1277 (discussing a situation where the likelihood of harm is greater than the likelihood of benefit). Although many people may think of medical treatment as being inherently beneficial, most treatments carry with them some level of physical invasiveness, pain, risk of side effects, or risk of iatrogenic injury or nosocomial infection. An iatrogenic injury is any adverse condition suffered by a patient as a result of medical treatment, especially infections acquired during the course of treatment, and a nosocomial infection is an infection acquired after admittance to the hospital. Dorland's Illustrated Medical Dictionary 812, 1151 (27th ed. 1988). Thus, few medical treatments can be regarded as purely benign.

64. Tomlinson and Brody argue that requiring health care professionals simply to act at the direction of patients would put them in the position of sharing moral liability for any harmful outcomes of treatment without allowing them to exercise free will. Tomlinson & Brody, Futility and Ethics, supra note 12, at 1278; cf. Prendergast, supra note 39, at 841 (asserting physicians' status as moral agents, but disputing current conceptions of futility). But cf. Murphy & Finucane, supra note 19, at 1644 (arguing that physicians limiting treatment on the grounds of futility are justified not by their own interests in autonomy, but because they are acting out the role imposed by a social contract that treatment should be limited under specified circumstances).

65. See e.g., Miles, supra note 28, at 311 (articulating physicians' duties not to prescribe therapies that cannot restore health to a dying person, not to cause pain and not to act inefficiently); Morreim, supra note 22, at 34 (noting that invasive life support that only prolongs the suffering of the dying can be seen as pointlessly cruel). But cf. Truog et al., supra note 19, at 1562-63 (asserting that physicians should not be required to take part in care that violates their own morals, while rejecting that a determination of "futility" is a proper basis for doing so). At least one commentator who believes that a determination of futility and the consequent decision not to provide treatment are solely medical responsibilities would nonetheless require a physician who makes such a determination to discuss it with the patient in order to allow the patient the opportunity to seek "alternative medical attendance." See Stell, supra note 15, at 493.

66. Cf. Daar, supra note 24, at 260-74 (examining the "integrity of the medical profession as an evolving common-law concept" in right to die cases).
to compel the provision of treatment that would violate the integrity of medicine as a profession. Because the goals of medicine include restoring health and easing suffering, but not simply appeasing a patient’s desires, a physician who provides requested but futile treatment fails to advance any proper goal of the medical profession.

By contrast, critics of physicians’ claim of authority to refuse treatment assert that even if a physician’s own autonomy interest is at stake, that interest must be secondary to the patient’s autonomous choice because the patient’s very life is at stake. Moreover, critics point out that in very few cases does a determination of futility involve the exercise of purely medical judgment that could be seen as falling within the realm

67. Faber-Langendoen, supra note 17, at 238 (citing American College of Physicians Ethics Committee, American College of Physicians Ethics Manual, 111 Annals Internal Med. 247 (1989)).

68. The asserted distinction between pursuing the proper goals of medicine and appeasing patient desires is also frequently raised in discussions of medicine’s response to infertility. Is infertility truly a medical problem, or is it a problem of patients’ frustrated social and biological desires? See Samuel Gorovitz, Progeny, Progress, and Primrose Paths in The Ethics of Reproductive Technology 125 (Kenneth D. Alpern ed.) (articulating opposing viewpoints as to whether in vitro fertilization is defensible as a proper function of medicine).

69. Faber-Langendoen, supra note 17, at 238-39 (“Clearly, temporary resuscitation of the patient with metastatic cancer falls well outside of these goals.”); Mitchell et al., supra note 21, at 71; cf. Prendergast, supra note 39, at 841 (arguing that the independence and fiduciary responsibility of the medical profession justify its ability to establish and adhere to standards of care); Schneiderman & Jecker, Futility in Practice, supra note 27, at 437 (asserting that their definition of futility is consistent with medicine’s historic goal of achieving a benefit above a minimal quantitative or qualitative level); Tomlinson & Brody, Futility and Ethics, supra note 12, at 1277 (arguing that to preserve itself as an instrument of social good the medical profession must be able to make some judgments regarding how its services will be delivered). But see Robert M. Veatch, Why Physicians Cannot Determine if Care is Futile, 42 J. Am. Geriatrics Soc’y 871, 871 (1994) (“[I]n deciding whether a life-prolonging ventilator serves some useful purpose, no one should really be interested in whether it serves merely the ends of medicine. The real question is whether it is good taking all spheres of the good into account.”).

Veatch and Spicer, by contrast, argue that the special role of health care professionals in society provides a basis for imposing on them the obligation to provide life-sustaining technology. Veatch & Spicer, supra note 27, at 27-28.

70. See Boozang, supra note 15, at 66 (“Because the conflict between physician and patient autonomy implicates whether the patient will live or die, the patient’s autonomy must supersede.”); accord Veatch & Spicer, supra note 27, at 25 (arguing that it would be offensive to deny life-sustaining care to a patient who believes in the value of biological life). Prendergast suggests that the concept of futility has developed in the context of the critically ill because it is there that a patient’s interest in autonomy is the greatest. He characterizes physicians’ reliance on futility in that context as an attempt to play an ethical trump card. Prendergast, supra note 39, at 838-39.

71. These would be limited to cases of physiological futility, which, as discussed above, are relatively rare. See supra notes 30-32 and accompanying text. In addition, Schneiderman’s suggestion that physicians be able to rely solely on their own experience raises a danger of faulty or biased recollections. See Charles Weijer & Carl Elliott, Pulling the Plug on Futility, 310 Brit. Med. J. 683, 684 (1995) (arguing that any criterion which allows doctors to rely solely on their own experience is problematic).
of the physician's professional expertise. Instead, many of the cases presented as paradigms of futility actually involve value-laden judgments about the worth of the patient's remaining life and the goals the patient seeks to advance through treatment.

Defying evidence that end-of-life decisions remain heavily influenced by physician values as a practical matter, despite the theoretical primacy of patient autonomy, critics of futility argue that judgments regarding the value of remaining life are beyond a physician's expertise and are instead judgments that only the patient can make. As an example, some commentators point to proposals that CPR be considered futile, and hence nonobligatory, in cases when the patient's likelihood of survival to hospital discharge is extremely low. These proposals, the critics argue, fail to recognize that a patient may place a high personal value on extra days or hours of life in the hospital, even if the patient has no realistic hope of

72. See Cranford & Gostin, supra note 28, at 307 (arguing that, in light of history of medical profession's blocking of patients' and families' ability to withdraw life-sustaining treatment, it is "difficult now to take seriously the claim that termination of treatment is a mere medical judgment devoid of social values and ethical conflict").

73. See Sorum, supra note 14, at 622-23 (arguing that a physician's unilateral decision not to provide CPR on grounds that survival to discharge is unlikely represents an inappropriate determination by the physician that the potential remaining life of the patient post-resuscitation is not worth living); Truog et al., supra note 19, at 1561; cf. Solomon, supra note 41, at 232-36 (reporting survey findings that physicians frequently couch quality of life conclusions in terms of medical judgments of futility).


75. See Boozang, supra note 15, at 70-71 (arguing that patient's right does not disappear because of extreme illness); Veatch & Spicer, supra note 27, at 17 (suggesting that futility means nothing); Youngner, supra note 12, at 2095 (pointing to instances when excluding patient values or characteristics, such as a willingness to tolerate an extreme disability or having a high pain threshold, would be objectionable). Indeed, a recent study demonstrates a tendency among many physicians to make judgments regarding the patient's quality of life without even discussing the question with the patient. See Curtis et al., supra note 41, at 127 (describing the study). But see Stell, supra note 15, at 488 (rejecting argument that a physician has a fiduciary obligation to offer treatments that benefit a patient and that the patient gets to determine what counts as a benefit).

Other commentators agree that such decisions involve value judgments that should not be vested solely in medical professionals, but suggest that societal values may properly play a role in making the decisions. See Ann Alpers & Bernard Lo, Futility: Not Just a Medical Issue, 20 Law Med. & Health Care 327 (1992).

Tomlinson and Brody reject the "values" criticism of futility doctrine by arguing that the very definition of the goals of medical treatment inherently involves value judgments, which in turn limit the range of treatment options a physician is obligated to consider. Tomlinson & Brody, Futility and Ethics, supra note 12, at 1276-77 (noting the arguments against futility judgments).

76. See Truog et al., supra note 19, at 1561 (comparing the goals of short- and long-term survival).
going home.\textsuperscript{77}

An additional objection to using futility to legitimize physicians' unilateral refusals of treatment is that the whole concept is currently so ambiguous and ill-defined that it does not justify shifting decisionmaking authority from patient to physician.\textsuperscript{78} Because the medical community, much less society at large, is unable to agree on the meaning of futility, the concept could prove dangerously malleable, allowing physicians to make nontreatment decisions based on personal, and perhaps biased, value judgments.\textsuperscript{79} These concerns about definitional vagueness, however, might be partially assuaged by medical societies' development, with public input, of clearly articulated standards for identifying cases of futility.\textsuperscript{80}

\textbf{D. Futility as a Mechanism for Rationing Care}

Regardless of their views on physicians' authority to refuse treatment on futility grounds, many commentators agree that a physician's assessment of futility should not mask individual judgments regarding a treatment's cost effectiveness.\textsuperscript{81} This view reflects a concern that any acceptable

\textsuperscript{77} Id. For example, Youngner points out that a patient may value achieving additional days of life in order to have the opportunity to say good-bye to a loved one or to greet the birth of a new family member. Youngner, supra note 12, at 2095.

\textsuperscript{78} See Lantos, supra note 12, at 82-83 (discussing futility as ambiguous for reasons of linguistics, research deficiencies, social and psychological factors, and disagreement between doctors); Curtis et al., supra note 41; see also supra text accompanying 29-42.

\textsuperscript{79} See Grant, supra note 61, at 331 (discussing danger of disability discrimination and subjective quality of life judgments in the guise of futility judgments); Giles R. Scofield, Medical Futility Judgment: Discriminating or Discriminatory, 25 Seton Hall L. Rev. 927, 929 n.16 (1995) (citing studies suggesting that physicians may make futility judgments in a discriminatory fashion); cf. Schneiderman & Jecker, Futility in Practice, supra note 27, at 437 (recognizing that "much of the resistance to futility . . . derives from the fear that it will serve as a maskografía for less defensible motivations").

\textsuperscript{80} For examples of guidelines issued by professional societies that have some bearing on questions of futility, see American Thoracic Society, Withholding and Withdrawing Life-Sustaining Therapy, 115 Annals Internal Med. 478 (1992); Task Force on Ethics of the Society of Critical Medicine, Consensus Report on the Ethics of Foregoing Life-Sustaining Treatments In the Critically Ill, 18 Critical Care Med. 1435 (1989); cf. Brennan, supra note 28, at 338 (recognizing need to build consensus regarding the meaning of futility and suggesting that ethics committees can play role in process); Stell, supra note 15, at 493 (arguing that hospitals should adopt written standards concerning withholding or withdrawing life-sustaining treatments on the grounds of futility, over the objections of patients or their surrogates, if necessary); Truog et al., supra note 19, at 1563 (pointing to need for development of social consensus regarding limitations on treatment).

Even some proponents of physicians' authority to make and act upon futility determinations recognize that ultimately a societal consensus regarding the meaning of futility is desirable, but maintain that physicians should get the ball rolling by offering proposed definitions. See Loewy & Carlson, supra note 27, at 431 (encouraging representative bodies to engage in a process of determining when specific treatment should be deemed futile); Jecker & Schneiderman, 1992 Guidelines, supra note 27, at 2198 (arguing for a public consensus); Tomlinson & Brody, Futility and Ethics, supra note 12, at 1280 (examining AHA guidelines for CPR and ECC).

\textsuperscript{81} See, e.g., Alpers & Lo, supra note 75, at 328 ("It offends the idea of justice to have life
rationing of resources devoted to medical care properly should be based on societal standards developed as a matter of public policy, and not on individual physicians’ “bedside rationing” decisions. Ad hoc physician rationing operating under the guise of futility judgments would heighten the already considerable danger of the physician’s personal biases infecting her decisionmaking process. Furthermore, endorsing physicians’ attempts to advance societal objectives by rationing care in individual cases departs from prevailing medical ethics standards, which permit no extrinsic interest to compromise a physician’s focus on advancing the best interests of her patient. Despite these concerns, many commentators acknowledge

and death decisions rest in the hands of individual doctors who, by invoking futility, can ration health care without explanation either to the patient or the community; Brennan, supra note 28, at 588 (arguing that physicians should not be able to make unilateral rationing decisions under the guise of futility); Cranford & Gostin, supra note 28, at 509 (arguing that society, not physicians, should set limits on the availability of some care); Jecker & Schneiderman, 1992 Guidelines, supra note 27, at 2198 (arguing that influence of money upon physicians is inappropriate); Tomlinson & Brody, Futility and Ethics, supra note 12, at 1280 (same); Veatch & Spicer, supra note 27, at 29 (same); Youngner, supra note 12, at 2095 (arguing that until we reach a public consensus, physicians should separate concerns about patient welfare from public policy issues). Not all commentators, however, believe the influence of monetary factors to be inappropriate. See, e.g., Prendergast, supra note 39, at 837 (“Monetary costs are one part of the sense of disproportion that generates the sense of futility.”).

82. “Rationing,” like “futility,” is a term whose casual use encompasses a range of concepts and whose precise meaning is subject to debate. Many commentators distinguish between “allocation” of health care resources, which involves a societal decision regarding the total level of resources to be devoted generally to a particular purpose like health care, and “rationing” of medical care, which involves whether a particular person shall receive a particular treatment. See Barry R. Furrow et al., Health Law 633 (2d ed. 1991). For diverse discussions of the theoretical and practical problems involved in health care rationing, see, e.g., Norman Daniels, Four Unsolved Rationing Problems: A Challenge, 24 Hastings Center Rep., July-Aug. 1994, at 27; Orendicher, supra note 8, at 308 (distinguishing between rationing based on type of service and rationing based on type of person); Symposium, The Law and Policy of Health Care Rationing: Models and Accountability, 140 U. Pa. L. Rev. 1505 (1992).

Jecker and Schneiderman attempt to distinguish rationing from futility by pointing out that “futility has no explicit distributive meaning but refers instead to a specific cause-and-effect relationship. Rationing, by contrast, always indicates a distributive choice, rather than a cause-and-effect logic.” Jecker & Schneiderman, Futility and Rationing, supra note 33, at 194. But see Prendergast, supra note 39, at 837 (“Where [monetary costs] predominate, the use of futility is properly one extreme case of rationing.”); Scofield, supra note 79, at 929 (disputing premise that futility decisions and rationing decisions are distinguishable).

83. See, e.g., Cranford & Gostin, supra note 28, at 509 (“If a line needs to be drawn . . ., then it is for society to draw it.”); Sorum, supra note 14, at 627; Veatch & Spicer, supra note 27, at 28-29.

84. See Alpers & Lo, supra note 75, at 328; Grant, supra note 61, at 334. Various studies suggest that physicians’ decisions are influenced by illegitimate, nonmedical factors. See, e.g., Gender Disparities in Clinical Decision Making, 261 JAMA 559 (1991); Mark B. Wenneker & Arnold M. Epstein, Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts, 261 JAMA 253 (1989); cf. Loewy & Carlson, supra note 27, at 430-31 (noting physicians’ inconsistency in making futility judgments in individual cases).

85. See, e.g., AMA Council on Ethical & Jud. Aff., Current Opinions, op. 2.09
that if physicians are authorized to make unilateral nontreatment decisions based on futility, consciousness of treatment costs inevitably may creep into the physician's calculus regarding the utility of treatment.86

Responding to this concern about futility judgments masking ad hoc rationing decisions, some commentators suggest that the development of standards regarding futile treatment should proceed on an institutional basis, for example, by professional medical societies87 or hospital ethics committees.88 These bodies are judged less likely to be influenced by objectionable biases and more likely to represent societal views, so that, if cost concerns do influence futility judgments, we can be somewhat more comfortable that those judgments comport with societal values.89 Critics of this institutional approach, however, point out that, if allocation decisions regarding scarce medical resources are at issue, delegating those decisions to groups of medical professionals still grants too great a prerogative to groups whose values may depart from societal values.90

Into this cacophony of voices debating who should make futility decisions and whether cost can play any proper role in those decisions, stepped Donald Murphy and Thomas Finucane. In a 1993 article,91 they forthrightly and unabashedly argued that futility standards should be used to advance cost containment goals. Murphy and Finucane essentially argued that a society characterized by scarcity of resources and an overabundance of medical needs can best achieve the cost containment necessary for improving access to beneficial medical care by limiting the resources spent on treatments offering the lowest probability of benefit. Furthermore, they argued that nontreatment policies based on futility are
an appropriate vehicle for doing so. In their view, a social compact to limit treatment in order to contain costs and thereby increase access overrides the individual's assertion of autonomy in medical treatment decision making.

Under Murphy and Finucane's proposal, an individual hospital or a consortium of hospitals in a community should take the lead in promulgating policies that deny CPR to patients falling into categories for which CPR has been judged futile. Murphy and Finucane's definition of futility is admittedly more expansive and less precise than some definitions suggested by other medical commentators. They reject both the concept of purely physiological futility and the adoption of specific, set thresholds for probability of benefit. Instead, they use futility to mean "treatment that is so unlikely to succeed that many people — professional and lay persons — would consider it not worth the cost." Thus, they frankly admit to the need for making value judgments. For this reason, they suggest that the public should play some role in developing and critiquing nontreatment policies.

This proposal is not simply the stuff of academic and professional journals. In fact, as noted above, hospitals in the Denver area, under the guidance of Donald Murphy, among others, are in the process of articulating guidelines for limiting treatment on the basis of medical futility. As part of this project, dubbed GUIDe, committees composed of a broad range of health professionals are drafting proposals for futile treatment.

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92. "We believe that our society must set explicit limits to allocate health care more justly in our society. . . . We believe that limits based on probability of benefit are more fair — and less painful — than the current limits in health care that are based on ability to pay." Id. at 1647. See also Donald J. Murphy, Can We Set Futile Care Policies? Institutional and Systemic Challenges, 42 J. Am. Geriatrics Soc'y 890 (1994).

93. Thus, Murphy and Finucane avoid the fray between advocates of physician authority and advocates of patient autonomy. "Instead of physician authority, we propose a social agreement among citizens to limit this particular treatment." See Murphy & Finucane, supra note 19, at 1644.

94. Murphy and Finucane include a number of categories of patients who are extremely unlikely, based on the medical literature, to survive to hospital discharge after CPR. Id. at 1642-43. These categories include bedfast patients with metastatic cancer, patients with Child's Class C cirrhosis, patients with HIV infection and two or more episodes of pneumocystis carinii pneumonia, patients with dementia requiring long-term care, comatose patients in the intensive care unit who do not awaken after 48 hours, patients with multiple organ system failure, and patients who have undergone unsuccessful CPR outside of the hospital. Id. The authors note, however, that these categories are just suggestions and that hospitals should consider local survival rates in establishing nontreatment policies. In addition, the authors suggest that therapies other than CPR could be limited on grounds of futility.

95. Id. While not adopting a specific threshold for the probability of benefit, the authors do note that the groups of patients described in their article, see supra note 94, all have a probability of survival to discharge following CPR of less than 3%. Id. at 1642.

96. Id. at 1644.

97. See Gianelli, Fix on Futility, supra note 4 (describing attempt to draft guidelines for futile care that will be shared with the public in two years).

98. "GUIDe" stands for Guidelines for Use of Intensive Care in Denver. Id.
care guidelines, which proposals will then be shared with the greater medical community and the public for comment and input. The ultimate goal—once consensus on the guidelines is achieved—is for hospitals in Denver collectively to refuse to provide the treatments deemed futile.99

This effort by Denver hospitals, and similar efforts by other facilities and groups around the country,100 raises a number of intriguing ethical and legal questions. Part III of this Article explores whether a rationing policy limiting treatment on the grounds of futility would run afoul of disability discrimination law. This analysis will focus primarily on whether a state’s adoption of a futility policy as part of its Medicaid program should be found to violate the law, but will also consider how hospitals’ independent implementation of such a policy, on a community-wide or facility-specific basis, might be analyzed.

III. ANALYZING FUTILITY POLICIES UNDER THE AMERICANS WITH DISABILITIES ACT

A. Setting the Scene

This Part explores how a futility policy designed to contain costs might be assessed for compatibility with the Americans with Disabilities Act (ADA).101 More specifically, the exploration will focus on the legitimacy

99. Id. See also Gianelli, Community Consensus, supra note 4 (describing attempts to minimize care to persons when life expectancy is close to none); Terese Hudson & Kevin Lumsdon, Are Futile-care Policies the Answer? Providers Struggle with Decisions for Patients Near the End of Life, Hospitals & Health Networks, Feb. 20, 1994, at 28.

100. Other places where attempts to establish futile care policies are proceeding on either the community or facility level include Sacramento, Spokane, Wisconsin, Santa Monica, and San Diego. Some of these efforts include considerations of cost in their reckonings; others focus primarily or solely on issues of patient dignity and professional authority. In addition, some efforts go beyond “simply” trying to identify care that is futile, and take on the larger task of identifying “inappropriate” care. See Gianelli, Fix on Futility, supra note 4; Hudson & Lumsdon, supra note 99. For a description of four hospitals’ futility policies, see Waisel & Truog, supra note 38, at 305-06.

Although not usually so characterized, Oregon’s effort to revamp its Medicaid program to prioritize treatments covered can be seen in part as an effort to accord futile care a low priority for coverage. For discussion of Oregon’s effort, see part III.B.2.

101. Invocation of a futility policy as a basis for refusing to provide life-sustaining treatment may also provoke other legal challenges, including a constitutional challenge (if state action is involved) based on the Fourteenth Amendment’s due process protection of life, and a statutory challenge based on the federal Emergency Treatment and Active Labor Act, claiming a statutory violation by any hospital that fails to provide requested life-sustaining treatment for a patient suffering an emergency medical condition. See, e.g., 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).

For other viewpoints on the ADA’s applicability to futility judgments, see E. Haavi Morreim, Futilitarianism, Exoticare, and Coerced Altruism: The ADA Meets its Limits, 25 Seton Hall L. Rev. 883 (1995); Scofield, supra note 79, at 927. For a consideration of the ADA’s applicability to a rationing scheme based generally on effectiveness criteria, see Philip G. Peters, Jr., Health Care Rationing and Disability Rights, 70 Ind. L.J. 491 (1995) (exploring the extent to which disability law limits health care rationing using a cost-effectiveness
of a policy like that proposed by Murphy and Finucane, with their specific proposals of classes of patients for whom CPR should be deemed futile.\textsuperscript{102} This Part will consider the disability discrimination issues posed by the adoption of such a policy in two different scenarios and will develop the arguments likely to be presented to a court called on to resolve those issues.

The first scenario examined is a state's adoption of a futility policy as part of its Medicaid program (the "Medicaid futility policy").\textsuperscript{103} In essence, this scenario posits that, in order to control health care costs,\textsuperscript{104} a state's Medicaid program decides no longer to fund medical interventions considered futile, as described by Murphy and Finucane. Accordingly, the state program would no longer pay for CPR provided to Medicaid recipients diagnosed with conditions rendering CPR futile, but would continue to pay for other forms of medical treatment, such as antibiotics or comfort care, indicated for those patients.

Two assumptions basic to most of this analysis of the Medicaid futility policy are that the State Medicaid agency itself develops and implements the futility policy and that the Medicaid program pays providers on a fee-

\footnotesize{\textsuperscript{102} See Murphy \& Finucane, supra note 19. For a description of their proposal, see text accompanying notes 91-96. I chose Murphy and Finucane's proposal for my model because it forthrightly admits its cost-containment purpose, and it contains sufficient detail to stimulate factual analysis. Because their proposed policy has not yet been implemented anywhere, it is necessary to hypothesize scenarios in which implementation might occur. I recognize that a complete analysis of such a policy under the \textit{ADA} would require greater factual detail than I am positing, but I will attempt in this Part's analysis to suggest how additional facts might figure therein.

\textsuperscript{103} Medicaid, enacted in 1965 along with Medicare, provides federal matching grants to states to supply medical care for poor persons who are disabled, blind, aged, or a member of a family with dependent children.\textsuperscript{104} Total Medicaid spending more than doubled between 1988 and 1992, increasing on average 22\% per year. Teresa A. Coughlin et al., State Responses to the Medicaid Spending Crisis: 1988 to 1992, 19 J. Health Pol'y Pol'y \& L. 837, 843 (1994). Federally mandated expansions, medical inflation, and recession are among the factors contributing to the rapid rise in spending. Id. at 843. Rather than making large cut-backs in their Medicaid programs to balance their budgets, states employed various novel and traditional budget programs to curb the effect of Medicaid's rapid growth. Id. at 858. Changes made within Medicaid to reduce the rate of spending included budget reductions, special revenue programs, greater reliance on managed care programs, and shifting other programs into Medicaid. Id. at 850. Budget reductions in Medicaid have had some unintended consequences. One study found that a reduction of Medicaid payments for drugs effective in treating schizophrenia caused persons in need of those drugs to seek hospitalization and emergency mental health services at community mental health centers, thereby shifting costs to the state. Stephen B. Soumeral et al., Effects of Limiting Medicaid Drug-Reimbursement Benefits on the Use of Psychoactive Agents and Acute Mental Health Services by Patients with Schizophrenia, 331 New Eng. J. Med. 650, 654 (1994). Although the number of Medicaid recipients continues to grow, the rate of Medicaid spending appears to be slowing down. Kaiser Report Cites Slowdown of Medicaid Spending Growth, Medicare \& Medicaid Guide (CCH) No. 827, at 1 (Nov. 10, 1994).}
for-service basis. Under this scenario, therefore, the State Medicaid program would essentially pay providers no fee for any service on the list of those deemed futile. I must acknowledge, however, that the probability that a real-world scenario would embody these assumptions is decreasing. Many State Medicaid programs are experimenting with the use of capitated managed care arrangements to provide medical services to some of their Medicaid beneficiaries. Thus, a scenario in which a risk-bearing managed care organization under contract with a Medicaid agency establishes a cost-conscious futility policy is also entirely plausible. Accordingly, Part III.C will begin to explore how changes in a Medicaid program's delivery and reimbursement of health care services might affect the ADA analysis.

The second scenario examined is a hospital's decision, made either individually or as part of a group of hospitals, no longer to provide patients with care deemed futile (the "hospital futility policy"). In this scenario, which reflects endeavors to develop institutional futility care policies, the hospital would unilaterally determine or agree with other hospitals to withhold CPR from patients for whom the intervention would be futile. Again, cost control is presumed to be a motive in this scenario. As we will see, however, the strength of this motivation may depend on whether the hospital will be reimbursed for the costs of providing such care by a public or private third-party payer, or whether the hospital itself is at least partially at risk financially for the costs of providing the care—either because the patient is uninsured or because the hospital's reimbursement arrangement with a managed care organization shifts that risk to the hospital. In any event, under the hospital's futility policy, CPR could be withheld from patients regardless of their ability to pay for such treatment.

105. See infra note 286 for a description of fee-for-service reimbursement.
106. See generally John Holahan et al., Insuring the Poor Through Section 1115 Medicaid Waivers, Health Aff., at 199 (Spring 1995).
107. One of the issues that would arise under such an arrangement would be whether care policies should be analyzed under Title II of the ADA, which applies to public entities (including state agencies), or under Title III, which applies to public accommodations. See infra notes 141-43 and accompanying text.
108. As a practical matter, some level of public discussion and public input regarding the futility policy is likely to be sought in either of these scenarios. Most proponents of futility limitations on the availability of medical treatments agree that a process of public consensus building should play some part in establishing those limitations. See supra notes 89-90. Based on Oregon's experience in seeking federal approval for its rationing plan, the element of public input may raise additional issues under the ADA. See infra note 137.
109. Some hospitals may assert an obligation to act as responsible "stewards" of health care resources even if they institutionally do not directly bear the cost of futile treatment. See Miles, supra note 3, at 514 (raising stewardship argument with respect to the Wanglie case). Moreover, it is worth bearing in mind that some institutions that are currently developing futility guidelines are prompted more by concerns regarding professional and institutional authority than by concerns regarding costs. See Gianelli, Fix on Futility, supra note 4.
110. It is easy to imagine additional scenarios in which an entity responsible for providing,
It bears emphasis that, in either of these scenarios, we are talking about a policy decision not to pay for (or provide, as the case may be) certain types of treatments for certain groups of patients. The purpose motivating this policy decision is to allocate health care resources in a fashion judged desirable. Although providers necessarily must implement any policy that denies futile care on a patient-by-patient basis by determining whether the patient and treatment at issue fall within the policy's excluded classes, this Article does not address individual medical treatment decisions centered on the desirability or appropriateness of a medical intervention for a particular patient.  

B. The ADA and Medical Care  

I. Background  

Congress enacted the ADA in 1990 to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” Congressional endorsement of this ambitious purpose marked the culmination of years of legislative efforts by disability rights advocates to achieve enactment of comprehensive antidiscrimination legislation. Prior to the ADA’s enactment, the primary legislation broadly guaranteeing the rights of persons with disabilities was Section 504 of the Rehabilitation Act of 1973, which prohibits grantees of federal funds from discriminating against persons with disabilities. In passing the ADA, Congress sought to build upon and broaden the protective scope of Section 504 by making the ADA
applicable to virtually all public actors.\textsuperscript{115}

The legislative findings and legislative history of the ADA reveal Congress's recognition of the magnitude of the problem of disability discrimination. Specifically, Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and . . . such forms of discrimination . . . continue to be a serious and pervasive social problem. . . ."\textsuperscript{116} In enacting its "clear and comprehensive national mandate" to treat this problem, however, Congress crafted a statute that is an odd mix of specific and general provisions. For example, while the statute provides detailed guidance for public transit operators regarding their statutory obligations,\textsuperscript{117} it merely paints with a broad brush the obligations generally attaching to public entities and public accommodations, leaving to the agencies and the courts the task of defining the meaning of the ADA's nondiscrimination mandate in particular contexts.\textsuperscript{118}

Health care is one area with respect to which the statutory language leaves the precise contours of the ADA's mandate far from clear.\textsuperscript{119} Although Congress listed "health services" as one of several critical areas in

\begin{itemize}
\item[115.] For one court's account of the legislative background of the ADA, see Fink v. Kitzman, 881 F. Supp. 1347, 1368 (N.D. Iowa 1995); see also Coleman v. Zatechka, 824 F. Supp. 1350, 1367 (D. Neb. 1993) ("Although the ADA provides persons with disabilities with the same rights and remedies as provided under the Rehabilitation Act, . . . the ADA is not limited to programs receiving federal funding, but rather applies to all public entities."). Section 501 of the ADA expressly states that "nothing in this chapter shall be construed to apply a lesser standard than the standards applied under Title V of the Rehabilitation Act of 1973 . . . or the regulations issued by Federal [sic] agencies pursuant to such title." 42 U.S.C. § 12201(a) (Supp. V 1993). Federal courts interpreting the ADA have looked to caselaw applying § 504 for guidance.
\item[116.] 42 U.S.C. § 12101(a) (2) (Supp. V 1993). In addition, Congress found that:
\begin{itemize}
\item[(a)] Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.
\end{itemize}
\item[119.] \textit{See generally} Lawrence O. Gostin, Legislative Report: The Americans with Disabilities Act and the U.S. Health System, Health Affs. at 248 (Fall 1992) (discussing how the ADA affects the health care system); Wendy E. Parmet, Discrimination and Disability: The Challenges of the ADA, 18 Law Med. & Health Care 331, 339-40 (1990) (arguing that the ADA is unclear about its impact on medical decisionmaking).
\end{itemize}
which disability discrimination persists, the statute does not indicate specifically how the ADA's charge applies to health care providers, payers, or policymakers. Nonetheless, courts have recognized that Section 504 and the ADA potentially apply to a variety of situations involving medical care, including a state's policy decisions regarding the funding or availability of medical services, actions taken to protect public health, denials of access to providers, and cases in which a patient's disability influenced the treatment provided. In addition, the ADA's implications for health care reform were highlighted by the response of the Secretary of Health and Human Services (HHS) in 1992 to Oregon's application for a Medicaid waiver that would allow the State to proceed with a plan to provide health insurance for all of its indigent residents by excluding certain services from coverage.

2. Rationing Care: The Oregon Experience

In August 1992, the Secretary of Health and Human Services (HHS) denied Oregon's request for a Medicaid waiver to permit implementation of its plan for rationing medical services provided to the State's Medicaid recipients. Perceived conflict with the ADA was the reason cited for the

121. Section 501(c) of the ADA exempts some insurance practices, including underwriting and classifying risks, from the ADA, unless the practices are used as a "subterfuge to evade the purposes of Subtitles I and III [of the ADA]." 42 U.S.C. § 12201(c) (1990). For further discussion of this exemption from ADA coverage, see infra part III.C.5.
122. See Alexander v. Choate, 469 U.S. 287, 303-04 (1985) (holding that while § 504 does try to assure equal treatment for disabled individuals in the health care field, it does not guarantee "equal results from the provision of state Medicaid").
125. See Woolfolk v. Duncan, 872 F. Supp. 1381 (E.D. Pa. 1995) (finding factual issue as to whether HIV-infected plaintiff was denied medical benefits based on his HIV status); Howe v. Hull, 874 F. Supp. 779 (N.D. Ohio 1994) (finding factual issue as to whether physician denied HIV-infected patient treatment for non-HIV-related drug reaction based on his HIV status); 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). The court in Howe recognized that discrimination in the provision of medical treatment may take a variety of forms: "[D]enial of the opportunity to receive medical treatment, segregation unnecessary for the provision of effective medical treatment, unnecessary screening or eligibility requirements for treatment, or provision of unequal medical benefits based upon the disability." Howe, 874 F. Supp. at 788 (citations omitted).
126. See Letter from Louis W. Sullivan, Secretary of Health and Human Services, to Barbara Roberts, Governor of Oregon, Aug. 3, 1992 (with accompanying three-page "Analysis
Secretary's denial, and this denial of Oregon's much ballyhooed rationing scheme signalled the ADA's potential to act as a roadblock to any health care reform that seeks to control costs by limiting services. While this Article does not aim to add to the copious commentary on the propriety or wisdom of the Secretary's judgment, briefly considering the nature of Oregon's plan and the reasoning behind HHS's denial may help inform our subsequent consideration of a futility-based rationing scheme's compatibility with the ADA.

In 1989, Oregon's legislature approved a plan to provide coverage under the State's Medicaid program to all Oregon residents living in poverty, while at the same time limiting the services covered by the program to a benefits package based on a prioritized list of medical services. The list, according to legislative directive, was to reflect "health services . . . ranked by priority from the most important to the least important, representing the comparative benefits of each service to the entire population to be served." The legislature assigned the task of compiling and ranking this list of all medical conditions paired with their corresponding treatments ("condition-treatment pairs") to the Oregon Health Services Commission (HSC), an eleven-member body appointed by the governor.

To accomplish this formidable task, the HSC undertook a complicated, multistep process. To simplify greatly, the HSC first


130. Id. § 414.715(1).

131. The following discussion of the process of devising the list is drawn primarily from
solicited input regarding both individual and community values attached to medical care. The vehicle the HSC used to seek individual values was a random-sample telephone survey of 1000 Oregonians, which asked participants to assign values to living in different health states, described in terms of functional impairments and the symptoms associated with a given condition. With this “values” information in hand, the HSC constructed and classified seventeen general categories of health care services, ranging from “essential” services (including treatment for acute fatal conditions, when that treatment prevents death and allows full recovery), to “very important” services (including one-time treatment for chronic, nonfatal conditions, when that treatment improves the patient’s quality of life), to services “valuable to certain individuals” (including infertility services and treatment for fatal or nonfatal conditions, when that treatment provides minimal or no improvement in the patient’s quality of life). Then, based on information gathered from panels of health care providers regarding the prognosis (whether death, survival with residual effects, or complete cure) and estimated costs for each condition, with and without its corresponding treatment, the HSC placed each of 709 condition-treatment pairs into one of these seventeen health care categories. The next step involved the HSC’s prioritizing each condition-treatment pair within its assigned category based on a “net-benefit formula” designed to reflect the assembled individual, community, and professional values. Finally, the HSC reviewed the list and made hand adjustments to its rankings to correct for any counterintuitive results. When the end result of this process—a prioritized listing of 709 condition-treatment pairs—was presented to the Oregon legislature, the legislature determined that the State would fund only those treatments ranked number 587 and higher on the list.

To implement this revamping of its Medicaid program, Oregon had to seek a waiver of certain federal Medicaid requirements from HHS.

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Michael J. Garland, Rationing in Public: Oregon’s Priority Setting Methodology, in Rationing America’s Medical Care: The Oregon Plan and Beyond 37 (Martin A. Strosberg et al. eds., The Brookings Institution 1992); see also Roggin, supra note 127, at 227; Stade, supra note 127, at 1900-95. It is worth noting that Oregon’s initial treatment ranking, produced in May 1990, was based purely on cost-effectiveness criteria, but the counterintuitive results of this approach led the HSC to start over using the more complex process described in the text. See Peters, supra note 101, at 502.

132. Information regarding community values attached to health care was sought at a series of public hearings and town meetings. See Stade, supra note 127, at 1992.

133. For a complete list of the 17 ranked categories, see Roggin, supra note 127, at 231 n.101. In general, the ranking favored acute care over chronic care, treatment for fatal conditions over that for nonfatal conditions, and complete cures over partial cures. See Peters, supra note 101, at 503 n.49.


135. Under § 1115 of the Social Security Act, a state Medicaid program must seek a waiver from HHS or from Congress if it deviates from certain federal Medicaid standards. See 42 U.S.C. § 1315(a) (1988). Oregon needed a waiver because its plan sought to expand Medicaid coverage to all Oregonians with an income below the federal poverty level and because the
After months of speculation and debate in health policy circles, the Secretary denied Oregon’s waiver request based on its apparent conflict with the ADA. The Secretary’s reasons for denial included both concerns stemming from the prioritization process described above and, in two instances, concerns regarding specific rankings of condition-treatment pairs. First, Oregon’s reliance on telephone surveys of the general public may have “quantifie[d] stereotypic assumptions about persons with disabilities.” In addition, in ranking the 709 condition-treatment pairs and making its final hand adjustments, the HSC partially relied on certain community values, including “quality of life” and “ability to function.” In these facets of the prioritization process, the Secretary found “considerable evidence that [the list] was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability. This is a premise that is inconsistent with the ADA.”

As additional evidence of incompatibility with the ADA, the Secretary pointed to the rankings for liver transplants for alcoholic cirrhosis of the liver and for life support for babies with extremely low birth weight, both of which fell below the funding cut-off point on the list. Because liver transplants for nonalcoholic cirrhosis of the liver were ranked high enough to be covered, the Secretary concluded that the coverage decision was contingent on the existence of alcoholism—a disabling condition under the ADA. Likewise, because medical therapy for low birth weight babies was ranked higher than treatment for extremely low birth weight babies, so that the former was covered while the latter was not, the Secretary found similar concerns under the ADA.

Thus, the Secretary found Oregon’s scheme problematic on two basic counts: It produced coverage distinctions that appeared to hinge on the existence of a disability, and its process for making coverage decisions relied in part on quality of life considerations presumed to devalue the quality of life with a disability. The Secretary, however, encouraged Oregon to try again. In revising its plan, the Secretary suggested, Oregon could consider a wide range of factors—including “the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases”—in allocating resources consistently with the ADA. These points may merit further examination when we plan’s benefit package would deviate from the federally mandated benefit package.


137. Sullivan letter, supra note 126, at 410.


139. Sullivan letter, supra note 126, at 411-12.

140. Sullivan letter, supra note 126, at 411. In suggesting these factors, the Secretary cited to Alexander v. Choate, 469 U.S. 287 (1985). For discussion of Alexander, see infra text accompanying notes 160-64.

In November 1992, after attempting to respond to the Department’s concerns by eliminating all references to quality of life and cutting certain information obtained from the
next turn to assessing a futility policy’s compatibility with the ADA.

This Article undertakes the mission of considering how the ADA’s nondiscrimination mandate might apply to a futility policy adopted in each of the scenarios described in Part IIIA. As a starting point, it should be noted that each scenario implicates a different Title of the ADA. The Medicaid futility policy, as a policy of a state agency, raises questions under Title II, which prohibits discrimination by public entities. The hospital futility policy, by contrast, is subject to the provisions of Title III, which prohibits discrimination by public accommodations. Because the two Titles’ statutory prohibitions are quite similar, however, this Article will focus primarily on analyzing the Medicaid futility policy under Title II and then shift its attention to how differences in statutory language or relevant facts might affect analysis of the hospital futility policy under Title III.

C. Title II and the Medicaid Futility Policy

Title II’s broad nondiscrimination provision provides that: “[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”

140. In relevant part, the ADA defines “public entity” as “any State or local government” and “any department, agency, special purpose district, or other instrumentality of a State or States or local government.” 42 U.S.C. § 12131(1) & (B) (Supp. V 1993).

142. In defining “public accommodation” the ADA sets forth a list of types of private entities that will be considered public accommodations if their operations affect commerce. Id. § 12181(7). The list includes the “professional office of a health care provider [or] hospital.” Id. § 12181(7)(F).

143. Title II’s general prohibition of discrimination provides:

Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subject to discrimination by any such entity.

Id. § 12132.

Title III’s general prohibition of discrimination provides:

No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.

Id. § 12182(a).
by any such entity." Because the term "public entity" includes states and their departments, agencies and other instrumentalities, a state's Medicaid program is subject to this statutory prohibition. In order to prove an ADA violation by a public entity, a plaintiff must show that (1) an individual with a disability was (2) excluded from or denied the benefits of a public entity, (3) by reason of that individual's disability, and (4) the individual was qualified to participate or receive the benefits in question. While these elements can be stated in formulaic fashion, their potential application to a state Medicaid program's adoption of a futility policy is anything but straightforward.

I. Individuals with Disabilities

The first element of a Title II case is by far the easiest to address and the least subject to counter-argument in the context of a Medicaid futility policy. Would the group of persons denied coverage for certain medical services due to a Medicaid program's adoption of a futility policy include an "individual with a disability," who would thus have standing to challenge the policy? The ADA's core definition of "disability" is an actual impairment that substantially limits one or more major life activities. While declining to attempt to list all impairments that could produce a disability, the Department of Justice's regulations implementing Title II offers the following nonexhaustive compilation: orthopedic impairments, visual impairments, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease, tuberculosis, drug addiction, and alcoholism. Thus, any of these impairments that substantially limits a particular person's ability to care for herself, to walk, to see, to breathe, or to work, for example, would qualify as a disability.

Without trying to identify all of the types of cases for which treatment might be limited under a futility policy, we can, simply by looking at Murphy and Finucane's proposed categories of patients for whom CPR

144. Id. § 12132.
145. Id. §§ 12131(1)(A) - (B).
146. Even prior to the ADA's enactment, state Medicaid programs, as recipients of federal funds, were prohibited by § 504 from discriminating against persons with disabilities. See, e.g., Alexander v. Choate, 469 U.S. 287 (1985); Doe v. Colautti, 592 F.2d 704 (3d Cir. 1979); Duquette v. Dupuis, 582 F. Supp. 1366 (D.N.H. 1984).
148. See Orentlicher, supra note 8, at 309 ("The definition of disability is broad and ordinarily will not be a serious hurdle for lawsuits claiming discrimination in health care rationing.").
149. See 42 U.S.C. § 12102(2) (1992). The term also extends to having a history of such an impairment or being regarded as having such an impairment. Id.
151. See id. (defining "major life activities").
should be deemed futile, begin to get a sense of whether those patients would be considered disabled for purposes of the ADA. For example, bedfast persons with metastatic cancer, HIV-infected persons who have twice suffered bouts of pneumocystis carinii pneumonia, and persons with multiple organ system failure are persons who almost certainly have impairments substantially limiting a major life activity. Upon reflection, it is quite difficult to imagine (or find in the medical literature) an example of a person for whom life-sustaining medical treatment would be deemed futile who would not also be "an individual with a disability."

At this point, a distinction must be drawn between the specific connotation that the term "futility" has acquired in the debate described in Part II of this Article and the more general meaning that the term denotes. The ongoing debate over the definition and implications of medical futility has focused specifically on instances when life-sustaining interventions are deemed to offer no meaningful benefit to a critically ill patient near the end of his life. By contrast, the more general denotation of futile care is any medical care that cannot produce an intended result. Using this general definition, a number of medical interventions in non-life-threatening contexts may be considered futile in the sense of offering no or only very marginal benefit. A classic example is the common practice of physicians prescribing antibiotics to "treat" viral colds or sore throats. With this distinction in mind, it should become

152. Cf. School Bd. of Nassau County, Fla. v. Arline, 480 U.S. 273, 281 (1987) (finding that plaintiff's need for hospitalization because of tuberculosis was "a fact more than sufficient to establish that one or more of her major life activities were substantially limited by her impairment").

153. Courts have recognized that temporary impairments that limit a major life activity should not be deemed disabilities because of their transitory nature. See McDonald v. Pennsylvania, 62 F.3d 92, 95-96 (3d Cir. 1995); Hutchinson v. United Parcel Serv., 883 F. Supp. 379, 395-96 (N.D. Iowa 1995). One could argue that because the impairments experienced by persons to whom a futility limitation on medical treatment would apply ordinarily reflect the penultimate stage in a process of progressively declining health, those impairments should not be deemed "disabilities" within the meaning of the ADA. To put it bluntly, impairments suffered immediately prior to death are only "temporary." At least two responses may be made to this argument. First, from the perspective of the patient experiencing the impairments, they are permanent; a return to able-bodied existence is virtually impossible. Second, although the extreme decline in health that renders life-sustaining treatment futile—and its attendant impairments—may be relatively short-lived, it is reasonable to assume that in most cases the patient has experienced progressively severe disability over a longer period of time. In other words, assessment of a person's "disability" must take into account the entire period of impairment.

154. Cf. Prendergast, supra note 39, at 836 ("[I]t is in the critically ill that appeals to futility appear most often in medical discussions."). As Dr. Prendergast explains, there are numerous occasions in clinical practice when a physician may reject the treatment request of a noncritically ill patient, but the physician is likely to rely on justifications other than futility of the treatment. Id.

155. One physician friend referred, anecdotally, to physicians "handing out ampicillin like candy" for viral sore throats. Telephone interview with Dr. Joseph Luna (Jan. 1, 1995). But see Prendergast, supra note 39, at 836 ("Erythromycin is not an appropriate treatment for the
obvious that a state's policy not to pay for medical care that is futile or nonbeneficial in this more general sense\textsuperscript{156} would not be limited in its effect to persons with disabilities, for certainly not everyone who goes to the doctor requesting treatment for the common cold is an individual with a disability. By contrast, a Medicaid futility policy focused, like Murphy and Finucane's proposal, on life-sustaining interventions for persons near the end of life would likely impact only persons with disabilities. In other words, "an individual with a disability" would be denied the state's payment for treatment (and probably the treatment itself) as a result of the futility policy.\textsuperscript{157}

Having concluded that a Medicaid futility policy, which excludes coverage for life-sustaining treatments along the lines proposed by Murphy and Finucane, would clearly affect some persons with disabilities and, in all likelihood, would affect only persons with disabilities, we turn now to consider the other elements of a Title II violation. Before beginning this discussion, however, a disclaimer is in order. Any perception, based on the following discussion, that the different elements tend to blur and blend at the edges is accurate. As some courts recognize explicitly\textsuperscript{158} and others demonstrate unwittingly, an attempt to draw clear lines around the concepts of benefit, denial based on disability, and qualification of a disabled individual is doomed to failure, or at least to severe confusion.

\textsuperscript{156} In fact, Oregon's plan to reform its Medicaid program can be seen, at least in part, as an attempt to exclude coverage for care that is futile in this more general sense. For example, of the seventeen general categories of health services devised by the HSC, the one ranked lowest was "[f]atal or nonfatal, minimal or no improvement in [patient's quality of well-being]." An example provided by the HSC of this type of treatment was "medical therapy for viral warts." See Roggin, supra note 127, at 231 n.101; see also supra note 133 and accompanying text.

\textsuperscript{157} It may be helpful to note that persons so affected by a Medicaid futility policy may in fact have two or more, possibly related, relevant physiological conditions. One condition is that which presents an immediate need for medical intervention (e.g., cardiac arrest). The second condition is the underlying condition (e.g., metastatic cancer) that impedes the ability of the patient to respond to a medical intervention provided in response to the first condition and thus renders that intervention futile. Another illustration is found in the Baby K case, where an infant's mother sought ventilator support (the intervention) to respond to the infant's breathing difficulty (the immediate condition). See In re Baby K., 832 F. Supp. 1022, 1024 (E.D. Va. 1993), aff'd, 16 F.3d 590 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994). However, the hospital wished not to provide the ventilator support on the grounds that the infant's anencephaly (the underlying condition) would render the support futile. Id. While the first condition conceivably could be a disability, it is the second, underlying condition that is the disability "by reason of" which the patient arguably is being denied medical treatment for purposes of the ADA. Cf. Morreim, supra note 101, at 895-97 (describing relationship of disabilities and secondary conditions).

\textsuperscript{158} Cf. Alexander v. Choate, 469 U.S. 287, 299 n.19 (1985) ("The question of who is 'otherwise qualified' and what actions constitute 'discrimination' under § 504 would seem to be two sides of a single coin; the ultimate question is the extent to which a grantee is required to make reasonable modifications in its programs for the needs of the handicapped.").
Thus, although the following sections of this Part are divided and labelled for organizational purposes, some overlap in the discussion is inevitable.

2. Denied Benefits by a Public Entity

As noted above, Title II generally prohibits a public entity from discriminating against a person with a disability by excluding her from participation in or denying her the benefits of any of its programs. Because the hypothetical Medicaid futility policy will not entirely exclude anyone from Medicaid coverage, the statutory proscription of denial of benefits seems more apt. That said, the question becomes: What is the benefit whose provision or denial is at issue?

a. Alexander v. Choate

The Supreme Court addressed the problem of defining the benefits offered by a state Medicaid program in Alexander v. Choate. The plaintiffs in Alexander challenged Tennessee’s reduction of the number of days of inpatient care for which the State’s Medicaid program would reimburse a hospital that cared for a Medicaid recipient. According to the plaintiffs, the reduction violated Section 504 of the Rehabilitation Act because it would produce a disproportionate adverse impact on individuals with a disability as a consequence of their greater needs for medical care. While accepting plaintiffs’ argument that Congress intended Section 504 to reach at least some cases of disparate impact discrimination, Justice Marshall concluded that Tennessee’s fourteen-day limitation on inpatient coverage did not deprive the plaintiffs of meaningful access to the benefits of the State’s Medicaid program.

This conclusion rests on two related trains of reasoning. First, under Tennessee’s program both persons with a disability and persons without a disability would be afforded “identical and effective hospital services fully available for their use, with both classes of users subject to the same durational limitation.” Thus, Tennessee did not deny the plaintiffs access to the benefit strictly defined as fourteen days of inpatient coverage. Second, Justice Marshall refused to define the relevant benefit other than strictly. He rejected plaintiffs’ contention that, because of their special medical needs, they should be accorded more days of coverage to allow them to receive the same “benefit.” Medicaid programs, he reasoned, do not provide a benefit amorphously defined as “adequate health care”:

Instead, the benefit provided through Medicaid is a

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159. In other words, the futility policy is likely to deny coverage for certain treatments for certain persons, but not to exclude those persons from the Medicaid program altogether.
161. See infra note 180 (distinguishing between differential treatment and disparate impact as bases for a discrimination claim).
162. Alexander, 469 U.S. at 290-303.
163. Id. at 302.
particular package of health care services, such as 14 days of inpatient coverage. That package of services has the general aim of assuring that individuals will receive necessary medical care, but the benefit provided remains the individual services offered—not "adequate health care." Thus, the only benefit the plaintiffs could show they were denied was a benefit the State's Medicaid program didn't offer.

b. Defining the "benefit"

In light of the Court's reasoning in Alexander, the legality of a Medicaid futility policy may turn, at least in part, on how the relevant benefit is defined. Persons with disabilities challenging the futility policy would seek to define the benefit as coverage for "life-sustaining medical interventions," such as CPR. Furthermore, they could argue, the futility policy would prevent that benefit from being equally accessible to persons with disabilities and those without disabilities, as required by the ADA. From this perspective, Alexander can be distinguished as involving a claim that a defined benefit was less valuable to persons with disabilities, while by contrast, the Medicaid futility policy violates the ADA by depriving persons with disabilities of equal access to a defined benefit. Moreover, any allegation that receipt of the defined benefit will afford some persons with severe disabilities no long-term utility fails to compel a different conclusion; the ADA focuses on equality of opportunity to achieve benefits, not on equality of outcome.

The State, by contrast, could defend the futility policy by asserting

164. Id. at 303.
165. See Doe v. Colautti, 454 F. Supp. 621, 628 (E.D. Pa. 1978), aff'd, 592 F.2d 704 (3d Cir. 1979) (concluding, after reviewing the Department of Health, Education and Welfare's analysis of regulations issued under § 504, that the analysis "suggest[s] that such a provider [of health or social services] need do no more than provide handicapped persons with the same services it provides to non-handicapped persons"). Cf. In re Baby K, 832 F. Supp. 1022, 1029 (E.D. Va. 1993) (rejecting hospital's reasoning because it "would lead to the denial of Medicaid services to anencephalic babies as a class of disabled individuals" and noting that "[s]uch discrimination against a vulnerable population class is exactly what the Americans with Disabilities Act was enacted to prohibit").
166. See Concerned Parents to Save Dreher Park Cent. v. City of W. Palm Beach, 846 F. Supp. 986, 990-91 n.11 (S.D. Fla. 1994) ("[T]he ADA does not require that persons with disabilities be given 'adequate recreational programs' or, for that matter, any recreational programs. However, the ADA does require that persons with disabilities be given equal access to whatever benefits the City offers to persons without disabilities.").
167. For example, Title III of the ADA requires that the services offered to persons with disabilities be modified if needed to provide them an "opportunity that is as effective as that provided to others." 42 U.S.C. § 12182(b)(1)(A)(iii) (Supp. V 1993). The legislative history to that section notes that, while the statute does not entitle persons with disabilities to an identical result, it does require that they "be afforded an equal opportunity to attain substantially the same result." House Comm. Energy and Commerce, H.R. 485, 101st Cong., 2d Sess. 57 (1990). Cf. 28 C.F.R. pt. 36, app. B, § 36.201(a) (explaining "full and equal enjoyment" of benefits under Title III).
that the relevant benefit offered by its Medicaid program is coverage for “nonfutile medical services” or, perhaps, for “nonfutile life-sustaining interventions,” and that this benefit is available equally to Medicaid recipients, with or without a disability. Characterizing the relevant benefit in this way is not inconsistent with the State’s prerogative to define the benefits available to its Medicaid recipients. The federal Medicaid Act endows the states with broad authority to determine the amount, scope, and duration of coverage of a service, subject to the requirement that states include “reasonable standards” for determining the extent of services consistent with the objectives of the Medicaid program. Accordingly, the State could argue that its coverage limitation is permissible and that any person who seeks to receive an intervention deemed futile is seeking a benefit not provided by the State’s program, just as if the person were seeking another noncovered benefit like elective cosmetic surgery, contact lenses, or experimental treatment.

This argument derives support from *Marshall v. McMahon,* in which recipients of in-home supported services (IHSS) who were mentally alert, but had physical disabilities challenged a California regulation providing protective supervision only to mentally impaired IHSS recipients. Finding no law that prevented a state agency from limiting services to meet mentally impaired persons’ specific needs for protective supervision, the court rejected the plaintiffs’ Rehabilitation Act and ADA

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168. This ability variously to characterize the benefit at issue reinforces David Orentlicher’s point that “it is not always possible to distinguish between rationing by type of service and rationing by type of patient.” Orentlicher, supra note 8, at 308. According to him, pursuing this distinction is less relevant ethically than determining the reasons for the denial of care. Id. As a legal matter, however, a court’s characterization of the relevant benefit could determine the outcome of a disability rights challenge to a rationing scheme.


171. IHSS was enacted in 1973 to provide supportive services in the homes of poor persons who are aged, blind, or disabled and who otherwise would need to be institutionalized. See *Marshall,* 22 Cal. Rptr. 2d at 222. Protective supervision, defined as “observing recipient behavior in order to safeguard the recipient against injury, hazard, or accident” is one type of service provided by IHSS. Id. at 222 (quoting Department of Social Services, Manual of Policies and Procedures at 30-757.17 [hereinafter MPP]). The Department of Social Services (the “Department”) limited the coverage of protective supervision to “non-self directing confused, mentally impaired, or mentally ill persons. . . .” Id. (quoting MPP at 30-757.171). The Department argued that the limitation was “logical” because protective supervision did not attempt to meet the recipient’s physical needs and, therefore, would “not prevent a medical emergency.” Id. at 224. Rather, protective supervision merely provided nonskilled observation to take the place of the “missing cognitive skill [of ‘non self-directing, mentally ill or mentally infirm’ persons necessary to] prevent harm from everyday hazards,” Id. at 224-25.
The mere existence of plaintiffs' disabilities could not support their claim of discrimination if the agency had denied them no covered service: "Merely being disabled does not constitute eligibility for state aid. The disabled person must require a service in the category of services the state offers."  

The court's reasoning in *Marshall* seems to lend strong support to the State's defense of its Medicaid futility policy: A person with a disability cannot cry foul when denied a benefit that the State provides to no one. This formulation of the argument, however, reveals one of its weaknesses. If the State's Medicaid program defines the covered benefit as "nonfutile medical treatment," but has drafted its futility policy to exclude only lifesustaining interventions, and only in the types of cases highlighted in the medical literature, the policy's challengers could argue that the State is applying its seemingly neutral coverage limitation in a discriminatory fashion. In other words, if the State defines Medicaid benefits as excluding coverage of futile medical treatments, but in practice continues to pay for antibiotics prescribed for the common cold or other treatments that provide no or extremely marginal benefits, the State appears to discriminate, in the general sense of the word, in applying its coverage limitation. And, persons with disabilities could argue, the basis of that discrimination is the existence and severity of a patient's disability.

c. Meaningful access

A straightforward way for the State to avoid the foregoing argument would be to define more narrowly the relevant benefit covered under its futility policy. By characterizing the benefit as "nonfutile life-sustaining treatment," the State would sidestep the problem of discriminatory implementation. Adoption of such a narrow definition, however, would likely prompt a different charge: The State has defined the relevant benefit in a manner that deprives persons with disabilities of meaningful access to it. To return to *Alexander*, the Court warned that "[t]he benefit itself... cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are
entitled...”

To determine whether Tennessee’s fourteen-day limitation on inpatient care denied recipients with disabilities meaningful access to the State’s Medicaid program, the Court focused on how much those recipients could benefit from the services remaining to them. “[N]othing in the record suggests that the handicapped in Tennessee will be unable to benefit meaningfully from the coverage they will receive under the 14-day rule.” In addition, the Court noted that the durational limitation did not apply only to particular disabling conditions and took effect regardless of the particular cause of a patient’s hospitalization. Arguably then, Alexander could be read as support for the proposition that a State’s adoption of a Medicaid futility policy that defines the relevant benefit as “nonfutile life-sustaining treatment” would deny some persons with disabilities of meaningful access to the State’s Medicaid program. First, persons with disabilities who might be denied life-sustaining treatment could argue that the policy effectively says to them: “The good news is... you’re covered by Medicaid. The bad news is... it won’t pay for interventions that could sustain your life.” By so characterizing the policy’s effect, its challengers could forcefully argue that persons with a disability who are potentially affected cannot be deemed to have meaningful access to the State’s Medicaid program. Moreover, unlike the limitation in Alexander, the Medicaid futility policy under consideration applies only to persons with particular disabling conditions, such as metastatic cancer, HIV infection, and multiple organ failure.

Despite its apparent strength, this “meaningful access” argument is subject to a rebuttal relying on the medical literature promoting the concept of medical futility. The State could emphasize all the benefits that its Medicaid program does offer persons for whom life-sustaining care might be deemed futile. Presumably, the program would continue to cover palliative care, nutritional support, comfort care, and other therapies designed, not to sustain the person’s life, but to make her remaining life as comfortable as possible. In light of all these benefits, denying a patient life-sustaining interventions that offer her no realistic prospect of medical benefit does not deprive her of meaningful access to the Medicaid program’s benefits. While a patient facing the potential withholding of life-sustaining treatment may argue that, for personal or religious reasons,

175. Alexander v. Choate, 469 U.S. 287, 301 (1985). In a footnote, Justice Marshall accepted a contention made by the U.S. government in its amicus brief: “Antidiscrimination legislation can obviously be emptied of meaning if every discriminatory policy is ‘collapsed’ into one’s definition of what is the relevant benefit.” Id. at 301 n.21.
176. Id. at 302.
177. Id. at 302 n.22.
178. This argument is related to the State’s argument that no modifications to or waivers of its futility policy should be made to accommodate persons who, even with accommodations, will be unable to benefit medically from the intervention provided. See infra text accompanying notes 253-54.
he will benefit from having his life sustained only briefly, the State could counter that the purpose of the Medicaid program is to provide medical assistance, not to provide medical means for patients to pursue their personal, nonmedical goals.\(^{179}\)

3. By Reason of Disability

a. Different treatment or disparate impact

Even if challengers to a Medicaid futility policy succeeded in convincing a court that the policy denied them meaningful access to the program’s benefits, they would still have to demonstrate that the denial was by reason of their disability. They could attempt this in one of two ways: (1) by showing that, because of their disabilities, the futility policy treated them differently from other Medicaid recipients; or (2) by showing that, although it treated them the same as others, the policy had an unjustifiably and disproportionately heavy impact\(^ {180}\) on persons with disabilities. Regardless of whether they pursued a differential treatment theory or a disparate impact theory, however, challengers need not show any discriminatory intent or animus on the state agency’s part.\(^ {181}\)

\(^{179}\) This tension between the use of medicine for medical goals and its use for nonmedical goals in some ways echoes the current debate over the extent to which the law of informed consent should require a physician to provide a patient not only information that is medically relevant to a treatment choice, but also any information that may be relevant to the patient’s personal or financial concerns. See Arato v. Avedon, 858 P.2d 598, 600 (1993) (holding that if trial court had instructed jury that physician had duty to disclose anything that might affect patient’s nonmedical interests, court would have committed error); see also infra note 252.


In Alexander, the Supreme Court assumed, without deciding, that Congress must have intended § 504 to reach some claims of disparate impact discrimination. In the same breath, however, the Court rejected the “boundless notion that all disparate-impact showings constitute prima facie cases under § 504.” Alexander v. Choate, 469 U.S. 287, 299 (1985).

The concept of disparate impact is also built into the ADA. Title III, which prohibits discrimination by public accommodations, specifically proscribes “the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities . . . .” 42 U.S.C. § 12182(b)(2)(A)(i) (Supp. V 1993) (emphasis added). The concept also appears in the regulations implementing Title II: “A public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities . . . .” 28 C.F.R. § 35.130(b)(8) (1995) (emphasis added).

\(^{181}\) Neither § 504 nor the ADA requires a showing of discriminatory intent. See New Mexico Ass’n for Retarded Citizens v. New Mexico, 678 F.2d 847, 854 (10th Cir. 1982) (“Section 504 plaintiffs need not prove discriminatory intent.”); Mayberry, 843 F. Supp. 1160 (not requiring discriminatory intent as an element of either a disparate impact or discriminatory treatment claim under the ADA). The Supreme Court concluded in Alexander that because Congress recognized that discrimination against persons with disabilities...
Given these alternatives, how would challengers to a futility policy likely frame the causation element of their case? At first glance, denial of treatment under the Medicaid futility policy would seem to hinge not on disability—since not all persons with disabilities would be denied treatment—but on factors such as the patient’s prognosis and the expected effectiveness of treatment. Thus, it might initially appear that any discrimination must be found in the policy’s impact. Yet comparison to cases in which a disparate impact on persons with a disability has been established demonstrates their dissimilarity to a case challenging the Medicaid futility policy.

The futility policy is not like a zoning regulation limiting the ability of unrelated persons to live together, which applies to everyone, but weighs more heavily on disabled persons because of their greater need of such living arrangements. Nor does it resemble a limitation on welfare benefits that terminates coverage for eighteen-year-old children unless they are expected to graduate from high school by age nineteen. That age limitation disparately impacts children with learning disabilities by disproportionately disqualifying them for benefits. The regulatory criteria just described (residents’ relationship and students’ age) are problematic because, although their impact was felt both by persons with disabilities and those without, they have a “particular exclusionary effect” on persons with disabilities. A policy employing futility as its criterion, by contrast, would not appear to be a facially neutral policy that adversely impacts persons with disabilities more heavily than others. Instead, the

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183. See Howard v. Human Serv. Bd. Dep’t of Social Welfare, 655 A.2d 1102, 1110 (Vt. 1994) (finding that “graduation by 19” requirement violates Title II of the ADA). In analyzing the discriminatory impact of this requirement, the Vermont Supreme Court relied on the standard articulated by the Supreme Court in Alexander: Does the requirement have a “particular exclusionary effect” on persons with disabilities? Does it “distinguish between those whose coverage will be reduced and those whose coverage will not on the basis of any test, judgment, or trait that the handicapped as a class are less capable of meeting or less likely of having.” Id. at 1106-07 (citing Alexander, 469 U.S. at 302). See also Cook v. Hairston, No. 90-3437, 1991 U.S. App. LEXIS 28537 (6th Cir. 1991) (unpublished opinion) (finding that regulation holding nursing home residents bound by actions of authorized representatives in applying for Medicaid benefits has a particularly exclusionary effect on persons with disabilities).

184. Professor Philip Peters suggests a number of ways in which an effectiveness-based rationing scheme using quality-adjusted life years (QALYs) to measure effectiveness could disfavor persons with disabilities. For example, a standard based on treatment outcomes generally could disfavor persons whose pre-existing disabilities caused them to have greater difficulty in fighting unrelated illness than otherwise healthy patients would have. Moreover, when lifesaving care is at issue, QALY use disfavors the provision of care for patients who will be disabled after treatment, “because saving the life of a disabled person with an impaired quality of life will theoretically generate fewer quality-adjusted life years than saving the life of a person whose quality of life would be better.” In addition, persons with disabilities may be
policy’s impact would be felt exclusively by persons with disabilities. The policy’s singular burden on the disabled suggests that the hypothetical policy implicates something more direct than a disparate impact. That said, how persuasively could challengers argue that the Medicaid futility policy actually treats some persons with disabilities differently from persons without disabilities by using criteria that directly prevent the former from receiving the relevant benefit?

b. Use of “neutral” criteria

In defense of its Medicaid futility policy, the State would dispute any disparate treatment claim by contending that the policy relies solely on criteria linked to a patient’s prognosis and the effectiveness of life-sustaining interventions in light of that prognosis. These criteria, the argument would go, are not based on disability, but are instead neutral. Although admittedly a judgment of futility in any particular case is probabilistic rather than absolute in nature, such a judgment provides a justifiable, content neutral basis for limiting treatment. In fact, the Secretary of HHS, in his letter rejecting Oregon’s waiver application, suggested “prevention of death” as one neutral factor on which a state permissibly could base medical resource allocation decisions.

Moreover, the fact that the futility policy may act to the disadvantage of some persons with disabilities does not demonstrate that the policy discriminates against those persons on the basis of their disabilities. In fact, the Supreme Court emphasized in Alexander that antidiscrimination legislation does not require a state making distributive decisions to adopt only those policies that are least disadvantageous to persons with disabilities.

Responding to the State’s claim of neutrality, critics of the Medicaid futility policy could argue that, despite the facial neutrality of the policy’s

disfavored if the scales used to measure quality of life undervalue the quality of life with a disability. See Peters, supra note 101, at 500-01.

185. Cf Orentlicher, supra note 8, at 310 (reasoning that, in the context of employer-provided health insurance, “[i]f an employer’s treatment exclusion applied exclusively to disabled persons, then the exclusion would face a much greater chance of invalidation under the ADA”).

186. See Sullivan letter, supra note 126, at 411. The letter also suggests the cost of medical procedures, the length of hospital stays and prevention of contagious diseases as neutral permissible factors; cf. Peters, supra note 101, at 527-28 (concluding that rationing based solely on survival rates should qualify as essential eligibility criteria).


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

Id. at 308.
exclusions, the criteria employed effectively discriminate against persons with certain severe disabilities in several ways. First, although the policy does not rely directly on a patient's disability in denying coverage for life-sustaining treatment, cases applying the ADA in the employment context have concluded that direct reliance is not essential for a showing of disparate treatment. For example, in *Ham v. Nevada*, an employer was sued for reassigning an employee following a drunk-driving arrest. When the employee sued, claiming that the employer discriminated against him based on his alcoholism, the employer responded that at the time of the reassignment it was unaware of the employee's alcoholism, and therefore, it could not have based its action on the disability. The court, however, reasoned that a prima facie case of disparate treatment is established when an employer justifies an adverse action based on conduct *caused by* a disability, even if the employer disclaims reliance on the disability itself.

An analogous argument could be made in the context of a public entity's alleged discrimination in the provision of services. In other words, one could argue that, although the Medicaid futility policy does not explicitly rely on disabilities in denying certain persons coverage for life-sustaining treatment, the purportedly "neutral" criteria on which the policy does rely—such as prognosis and ineffectiveness of treatment—are inherently connected causally to those persons' existing medical conditions and disabilities. Consequently, the futility policy should be treated as relying on disability, despite its lack of explicit reference to disability.

189. Id. at 457-58 ("[A]n employer 'relies' on a handicap when it justifies termination based on conduct caused by the handicap. An employer does not 'rely' on a handicap when it can point to behavior that is not causally related to the handicap.") (quoting Teahan v. Metro-North Commuter R.R. Co., 951 F.2d 511, 515 (2d Cir. 1991)).

Both the Seventh and Sixth Circuit Courts of Appeal, however, have recently come to a different conclusion in drunk driving cases. See Despears v. Milwaukee County, 83 F.3d 635 (7th Cir. 1995); Maddox v. University of Tenn., 62 F.3d 845 (6th Cir. 1995). In *Despears*, Chief Judge Richard Posner reasoned that while Despears's alcoholism could be seen as a "cause" of his drunk-driving arrest, it was not the sole cause or compulsion for the event. Instead, Despears's voluntary choice to drive while drunk also contributed to the action that resulted in his demotion. As a result, allowing ADA liability to attach in those circumstances "would indirectly but unmistakeably undermine the laws that regulate dangerous behavior." *Despears*, 63 F.3d at 637. No such concerns about conflict with the aims of the criminal law readily appear in the case of the Medicaid futility policy.

190. Such would appear to be the implicit rationale behind the court's conclusion in *Thomas v. Davidson Academy*, 846 F. Supp. 611, 618-19 (M.D. Tenn. 1994). In that case, decided under Title III of the ADA, a student sought to enjoin a private school from expelling her based on her allegedly hysterical behavior after cutting herself while at school. The court pointed out that the plaintiff's reaction to her injury resulted from her awareness that an autoimmune disorder she suffered from could interfere with her body's clotting mechanisms. The court concluded that by expelling her based on her behavior, the school had denied its services on the basis of the student's disability. Id. at 619. *But cf. Hedberg v. Indiana Bell Tel. Co.*, 47 F.3d 928 (7th Cir. 1995) (finding that termination based on tardiness and lack of a work ethic did not violate the ADA when the employer was not aware of the employee's disability).
Additional evidence that the futility policy's limitations are indeed based on disability can be found in the State's attempt to control medical costs by imposing a coverage limitation whose burden falls solely on persons with disabilities. Unlike Alexander, where the State's attempt to cut costs by decreasing the duration of inpatient coverage imposed a burden on any Medicaid recipient, disabled or not, who required hospitalization extending beyond the coverage limitation, the deprivation imposed by a futility policy like that proposed by Murphy and Finucane will be visited exclusively on persons with certain severe disabilities. In an analogous situation, a court ruled that an extreme disparity between the extent of budget cuts imposed on programs for the disabled and cuts affecting the nondisabled population was some evidence of discrimination on the basis of disability.\footnote{See Concerned Parents to Save Dreher Park Ctr. v. City of W. Palm Beach, 846 F. Supp. 986 (S.D. Fla. 1994). In this case, West Palm Beach responded to budget constraints by cutting the allocation to its Department of Leisure Services in a fashion that effectively and completely eliminated all previously existing recreational programs for persons with disabilities, but retained programs for the nondisabled population. The court, in finding discrimination based on disability, was careful to clarify that its ruling was not based on a showing of discriminatory funding per se, but was also based on the City's failure to demonstrate that its remaining recreational programs provided persons with disabilities with equal access to their benefits. Id. at 992 n.14.}

Finally, and most fundamentally, opponents of the Medicaid futility policy could show that the medical literature providing the foundation for the policy is infected with subjective judgments implicitly devaluing the quality of life with a severe disability.\footnote{Cf. Orentlicher, supra note 8, at 311 ("[C]ourts may be concerned that eligibility criteria often reflect not medical judgments but value judgments about quality of life."); accord Peters, supra note 101, at 534-37 (discussing how including quality-of-life considerations in effectiveness criteria disfavors persons with disabilities).} For example, articles in the medical literature on futility commonly adopt survival to hospital discharge as the relevant endpoint against which a medical intervention's probable utility or futility should be assessed. This choice of endpoint implicitly deems life maintained in a hospital as valueless, disregarding the value the patient or the patient's surrogate may attach to that life despite its limitations.\footnote{See Mitchell et al., supra note 21.}

Particularly apparent in some of the medical commentary is the devaluation of the lives of persons whose disability affects their neurological functioning. For example, some commentators suggest that life-sustaining nutritional support is futile for persons in a persistent vegetative state,\footnote{Accord Waisel & Truog, supra note 38, at 306 (arguing that "qualitative definitions that hinge on location are questionable"); cf. Einer Ellehage, Allocating Health Care Morally, 82 Cal. L. Rev. 1449, 1495 (1994) (noting value judgments implicit in two-year survival measures).} despite their potential to live for many years if provided with medical support. Murphy and Finucane include as a recommended category of patients for whom CPR should be deemed futile
"Patients with Dementia requiring Long-term Care." Tellingly, the studies on post-resuscitation survival on which Murphy and Finucane base this recommendation deal with a broad group of long-term care recipients, without specifically singling out patients with dementia. Thus, inclusion of the dementia qualifier would appear to reflect the authors' value judgment that dementia makes a life less worth attempting to save.

This evidence showing that quality-of-life value judgments provide an underpinning of the Medicaid futility policy would detract considerably from the State's assertions that the policy depends on neutral criteria that do not discriminate based on disability. Instead, it reveals the policy as falling short of the standards the Secretary of HHS articulated in denying Oregon's waiver application: "Any methodology that would intentionally ration health care resources by associating quality of life considerations with disabilities does not comport with the mandate of the ADA." Although the quality of life judgments inherent in a futility policy based on Murphy and Finucane's proposal may be less blatant than the judgments that Oregon's telephone survey sought, they are every bit as real and as troubling.

Moreover, that physicians, rather than ordinary citizens, make the judgments does not somehow sanitize them. While courts should accord substantial weight to the professional medical judgment of physicians or public health officials regarding the qualification of an individual with a disability for public benefits or the risk posed by that person's employment, a physician's quality-of-life value judgment remains just that—a subjective value judgment that may be infected with stereotypic assumptions regarding the value of life with a severe disability.

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195. Murphy & Finucane, supra note 19, at 1642-43.
196. See generally G.E. Applebaum et al., The Outcome of CPR Initiated in Nursing Homes, 38 J. Am. Geriatrics Soc'y 197 (1990); Sissay Awoke et al., Outcomes of Skilled Cardiopulmonary Resuscitation in a Long-Term-Care Facility: Futile Therapy?, 40 J. Am. Geriatrics Soc'y 593 (1992); Donald J. Murphy et al., Outcomes of Cardiopulmonary Resuscitation in the Elderly, 111 Annals of Internal Med. 199 (1989) (discussing the success rate of cardiopulmonary resuscitation in the elderly). To be fair, it should be noted that the study by Murphy et al. does present data showing "a strong relation between prognosis following resuscitation and both level of consciousness and level of function." Murphy et al., supra, at 292. The authors indicate that they did factor patients with dementia into their study under their general category of impairment and chronic disease. Murphy and Finucane's recommendation for denying CPR to recipients of long-term care, however, attaches significance only to dementia and not to any other chronic impairment that might affect prognosis.
197. Murphy and Finucane do not explain why they make the leap from data suggesting that recipients of long-term care generally will not survive to be discharged from the hospital after resuscitation to the conclusion that only long-term care recipients with dementia be denied CPR.
200. In fact, evidence suggests that health professionals do hold negative beliefs about
Consequently, disability rights advocates would argue that only a futility policy stripped entirely clean of value judgments regarding quality of life—in other words, a policy based solely on purely medical indicators of physiological futility—could possibly withstand scrutiny under the ADA.

c. Use of categorical exclusions

Challengers could point to one final element of the Medicaid futility policy, in addition to its implicit quality of life judgments, as offending the ADA's nondiscrimination mandate. The policy calls for categorical judgments, rather than individualized assessments, regarding the futility of life-sustaining treatment. The courts have judged policies implementing categorical exclusions particularly suspect because they are likely to embody stereotypic generalizations about persons with disabilities. For example, in *Garrity v. Gallen*, a case involving rehabilitative services provided to persons with mental retardation, the court found that state officials had violated Section 504 by making placements and providing services "based not on an individual assessment of the abilities and potentials of each resident but on the generalized assumption that certain groups of people... are unable to benefit from certain activities and services." The court found such "blanket discrimination" inconsistent with Section 504's fundamental premise of "the need for individualized treatment." So too, a policy requiring that all bedfast persons with metastatic cancer be denied life-sustaining treatment—without opportunity for inquiry into possible benefit to the particular patient—should be deemed inconsistent with the ADA.

persons with disabilities and that those beliefs infect the providers' decisionmaking. *See* Scofield, supra note 79, at 934 & nn.28, 29 (citing studies).

201. *See* supra notes 30-31 (describing physiological futility); *cf.* Elhauge, supra note 193, at 1459, 1514 (arguing that only an absolutist approach to health care, where society is obliged to provide all health care offering any positive benefit, is immune from attacks of discrimination, but rejecting such an approach as untenable because it would consume all of society's resources); Orentlicher, supra note 8, at 312 (arguing that unless a treatment would fall within a physiological definition of futility, a patient should be found to satisfy the ADA's eligibility requirement).


204. Id. at 214.

205. Id. at 213-14; *cf.* Stillwell v. Kansas City, Missouri Bd. of Police Comm'r's, 872 F. Supp. 682, 688 (W.D. Mo. 1995) (invalidating policy that person with only one hand cannot be licensed as armed security guard); Anderson v. Little League Baseball, 794 F. Supp. 342, 345 (D. Ariz. 1992) (holding that individualized assessment by public accommodation is necessary in determining whether the participation of a person in a wheelchair as an on-field base coach poses a direct threat to the health and safety of little league ballplayers).

206. The point could also be made for persons in any of Murphy and Finucane's other proposed categories. *See* Murphy & Finucane, supra note 19, at 1642-43 (defining categories in which life-sustaining treatment would be futile).
Two responses to the foregoing argument are likely. First, the State could concede the ADA's focus on individualized assessment, but argue that the Medicaid futility policy is not incompatible with that focus. As a practical matter, a physician will need to examine each Medicaid recipient potentially affected by the policy to determine whether that person falls into one of the categories covered by the policy. As a result, the physician determining the applicability of the exclusionary categories undoubtedly will be influenced by each patient's individual circumstances. Second, the ADA's requirement of individualized assessment is not absolute. The statute should not be seen as prohibiting a state Medicaid program's adoption of a category-based futility policy if the categories used reflect statistically sound correlations between medical treatment and lack of patient benefit. In that case, the State would argue, prohibiting the use of categories would preclude efficient use of information without providing additional protection to persons with disabilities.

d. "Evenhanded treatment" and discrimination among the disabled

Not only would the State seek to puncture and deflate arguments showing the causal linkage between disability and the Medicaid futility policy's denial of benefits, it could also shift the debate's focus by citing copious authority for the proposition that disability discrimination law's primary purpose is to assure "evenhanded treatment" of persons with disabilities vis-à-vis their nondisabled counterparts. From the perspective of comparing treatment of persons with disabilities, as a group, with treatment of those without disabilities, a realistic appraisal of the futility policy's effects suggests that, while some persons with certain severe

207. Cf. Traynor v. Turnage, 485 U.S. 535, 560 (1988) (acknowledging that "an agency legitimately could eschew individualized assessments of disabled individuals' qualifications if it were evident, as a matter of medical fact, that a particular disqualifying characteristic always is associated with a particular disability") (Blackmun, J., with whom Brennan, J. and Marshall, J., join, dissenting); Buck v. United States Dep't of Transp., 56 F.3d 1406 (D.C. Cir. 1995) (finding that the ADA does not require an agency that has established a safety standard that an individual with a certain disability cannot possibly meet to engage in the pointless exercise of allowing such an individual to try and meet the standard); cf. also Crossley, supra note 45, at 1654 n.279 (noting the permissibility of statistical correlations in individual medical treatment decisionmaking); Peters, supra note 101, at 508 (noting that "courts tolerate broader classifications when substantially all excluded persons are unqualified or when individualization is highly impractical").

208. See, e.g., Alexander v. Choate, 469 U.S. 287, 304 (stating that § 304 "seeks to assure evenhanded treatment and the opportunity for handicapped individuals to participate in and benefit from programs receiving federal assistance"); Gramer v. Florida, 885 F. Supp. 1545, 1553 (M.D. Fla. 1995) (finding that "disability statutes do not ensure 'evenhanded treatment' as compared to other disabled persons"); Flight v. Gloecker, 878 F. Supp. 424, 426 (N.D.N.Y. 1995) ("Section 504 was not intended to be used to advance claims of discriminatory distribution of services to handicapped persons . . ."); Wolford v. Lewis, 860 F. Supp. 1123, 1135 (S.D. W. Va. 1994) (finding "no requirement that all disabled persons be provided the same benefits as long as they receive 'evenhanded treatment' in relation to the nondisabled").
disabilities will lose some coverage under the policy, the vast majority of persons with disabilities will suffer no ill effects at all. In fact, if the Medicaid program reaps real cost savings from its futility policy, persons with disabilities, as a group, are likely to benefit from any expanded access or coverage made possible thereby. Therefore, the State would argue, while the futility policy will result in limited coverage denials for some persons with severe disabilities, the policy's overall effect is not to deny persons with disabilities evenhanded treatment.

Moreover, since most persons with disabilities will be untouched by the Medicaid futility policy, it appears that what really troubles the policy's challengers is their perception that persons with the most severe disabilities are getting the short end of the stick, as compared both to persons without disabilities and to persons with less severe disabilities. For example, the policy does not deny coverage for life-sustaining treatment to all persons with cancer, only to bedfast patients with metastatic cancer. Likewise, treatment is not deemed futile for all patients with AIDS, only AIDS patients who already have suffered more than one episode of pneumocystis carinii pneumonia. Thus, the State could argue, the challengers' real claim is that the policy discriminates among persons based on the nature of their disability. But, because the proclaimed goal of disability discrimination law is to ensure evenhanded treatment of persons with disabilities in relation to those without disabilities, some courts have questioned whether the law even applies to claims of differential treatment of persons with different disabilities.

For example, in Williams v. Secretary of the Executive Office of Human Services, mentally disabled plaintiffs claimed that the State's Department of Mental Health violated the ADA by operating its residential services in a discriminatory fashion. They alleged discrimination in the Department's disproportionate denial of residential placements for persons suffering from a combination of mental disabilities and substance abuse. As a result, the plaintiffs argued, a disproportionately high number of such dual-diagnosed individuals ended up being discharged to the streets and to shelters. The Massachusetts Supreme Court, however, rejected this argument on the grounds that "an agency does not obligate itself to make services available to persons with different or complicating disabilities"

209. *Accord* Morreim, supra note 101, at 919. Language in *Alexander* suggests that analyzing a policy's effect on persons with disabilities entails considering how the policy might impact various subclasses of that population. See *Alexander*, 469 U.S. at 308 ("[T]he State would then have to balance the harms and benefits to various groups to determine, on balance, the extent to which the action disparately impacts the handicapped.").

210. *See* Murphy & Finucane, supra note 19, at 1642.

211. *See* Colin K. by John K. v. Schmidt, 715 F.2d 1, 9 (1st Cir. 1983) (expressing "serious doubts" that § 504 provides a claim "vis-à-vis other handicapped individuals").


213. Id. at 447.

214. Id.
simply by treating individuals with a single disability.\textsuperscript{215}

By extension, this conclusion could apply to a state Medicaid program's decision to fund most medical services for persons with a disability, but not to fund life-sustaining therapy for persons with disabilities whose prognosis renders such treatment futile.\textsuperscript{216} This argument finds support in the concept, embodied in both caselaw\textsuperscript{217} and the ADA's implementing regulations,\textsuperscript{218} that an agency's decision to provide services to one subclass of persons with disabilities should not be taken to compel the agency to provide those services or like services to all subclasses of persons with disabilities. This limitation on disability discrimination law's reach prevents the law from intruding too deeply in a state's resource allocation decisions.\textsuperscript{219}

Despite the facial appeal of these arguments, challengers of the Medicaid futility policy would question whether the principles cited are logically applicable to the problems the policy poses. In the cases cited above, an agency chose to extend benefits to one group of individuals with a disability, but not other groups. By contrast, the State's implementation of the futility policy as part of its Medicaid program will extend medical benefits to all members of the general population meeting certain

\begin{itemize}
\item[215.] Id. at 453.
\item[216.] Cf. Johnson v. Thompson, 971 F.2d 1487, 1493 (10th Cir. 1992), \textit{cert. denied}, 113 S. Ct. 1255 (1993) (reasoning that § 504 does not prohibit discrimination among persons with the same disability because such discrimination is not solely on the basis of disability).
\item[217.] See Traynor v. Turnage, 485 U.S. 535, 551 (1988) (upholding Veterans Administration policy that persons with primary alcoholism cannot take advantage of exception to ten-year delimiting period for use of GI Bill benefits, which exception is available generally to veterans who delayed their education because of a disability not resulting from willful misconduct); Easley v. Snider, 36 F.3d 297, 305 (3d Cir. 1994) ("The regulations implementing [the Rehabilitation Act and the ADA] contemplate reaching groups of disabled without incurring obligations to other groups of handicapped."); Wolford v. Lewis, 860 F. Supp. 1123, 1135 (S.D. W. Va. 1994) ("[T]here is no requirement that all disabled persons be provided the same benefits as long as they receive 'evenhanded treatment' in relation to the nondisabled.").
\item[218.] Regulations implementing the ADA provide that the statute does not prohibit "a public entity from providing benefits, services, or advantages to individuals with disabilities or to a particular class of individuals with disabilities, beyond those required by this part." 28 C.F.R. § 35.150(c) (1995). In promulgating this regulation, the Department of Justice explained:

\begin{quote}
Paragraph (c) has been revised to clarify that State and local governments may provide special benefits, beyond those required by the nondiscrimination requirements of this part, that are limited to individuals with disabilities, without thereby incurring additional obligations to persons without disabilities or to other classes of individuals with disabilities.
\end{quote}


\item[219.] Cf. Traynor, 485 U.S. at 549 (despite extension of § 504 to the programs of Executive agencies, "Congress is entitled to establish priorities for the allocation of the limited resources available . . ."); Alexander v. Choate, 469 U.S. 287, 299 (1985) ("Any interpretation of § 504 must therefore be responsive to two powerful but countervailing considerations—the need to give effect to the statutory objectives and the desire to keep § 504 within manageable bounds.").
\end{itemize}
eligibility requirements, but deny specific medical benefits solely for persons with certain severe disabilities. In other words, the State's adoption of the futility policy is properly characterized as a restriction of benefits, not as an extension of benefits specifically targeted to aid a particular subclass of persons with disabilities. The policy's challengers would invoke the ADA, not as a sword to secure expanded state programs for persons with disabilities, but instead as a shield to protect persons with severe disabilities from discriminatory cutbacks in medical services historically covered under Medicaid.

Thus, the questions the Medicaid futility policy presents are factually and substantively distinguishable from those found in cases like Williams, where plaintiffs tried to use disability discrimination law as a vehicle for increasing service or benefit levels. Moreover, some courts have endorsed the use of disability discrimination law to prevent discrimination among different groups of persons with disabilities. These courts suggest that Congress's goal of preventing uneven treatment of persons with disabilities vis-à-vis those without disabilities should not be seen as the exclusive purpose of the ADA. Instead, the ADA is also violated when discrimination occurs among persons with different disabilities or varying degrees of disability. Indeed, courts have signalled that the

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220. Persons eligible for Medicaid are divided into categorically needy individuals, medically needy individuals, and some other specialized categories. States are required to provide Medicaid for the categorically needy persons receiving public assistance because of their poverty and their status as blind, disabled, aged, or a specified member of a family with dependent children. States may, at their option, provide Medicaid coverage for the medically needy—persons who would qualify as categorically needy if their income level were lower, but who have insufficient income to pay their medical bills. See Introduction to Medicaid, 3 Medicare & Medicaid Guide (CCH) ¶ 14,010, at 5909 (1993).

221. That the treatments now deemed futile by Murphy and Finucane and others have previously been provided as a matter of course can be seen from reviewing some "right to die" cases decided during the 1970s and 1980s. For example, in the only right to die case to reach the United States Supreme Court, Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261 (1992), the medical treatment of a woman in a PVS was paid for by Missouri's Medicaid program. Cf. Cranford & Gostin, supra note 28, at 307 (noting irony in medical profession's current claim that futility is a purely medical judgment in light of profession's past history of blocking patients' and families' ability to discontinue or withhold life-sustaining treatment).

222. Cf. Duquette v. Dupuis, 582 F. Supp. 1365, 1369 (D.N.H. 1984) (finding no § 504 violation where "plaintiff attempts to transform the § 504 shield against invidious discrimination into a sword to secure expanded state aid programs and equal medical assistance benefits for all classes of handicapped persons").

223. See Helen L v. Didario, 46 F.3d 325 (3d Cir. 1995) (noting that Congressional statement of concern regarding discrimination in institutionalization would be a non sequitur if Congress were concerned only about disparate treatment of the persons with disabilities as compared to their nondisabled counterparts, "as only disabled persons are institutionalized").

In addition, courts have noted that in Traynor, 485 U.S. at 548, a case that is often cited for the "evenhanded treatment" principle, the plaintiffs were not discriminated against because they were alcoholics, but because the Veterans Administration deemed that their alcoholism was the result of their willful misconduct. See, e.g., Helen L., 46 F.3d at 328; Martin v. Voinovich, 840 F. Supp. 1175, 1191 (S.D. Ohio 1993).

224. See Martin, 840 F. Supp. at 1192. The court in Martin reasoned:
severity of a disability may itself be treated as a disability in determining whether discrimination has occurred. The futility policy's challengers would emphasize, therefore, that the policy does not deny all persons with cancer, organ failure, or HIV infection coverage for life-sustaining treatment, but only persons suffering the severest forms of those disabilities. In this light, the policy appears to exemplify discrimination based on the severity of the recipient's disability.

4. Qualified Individual with a Disability

The final element that challengers to a state's Medicaid futility policy would have to prove to demonstrate a violation of Title II of the ADA is that the policy discriminates against "qualified" individuals with disabilities. Title II defines a "qualified" individual with a disability as one who:

[A]s a matter of statutory construction, nothing in the language of § 504 suggests that it can never apply between persons with different handicaps. Rather, the language of § 504 evinces an intent to eliminate handicap-based discrimination and segregation. A strict rule that § 504 can never apply between persons with different disabilities would thwart that goal. Such a rule would, in effect, allow discrimination on the basis of disability. The relevant inquiry is whether the application of § 504 between persons with different or varying degrees of disability furthers the goal of eliminating disability-based discrimination.

Id. The court went on to note that the analysis under the ADA would be identical. Id. See also Wagner v. Fair Acres Geriatric Ctr., 49 F.3d 1002, 1016 n.15 (3d Cir. 1995) ("While section 504 does not apply to programs choosing among similarly handicapped people, an action under section 504 exists if a program is found to discriminate between distinct classes of handicapped persons."); Henderson v. Bodine Aluminum Co., 70 F.3d 958 (8th Cir. 1995) (finding a likelihood that the plaintiff could prove that health insuror's refusal to pay for high dose chemotherapy for breast cancer, while covering the treatment for other types of cancer, violated the ADA); Garrity v. Gallen, 522 F. Supp. 171, 211 (D.N.H. 1981) (discussing Congressional intent behind § 504).

225. See Plummer by Plummer v. Branstad, 731 F.2d 574, 578-79 (8th Cir. 1984) (assuming in dicta that severity of disability can itself be a disability); Jackson v. Fort Stanton Hosp., 757 F. Supp. 1243, 1299 (D.N.M. 1990) (citing Plummer, "the severity of the plaintiff's handicap is itself a handicap which, under § 504 cannot be the sole reason for denying the plaintiff access to community programs"); cf. Wagner, 49 F.3d at 1016 n. 13 (reasoning that a nursing home's refusal to admit a patient with Alzheimer's disease and resulting aggressive behavior could constitute discrimination based on handicap even though the nursing home accepted other Alzheimer's patients); Wolford v. Lewis, 860 F. Supp. 1123 (S.D. W. Va. 1994) (noting that plaintiff's claim of disparate treatment as among persons with disabilities did not allege the disparity was based on degree of disability and hence was not actionable under § 504).

226. An exception to this proposition would exist if the state Medicaid program adopted a futility policy that excluded coverage of life-sustaining treatments for persons in a persistent vegetative state. While Murphy and Finucane do not include PVS patients as one of their categories of patients for whom CPR should not be provided, other commentators have suggested that life-sustaining medical treatment for PVS patients is futile. See supra note 22. In the case of PVS, it is difficult to speak of more and less severe forms of the condition. Because presumably all persons with PVS would be treated similarly, however, challengers of the futility policy could rely on the more straightforward argument that all persons with PVS were being denied benefits based on their disability.
or without reasonable modifications to rules, policies, or practices... meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.\textsuperscript{227} Thus, the question of the plaintiffs' qualification is tied to the State's chosen eligibility criteria. In establishing those criteria, however, the State is not free to use factors that will exclude persons with disabilities. As the regulations promulgated under Title II clarify, a public entity cannot use eligibility criteria that "screen out or tend to screen out... any class of individuals with disabilities from fully enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered."\textsuperscript{228}

Thus, analysis of whether persons denied life-sustaining treatment under the futility policy are qualified entails identifying the criteria the State employs to determine eligibility for its Medicaid program and for life-sustaining medical interventions,\textsuperscript{229} determining whether those criteria exclude persons with disabilities, and if so, assessing whether those criteria are necessary for the State's operation of its Medicaid program. One additional factor, however, figures in: The ADA requires a public entity to make reasonable modifications to its policies when necessary to avoid disability discrimination, "unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."\textsuperscript{230} Thus, even if exclusionary criteria are essential to a program's operation, the public entity may be required to make reasonable modifications to its policies to accommodate the needs of persons with disabilities.\textsuperscript{231} The reasonableness of a particular modification is to be determined based on a fact-specific, case-by-case inquiry.\textsuperscript{232}

How might these principles be given meaning with respect to a State's Medicaid futility policy?

\textbf{a. Qualification: essential eligibility criteria}

As a preliminary matter, it is unnecessary for a state implementing a futility policy as part of its Medicaid program to alter its basic eligibility criteria for Medicaid participation. These criteria are established by the

\textsuperscript{228} 28 C.F.R. § 35.130(b)(8) (1995).
\textsuperscript{229} Because analysis of "qualification" depends on what eligibility criteria the State chooses for receipt of a benefit, it may also by extension depend on how the benefit is defined. The question of defining the relevant benefit is discussed in part III.C.2 of this Article. For purposes of the instant analysis, I am assuming that the relevant benefit is life-sustaining medical treatment.
\textsuperscript{230} 28 C.F.R. § 35.130(b)(7) (1995).
\textsuperscript{231} See Pottgen v. Missouri State High Sch. Activities Ass'n, 40 F.3d 926, 929-31 (8th Cir. 1994) (reasoning that § 504 and Title II require initial inquiry into essential nature of eligibility requirement, followed by consideration of whether plaintiff can meet the requirement with or without modification).
\textsuperscript{232} Staron v. McDonald's Corp., 51 F.3d 353, 356 (2d Cir. 1995).
federal Medicaid statute and are largely income and status based. Of more concern is the eligibility criteria the State program uses to determine who, among all Medicaid recipients, is qualified for coverage for life-sustaining interventions. By implementing a futility policy, the State effectively establishes as an eligibility criterion the probability that a Medicaid recipient will receive a medical benefit from life-sustaining treatment. Rather than determining the probability of benefit in each case, however, the futility policy, based on the medical literature, creates categories of persons deemed insufficiently likely to benefit from life-sustaining interventions.

Determining whether an eligibility requirement is essential to a program entails an inquiry into the requirement’s importance to the program’s ability to meet its targeted goals. In defending a cost-conscious futility policy, the State would argue that requiring probability of benefit from medical treatment as a condition of coverage is essential for a medical assistance program, like Medicaid, that seeks to maximize the health of an indigent population while operating in a world of scarce medical resources. The uncontrolled increase in Medicaid spending has made difficult rationing choices inevitable; accordingly, the ability to exclude nonbeneficial care from coverage is essential to the State’s efforts to focus health care resources where they can achieve the most benefit. While the State could save money by employing alternative methods of rationing care (for example, by utilizing queues, cost-based exclusions, higher patient copayments, and lower coverage limits), those methods are not designed to maximize health outcomes achievable from limited resources.

233. Because one category eligible for Medicaid coverage is needy persons who are disabled for purposes of the federal Supplemental Security Income program, see supra note 220, it seems safe to assume that some number of persons with disabilities potentially affected by the futility policy’s implementation will satisfy the basic eligibility criteria for Medicaid coverage. Of course, if a state adopted a futility policy as part of a comprehensive redesign of its Medicaid program, it might revise its basic eligibility criteria for Medicaid coverage. See supra part III.B.2 for a description of such an effort by Oregon.

234. See Pottgen v. Missouri State High Sch. Activities Ass’n, 40 F.3d 926, 929 (8th Cir. 1994) (describing how age limit was an essential eligibility requirement of interscholastic baseball); Esley v. Snider, 36 F.3d 297, 303 (3d Cir. 1994) (“[M]ental alertness of the physically disabled who participate in the program is an essential dimension without which the objectives of the program cannot be recognized.”). The ADA’s legislative history indicates that an eligibility requirement is “necessary” if its elimination would cause a “substantial interference with the operation” of the program. H.R. Rep. No. 485, 101st Cong., 2d Sess. pt. 4, at 58 (1990), reprinted in 1990 U.S.C.C.A.N. 512, 547.

235. Cf. Aughe v. Shalala, 885 F. Supp. 1428 (W.D. Wash. 1995) (accepting government’s contention that completion of school by age 19 is an essential eligibility requirement for the AFDC program because “[b]y cutting off aid to those over eighteen the fiscal viability of the AFDC can be maintained”).

236. Peters, supra note 101, at 517. As an alternative, the State could argue that its futility policy is nothing more than a specific embodiment of the more general, essential eligibility requirement for Medicaid coverage—that the treatment sought be “medically indicated.”
What if, instead of directly adopting a futility policy and implementing it by limiting reimbursement to providers, the State Medicaid program indirectly adopted a futility policy by contracting with managed care providers who then implemented a futility policy as a case management or utilization review device. In that event, the State’s arguments would become more complex and could overlap with the arguments developed in Part III.D, regarding the hospital futility policy. The factual variations existing among Medicaid managed care programs prevent the full development here of arguments regarding the essential nature of such indirectly adopted policies, but at least two factors would likely figure significantly in those arguments: First, to what extent has the State Medicaid agency established parameters for the types of case management and utilization review mechanisms employed by the managed care contractor? Second, to what extent will any savings reaped from a futility policy be reinvested in providing services for Medicaid beneficiaries, as opposed to representing profit or additional income for the managed care provider?

In any event, challengers of the Medicaid futility policy would contest the essential nature of the "probability of benefit" eligibility criterion on several grounds. First, states historically have operated their Medicaid programs without imposing futility-based exclusions. A three-decade heritage of pursuing the program’s goals without employing the criterion in question suggests that the criterion is not truly essential to the program’s operation. Moreover, the contention that today’s urgent need to control Medicaid spending makes the criterion essential to the program’s

Because the treatment excluded as futile offers only a miniscule probability of benefit to a patient, that treatment is not medically indicated according to professional standards, and thus the patient seeking the treatment has not met this eligibility requirement. See Morreim, supra note 101, at 902 (arguing that "[t]o be qualified for medical services is to have an illness or injury that needs, and can be helped by, medical care"). But see Scofield, supra note 79, at 943 (suggesting that the “qualification” requirement demands only that an individual be in need of medical treatment).

237. Numerous states are experimenting with providing services to Medicaid beneficiaries by enrolling them in managed care arrangements. By 1994, 23% of the Medicaid population was enrolled in some form of managed care. See Jane Perkins & Lourdes A. Rivera, EPSDT and Managed Care: Do Plans Know What They are Getting Into?, Clearinghouse Rev. (Mar. 1994), at 1248. Although different states’ programs take different forms, Holahan et al., supra note 106, at 201-02 (describing several state programs), the management of care generally occurs through one of three basic models:

(1) fee-for-service case management, under which a health care provider, usually a primary care doctor or clinic, receives a monthly case management fee per enrollee to perform gatekeeping and coordination of services; (2) fully capitated systems, under which a provider, usually a health maintenance organizations [sic] (HMO), is paid a preset, or “capitated,” rate per enrollee and is at risk for excessive medical expenditures; or (3) partially capitated systems, under which a provider, usually a primary care physician or clinic, receives a capitated rate per enrollee and is at risk for a limited package of services.

Perkins & Rivera, supra, at 1248.
continued ability to pursue its goals suffers from the lack of evidence that imposing a futility exclusion will have any significant effect in controlling Medicaid spending.\textsuperscript{228} In fact, Murphy and Finucane themselves frankly admit that refusing to provide CPR to patients in their proposed categories may have no significant cost-saving effect.\textsuperscript{229}

Finally, the challengers would argue, if the State indeed deemed the probability of benefit criterion essential to its efforts to control Medicaid spending and target resources to those services likely to produce benefit, surely the State would apply that criterion across the board to all Medicaid-covered services. A similar argument proved successful in Coleman v. Zatechka,\textsuperscript{230} in which a student who used a wheelchair and required the services of a personal attendant challenged the University of Nebraska's refusal to assign her a roommate. The University argued that the plaintiff was not qualified to participate in its roommate assignment program because her wheelchair would require her to use more space than that allotted to a double room occupant and her personal attendant would visit the room at least three times a day.\textsuperscript{231} The court found these eligibility requirements were not essential to the University's roommate assignment program, partly because the University imposed no limitations regarding the amount of space utilized or the number of daily visitors with respect to students without disabilities participating in the program.\textsuperscript{232} Similarly, in

\textsuperscript{228} See Joan M. Teno et al., Prognosis-Based Futility Guidelines: Does Anyone Win?, 42 J. Am. Geriatrics Soc'y 1202 (1994) (describing results of study showing that the implementation of futility guidelines produced only modest savings). Whether imposing treatment-limiting futility policies will save money is part of a broader debate regarding the cost savings that might result from limiting medical treatment at the end of life. Other practices that some have suggested would decrease medical costs include increasing use of advance directives, DNR orders and hospice care. Studies estimating the likely cost savings from such practices, however, have come to mixed conclusions. See 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, 544 (1994) (concluding that it is unlikely that advance directives, hospice care, or the elimination of futile care will have a significant effect on cost savings at the end of life); Anne A. Scitovsky, "The High Cost of Dying" Revisited, 72 Milbank Q. 561, 586 (1994) (same).

Dr. Haavi Morreim disputes these findings regarding the extent of cost savings in part by pointing out that studies focusing on end-of-life care do not take into account the cost of continued maintenance, potentially for many years, of patients in PVS. See Morreim, supra note 101, at 911 n.92. Because Murphy and Finucane's model for futility policies does not include the termination of life-sustaining care for PVS patients, Morreim's point is not germane to the hypothetical Medicaid futility policy discussed in the text. Were a real-world futility policy excluding that care challenged, however, the point could assume some significance. The level of significance would depend upon the availability of data showing costs incurred as the result of various interventions that sustain the life of a PVS patient.

\textsuperscript{229} See Murphy & Finucane, supra note 19, at 1644 ("[T]he actual monetary savings from new DNR policies would be small.").


\textsuperscript{231} Id. at 1368-70.

\textsuperscript{232} Id. at 1370. The court displayed little patience with the University's attempt to apply different standards to persons with disabilities:

If these additional requirements were actually intended to screen out undesirable
the context of the Medicaid futility policy, it seems logical that a probability of benefit criterion truly deemed essential to controlling costs by excluding coverage of nonbeneficial services would be applied to all medical treatments (thus impacting both persons with and without disabilities), rather than solely to life-sustaining treatments (impacting exclusively persons with severe disabilities).24

b. Qualification: reasonable modifications

Even if the "probability of benefit" criterion implicit in the futility policy were judged essential to the Medicaid program, opponents of the futility policy could still argue that the ADA requires the policy to be modified in order to operate in a less discriminatory fashion. One real evil of the futility policy, from the disability rights perspective, is its blanket denial of life-sustaining interventions for persons with certain severe disabilities, based in part on nonmedical assumptions regarding their quality of life. A modification that would ameliorate this evil would be to require an individualized assessment of each patient's probability of benefit in light of the patient's own valuing of the quality of her life and extensions thereof before coverage for any treatment could be denied.245

Id. 243. For discussion of this point in a different context, see supra text accompanying notes 154-57.

244. See text accompanying supra note 202.

245. Conceivably, challengers of the futility policy could seek that the policy be modified by requiring a lower threshold showing of probability of benefit or by waiving the probability of benefit requirement altogether. It seems unlikely, however, that either lowering the threshold of probability or waiver would be seen as a reasonable accommodation in this case. See Pottgen v. Missouri State High Sch. Activities Ass'n, 40 F.3d 926 (8th Cir. 1994); Aughe v. Shalala, 885 F. Supp. 1428 (W.D. Wash. 1995) (waiving an essential eligibility requirement for the AFDC program would "essentially rewrite the statute [and] must be seen as a fundamental alteration in the nature of the program"); see also Peters, supra note 101, at 529. But see Jackson v. Florida High Sch. Activities Ass'n, 899 F. Supp. 579, 586 (M.D. Fla. 1995) (finding that waiving age requirement would not fundamentally alter the nature of an interscholastic athletics program). Because the futility policy would deny coverage only for persons with disabilities, waiving the probability of benefit criterion for all such persons would effectively gut the policy. Similarly, allowing a lower threshold showing of the probability of benefit (e.g., requiring only 1% chance of benefit as opposed to 5%) for all those persons would seem to fundamentally alter the nature of the futility policy.

246. Cf. Traynor v. Turnage, 485 U.S. 535, 553 (1988) (Blackmun, J., dissenting) (arguing that § 504 requires individualized assessment in each particular case of whether primary alcoholism was the result of willful misconduct and that irrebuttable presumption therefore violates § 504).
By so modifying the policy, the State could avoid making coverage decisions "based not on an individual assessment of the . . . potentials of each [recipient] but on the generalized assumption that certain groups of people . . . are unable to benefit from certain . . . services." 247

The State, however, would likely strenuously object to this proposed modification of its futility policy as imposing an undue administrative and financial burden on the State's Medicaid program. In addition to the possible financial burden of funding life-sustaining treatment in some number of additional cases, 248 the modification would certainly create financial and administrative burdens flowing from the mandatory individualized assessment of each person subject to the futility policy. 249 These burdens would be undue, the State would argue, particularly in light of the high level of individualization present in the futility policy itself. The policy's exclusions are not blunt instruments like traditional insurance exclusions, but instead are focused on individual prognoses. 250

Moreover, the proposed modification of the futility policy arguably would fundamentally alter the State's Medicaid program in at least two ways. First, the State could assert that its adoption of a rationing scheme reflects the State's philosophical commitment to maximizing the health of the State's community of residents. Aside from any adverse financial impact that requiring individualized assessments of futility might have on the State's ability to fulfill that commitment, the individualization requirement would symbolically and powerfully deny the validity of the State's focus on the collective welfare of its citizens. 251 This denial of the

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248. Dr. Morreim asserts that the financial burdens imposed would likely be great because, in the absence of some kind of limitation, patients will be able to demand "virtually any exotic treatment for virtually any patient's need." See Morreim, supra note 101, at n.92. She goes on to include in her parade of horribles the resource diversion that will occur when "more nurses must be dedicated to intensive care for demented octogenarians with new organ transplants." Id. at 917. Even if the logic of disability rights argument against a Murphy-and-Finucane-style futility policy could be extended to other limitations on the coverage of medical treatment (itself a debatable point), Morreim does not take into account that the defendant bears the burden of proving that undue burdens will actually result from a proposed accommodation. See Junellis v. Snider, 68 F.3d 648 (3d Cir. 1995). Thus, unless the State could show that its conducting an individualized futility assessment would result in many patients demanding and receiving what Morreim calls "exoticare," the State will fail to carry its burden.
249. Cf. Traynor, 485 U.S. at 551 n.12 (reasoning that to require the Veterans Administration to make an individualized determination of each veteran's willfulness in drinking would saddle the government with additional administrative and financial burdens not contemplated by Congress when it extended the coverage of § 504 to federal programs).
250. See Peters, supra note 101, at 531.
251. For an argument supporting the need to shift focus from individual medical need to
State's sovereign power to choose and pursue its health policies would constitute a fundamental alteration of its Medicaid program. Second, the individualization modification could be depicted as forcing the State to legitimize Medicaid beneficiaries' use of state-funded medical services to pursue whatever ends they please, whether those ends involve medical benefit or not. While the State is free to choose as a matter of policy to design its Medicaid program to maximize the health and personal fulfillment of Medicaid recipients, the State has instead chosen to design its program to maximize health alone. Thus, the State would argue, the proposed modification would expand the scope of the State's policy goal and thereby fundamentally alter the program in a way not required by the ADA.

In addition to the foregoing, two final arguments are available to defend the Medicaid futility policy. First, the courts have made it clear that disability discrimination law does not require a program's modification to accommodate a person with a disability if, even after the modification, the person would be unable to benefit from participating in the program. Thus, for example, a nursing school need not change its curriculum to accommodate a hearing impaired applicant when her disability would preclude her from being licensed or employed as a registered nurse.

Community health in health policy and the utility of using categorical exclusions in doing so, see Daniel Callahan, Rationing Health Care: Will It be Necessary? Can It be Done Without Age or Disability Discrimination?, 3 Issues L. & Med. 353 (1989). Callahan argues:

[A] shift from individual decisionmaking to the use of categorical standards ... would prod us to develop a philosophy of health care that looked to the common good, to meeting reasonable individual needs, but not all needs, and to getting us off that uncontrollable express train called unlimited medical progress.


252. Cf. Easley v. Snider, 36 F.3d 297, 305 (3d Cir. 1994) (reasoning that to require the state to allow persons who are not mentally alert to qualify for attendant care services through the use of surrogates would change the focus of the attendant care program).

Norman Daniels makes a similar point in a different context with respect to Medicaid funding of nontherapeutic abortions:

Non-therapeutic abortions do not count as health-care needs, so if Medicaid has as its only function the meeting of the health-care needs of the poor, then we cannot argue for funding the abortions just like any other procedure .... But if Medicaid should serve other important goals, like ensuring that poor and well-off women can equally well control their bodies, then there is justification for funding abortions.


253. Southeastern Community College v. Davis, 442 U.S. 397 (1979). Southeastern Community College was the first case the Supreme Court decided under § 504, and in interpreting § 504's "otherwise qualified" limitation, the Court read the statutory language to reach only persons who can meet all of a program's requirements "in spite of" their disabilities. Id. at 406. The Court, however, did recognize that § 504 could in some instances require a program to modify an existing program whose requirements were "unreasonable and discriminatory." Id. at 412-13. While the Court's holding in Southeastern Community College has generated some confusion and consternation regarding the meaning of § 504's "otherwise
By analogy, it can be argued that no modification of the futility policy should be required because no conceivable modification will enable the persons affected by the policy to receive any medical benefit from life-sustaining interventions. Because this medical benefit is the “ultimate benefit” that the Medicaid program seeks to achieve, it need not provide accommodations in order to allow a Medicaid recipient to receive a different, nonmedical benefit.\(^2\)

Second, the State could argue that, as a prudential matter, the proposed modification simply falls beyond the bounds of what the ADA arguably requires. As the Supreme Court warned in *Alexander*, disability discrimination law must be interpreted in light of “two powerful but countervailing considerations—the need to give effect to the statutory objectives and the desire to keep [the statute] within manageable bounds.”\(^2\) Thus, Section 504 and the ADA do not represent absolutist approaches to disability discrimination.\(^2\) Instead, they consider the

qualified” language, at least some courts have drawn a message from *Southeastern Community College* that would be pertinent to a state Medicaid program’s obligation to modify its futility policy. The Fifth Circuit stated: “[T]he Supreme Court’s decision in *Southeastern Community College* says only that § 504 does not require a school to provide services to a handicapped individual for a program for which the individual’s handicap precludes him from ever realizing the principal benefits of the training.” Camenisch v. University of Tex., 616 F.2d 127, 133 (5th Cir. 1980). *Accord* Nathanson v. Medical College of Pa., 926 F.2d 1368, 1383 (3d Cir. 1991) (finding that benefits are not required if the student would not recognize the benefit); New Mexico Ass’n for Retarded Citizens v. New Mexico, 678 F.2d 847, 853-54 (10th Cir. 1982) (stating “refusal to affirmatively modify an education program is not discrimination under § 504 if the handicapped recipient thereafter would remain unable to obtain the program’s ultimate benefits”).

254. Again, analogizing to *Southeastern Community College* could be helpful. While Ms. Davis possibly may have believed that she would receive some personal benefit from attending nursing school despite her inability to be employed as a nurse, that desire to obtain a personally defined benefit different from the benefit identified by the program as its goal apparently would not provide a basis for claiming a right to modifications. *See Southeastern Community College*, 442 U.S. at 413 n.12 (“Southeastern’s program, structured to train persons who will be able to perform all normal roles of a registered nurse, represents a legitimate academic policy. . . . Nothing in the Act requires an institution to lower its standards.”). When life support has been deemed futile for a patient, a personal benefit such as seeing the birth of a grandchild will not be realized, therefore modification on the basis of that benefit is not warranted. *See also Easley*, 36 F.3d at 306 (“[T]his is a case where an additional handicap, a severe degree of mental disability, renders participation in the program ineffectual.”).


256. Michael Rebell examines characteristics such as the lack of a history of de jure segregation and the presence of inherent limitations posed by disability—distinguishing issues of disability discrimination from issues of race discrimination. In light of such distinctions, courts dealing with cases involving claims of disability discrimination should abandon analytical constructs, employed in the context of race discrimination claims. Instead, Rebell argues that courts should focus on the real issue in the disability context: How much structural change should society undertake to accommodate the needs of the disabled? Thus, Rebell rejects an absolutist approach to disability discrimination law. Michael A. Rebell, *Structural Discrimination and the Rights of the Disabled*, 74 Geo. L.J. 1435, 1444 (1986) (citing Justice Marshall’s opinion in *Alexander*, 469 U.S. at 308-09).
effects of disability on a person's "qualification" and require only that "reasonable" accommodations be made for a person's disability. Consequently, while Congress may have used bold language in declaring the ADA a "clear and comprehensive national mandate for the elimination of discrimination," the courts have characterized disability discrimination law as creating a "mushy" question: Where on the spectrum of possible accommodations should the line be drawn between those that are reasonable and those that are not?

From the State's perspective, this need to keep disability discrimination laws within "manageable bounds" becomes particularly acute when those laws are invoked to inhibit a state's ability to establish priorities in allocating scarce resources. This proposition rings especially true when disability discrimination law is used to mount a challenge to a state's allocation decisions regarding medical resources in its Medicaid program. A partial justification for a hands-off approach in this area lies in the courts' practice of deferring to judgments of public health officials and other state agents when those judgments are based on medical data.

A more fundamental explanation, however, lies in the courts' unwillingness to find that disability discrimination law creates obligations for a state's Medicaid program beyond the multitude of obligations imposed by the federal Medicaid statute and regulations. As one district court reasoned:

The relevance of the general provisions of § 504 are [sic] ... eroded by the fact that the federal Medicaid Act sets out detailed and explicit funding conditions which must be fulfilled by states to earn program approval from the Secretary of Health and Human Services. ... [T]he fact that Congress did not include explicit conditions concerning distribution of Medicaid funds among all classes of handicapped persons in the relevant

258. See Doherty v. Southern College of Optometry, 862 F.2d 570, 575 (6th Cir. 1988) (concluding that after Alexander the proper inquiry is "the rather mushy one of whether some 'reasonable accommodation' is available to satisfy the legitimate interests of both the grantee and the handicapped person"); Ham v. Nevada, 788 F. Supp. 455, 460 (D. Nev. 1992) (same).
259. See Williams v. Secretary of the Executive Office of Human Servs., 609 N.E.2d 447, 454 (Mass. 1993) ("Courts do not determine whether an agency's allocation of resources or provision of services is efficient or in proportion to the obvious and pressing need of the disabled within the Commonwealth."); cf. Traynor v. Turnage, 485 U.S. 555, 543 (1988) (reasoning that extension of § 504 to federal Executive agencies should not be seen as limiting Congress's ability to establish priorities for the allocation of the limited resources available); Moddero v. King, 871 F. Supp. 40, 43 (D.D.C. 1994) (accepting plaintiff's claim that a Federal Employees Health Benefits plan cannot distinguish between physical and mental illness with respect to coverage because it would "invite challenges to virtually every exercise of OPM's discretion with respect to the allocation of benefits amongst an encyclopedia of illnesses"); Orenlüler, supra note 8, at 1091 ("To allow for reasonable responses to the problem of rising costs, courts are not likely to require treatment when the patient would gain little benefit.").
260. See supra note 199.
Medicaid funding condition provisions, ... indicates that Congress never intended that § 504 be construed to impose fund distribution conditions on state recipients in addition to the explicit conditions of [the federal Medicaid statute].

Similarly, in Alexander the Supreme Court found no evidence that in enacting Section 504 Congress "desired to make major inroads on the States' longstanding discretion to choose the proper mix of amount, scope, and duration limitations on services covered by state Medicaid." Thus, if a futility policy satisfies the Secretary of HHS that it meets Medicaid's statutory and regulatory requirements, a court should not second guess that judgment.

Following this line of the State's reasoning to its conclusion, close scrutiny of the allocation decisions inherent in state Medicaid programs ultimately is simply beyond the purview of what Congress intended disability discrimination law to address. To allow the ADA to be used as a vehicle for scrutinizing a state's complex health policy decisions would be to permit the statute to escape from its manageable bounds. As partial support for this argument, the State could cite Alexander, in which Justice Marshall noted that Congress's focus in enacting Section 504 was on "several substantive areas — employment, education, and the elimination of physical barriers to access — in which it considered the societal and personal costs of refusals to provide meaningful access to be particularly high." Moreover, the State would emphasize, this argument is borne out by the decided cases. Courts have been loath to grant relief in cases alleging disability discrimination in the allocative policies of a state Medicaid program. The Court's willingness to grant relief in cases involving Medicaid has been confined to cases involving some nonallocative denial of access to the program itself or its benefits.

263. See Duquette, 582 F. Supp. at 1372 (emphasizing fact that Secretary of HHS had authorized New Hampshire's challenged Medicaid eligibility requirements). Of course, this line of reasoning does not make clear whether the Secretary of HHS, in deciding whether to approve a state's Medicaid program or whether to grant a state's request for a waiver of federal Medicaid requirements, should only take into account the program's compliance with Medicaid standards or should also consider any evidence of disparate treatment or impact based on disability. It appears from his denial of Oregon's waiver request that former Secretary of HHS Louis Sullivan believed that the broader scope of examination was appropriate.
264. Alexander, 469 U.S. at 306-07 (footnotes omitted); see Rebell, supra note 256, at 1457 ("At the core of the Court's holding [in Alexander] was an interpretation of the legislative history that viewed hospital benefits as a low priority area to which section 504 coverage should not be extended.").
265. See Alexander, 469 U.S. 287 (limiting hospital coverage to 14 days per year); Doe, 592 F.2d 704 (limiting coverage for inpatient stay in mental hospital to 60 days); Duquette, 582 F. Supp. at 1366 (extending Medicaid eligibility to blind persons under the age of 18, but not to persons under 18 with any other disability).
Thus, the State would argue that the appropriate response for a court presented with disability discrimination claims relating to the State's Medicaid futility policy is, in the vernacular, to "butt out."

5. The Insurance Exemption

Regardless of the resolution of the foregoing arguments, the State could also defend its Medicaid futility policy as falling within the safe harbor that the ADA provides for insurance practices. Section 501(c) of the ADA provides that the statute should not be read to prohibit insurers, hospitals, HMOs, or benefit plan sponsors from "underwriting risks, classifying risks, or administering risks" consistent with state law, so long as the covered practice is not a subterfuge to evade the purposes of the ADA. The purpose of Section 501(c), according to the ADA's legislative history, is to maintain the latitude enjoyed by insurers and employers in designing and administering insurance products and benefit plans consistent with "basic principles of insurance risk classification." Congress did not want the ADA to be construed as prohibiting all actions that would treat disabled persons differently under an insurance or benefit plan when those persons represented an increased hazard of death or illness.

The State could seek the shelter of Section 501(c) by arguing that its Medicaid policy is simply an example of how the State, as the sponsor of a bona fide benefit plan, seeks to classify and administer risks. The Interim Enforcement Guidance issued by the Equal Employment Opportunity Commission (EEOC) in September 1993 offers some support for this position. These guidelines, which deal specifically with the application of Section 501(c) to employer-provided health insurance programs, provide examples of insurance practices that, while embodying a disability-related distinction, should be considered actuarially justifiable and therefore not a subterfuge for evading the purposes of the ADA. Of particular note is the final example: An insurer's proof that a disability-specific treatment for which coverage is sought does not provide any medical benefit justifies a disability-based exclusion of coverage. Thus, in an analogous context,

prima facie case of discrimination where Medicaid-eligible residents of board and care homes and nursing homes alleged that they were deprived of access to the Medicaid program because they lacked transportation to the services of health care providers); Cook v. Hairston, No. 90-3437, 1991 WL 253302, at *4-5 (6th Cir. Nov. 26, 1991) (unpublished opinion) (finding that law allowing the appointment of a personal representative for nursing home residents for purpose of applying for Medicaid could have a disparate impact on persons with disabilities).


269. Id.

the EEOC has arguably found that excluding coverage for futile treatment is well within the realm of insurance practices that Congress intended to leave undisturbed by the ADA. Finally, the language of Section 501(c) itself suggests that risk classification schemes employed by a public entity should not even be scrutinized as potential subterfuges; the statute provides that the excepting language of Section 501(c) "shall not be used as a subterfuge to evade the purposes of [Titles] I and III." This provision suggests that a Title II entity's use of a disability-related classification may stand, even if it can be characterized as an attempt to evade Title II's purposes.\(^{271}\)

The State's reliance on the insurance exemption, however, is subject to challenge on several grounds. First, opponents of the futility policy could argue that Congress intended Section 501(c) to apply to the insurance industry as commonly understood—to the practices of employer-provided and other commercial insurance—and not to the policies embodied in a state's health insurance program.\(^{272}\) Second, even if Section 501(c) applies to a state Medicaid program, the type of rationing decision embodied in a cost-conscious futility policy is arguably not the type of risk-classification practice that Section 501(c) shields. Risk classification practices seek to determine an individual's (or a group's) likelihood of becoming ill and incurring covered expenses with the purpose of either excluding the individual or charging him a higher premium in order to protect the group's pooled resources. The futility policy, by contrast, focuses on which among those patients who are already a part of the group and are already ill will receive the least benefit from the expenditure of pooled resources. Thus, the Medicaid futility policy is not the type of risk classification practice that falls within Section 501(c).\(^{273}\)

[hereinafter EEOC Interim Guidance].

271. Accord Rodriguez v. City of Aurora, 887 F. Supp. 162 (N.D. Ill. 1995) (finding that the "subterfuge" exception applies only to actions brought under Titles I and III).

272. This seems to have been the primary intent of both Congress and the regulatory bodies responsible for drafting regulations. For example, the provisions of § 501(c) are repeated in the regulations of Title I regarding employee benefit plans and Title III regarding public accommodations, 29 C.F.R. § 1630.16(f) and 28 C.F.R. § 36.212 (1995), but not in the public services regulations under Title II. This interpretation would also explain why the subterfuge provision in § 501(c) refers only to Titles I and III of the ADA. See supra text and accompanying note 271. At least one commentator, however, has suggested that the protective scope of § 501(c) would extend to "publicly-funded health plans which use underwriting calculations to predict risks and shape coverage." See Peters, supra note 101, at 511 n.98.

273. See Orentlicher, supra note 8, at 311-12 (advocating narrow construction of "risk classification"); Peters, supra note 101, at 511-12 (arguing that the ADA authorizes risk classification schemes). Professor Peters reasons as follows:

[T]he statutory exemption for underwriting practices does not appear to sanction the use of... measures of a given treatment's effectiveness. Unlike restrictions based on underwriting risks, eligibility restrictions based on effectiveness are not based on the risk of subscriber illness and its predicted cost. They are based, instead, on predicted outcomes. Patients whose care is relatively ineffective are not
Finally, challengers may argue that even if the State’s Medicaid futility policy falls within the general scope of Section 501(c), a policy that excludes coverage of nonbeneficial treatment only when life-sustaining treatment is at issue is not actuarially justifiable. The EEOC’s Interim Guidance supports this argument, for it indicates that a health insurance plan that excludes coverage for a disability-specific treatment on grounds of lack of benefit, but that covers treatment for other conditions that similarly are of no medical value, may be found to violate the ADA.274 In sum, a failure of the State Medicaid program to make futility-based coverage decisions across the spectrum of critical and noncritical care may prove a stumbling block to the program’s ability to seek shelter under Section 501(c).

D. Title III and the Hospital Futility Policy

Let us turn now from the swirl of arguments regarding a Medicaid futility policy’s validity under Title II of the ADA and consider our second scenario—a hospital’s adoption of a futility policy for cost control purposes. In doing so, we enter the realm of Title III of the ADA, which applies to public accommodations.275 Title III, like Title II, states a general prohibition of discrimination: “No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, ... of any place of public accommodation by any person who owns, leases ... or operates a place of public accommodation.”276 Unlike Title II, however, Title III gives specific guidance on construing the general prohibition and articulates specific actions that constitute illegal discrimination.277

In general, a plaintiff asserting a Title III violation must prove that he has a disability, that the defendant operates a place of public accommodation, and that the defendant denied his full and equal enjoyment of its services because of his disability.278 Arguments regarding satisfaction of

necessarily any more costly or financially risky than other patients. Their care does not present the kind of cross-subsidization problems that standard underwriting practices are meant to solve.

Peters, supra note 101, at 511-12. One response to this argument is that, by its terms, § 501(c) applies not only to risk classification and underwriting practices, but also to risk administration practices, and that the reference to risk administration should be construed broadly as encompassing the type of cost-benefit and cost-effectiveness decisions that health maintenance organizations routinely make.

274. See EEOC Interim Guidance, supra note 270, at 476 n.10.
277. See 42 U.S.C. § 12182(b) (“Construction”) and subsections (1) (“General prohibition”) and (2) (“Specific prohibitions”) thereto. It should be noted, however, that some of Title III’s specific statutory provisions are mirrored in the regulations promulgated under Title II. See 28 C.F.R. pt. 35, app. A, § 35.130 (1995).
these elements in a case involving a hospital futility policy can be expected to parallel, by and large, the arguments set forth above regarding Title II and a Medicaid futility policy. Specifically, arguments regarding whether the policy’s challenger is disabled, how to define the relevant benefit or services, and whether the denial of life-sustaining treatment under a futility policy is based on disability would likely track the parallel Title II arguments. Whether a hospital’s adoption of a cost-conscious futility policy falls within the exemption for insurance practices would in many respects be analyzed similarly to Section 501(c)’s application to the Medicaid futility policy. Additional analysis is needed to determine whether the plaintiff is qualified for the services and whether the hospital is required to modify its policy to accommodate persons with disabilities. Distinctions between Titles II and III and distinctions between the two factual settings involved may lead to different arguments.

1. “Qualification” Under Title III

Unlike Title II, Title III’s general prohibition contains no explicit “qualification” requirement for the disabled person alleging discrimination. At first blush, this distinction might be taken to indicate that a Title III court, without citing authority for the additional requirement, also would require the plaintiff to show that she was denied services under circumstances giving rise to the inference that such denial was based solely on her disability. Id. Courts applying § 504 of the Rehabilitation Act have imposed a similar requirement based on § 504’s “solely by reason of . . . disability” language, but Title III of the ADA appears on its face to apply broadly to any discrimination “on the basis of disability.” 42 U.S.C. § 12182(a). A showing that the defendant failed to make reasonable policy modifications in order to provide services to individuals with disabilities may satisfy the “denial of services” element of the claim, as discussed below. See 42 U.S.C. § 12182(b)(2)(A)(ii); see also Thomas v. Davidson Academy, 846 F. Supp. 611, 617 (M.D. Tenn. 1994) (stating that the refusal of the Academy to modify its disciplinary action against a student with a disability would amount to a denial of services under the ADA).

279. See supra part III.C.1.
280. See supra part III.C.2.
281. See supra part III.C.3.
282. See supra part III.C.5. The important legal distinction here is that § 501(c)(1) refers specifically to hospitals as actors within its protective scope. Challengers of the futility policy, however, might still try to argue that the reference, when viewed in context, should include only hospitals functioning as insurers or administrators of benefit plans. See 42 U.S.C. § 12201(c)(1) (Supp. V 1993).
283. The discussion that follows in the text focuses on a specific paradigm of how a futility policy might come to be: a hospital’s adoption of such a policy explicitly for the purpose of cutting costs. This paradigm was chosen both to reflect a specific proposal put forth in the medical literature and to provide a focus to the discussion. However, when institutions actually adopt futility policies, their motivations may be less clear and less overt. Like the rest of us, decisionmakers within hospitals are influenced by many political factors, both internal and external. In addition, this discussion does not take into full account the other Title III institutions, such as nursing homes, that might adopt a futility policy, nor does it discuss in any depth the various roles that a hospital might play within an integrated delivery system. It is not the purpose of the discussion in the text to account for all the analytical nuances that each factual variation might introduce, but to provide a framework and suggestions for analyzing different situations.
plaintiff's ability to satisfy any qualifications or eligibility criteria established by a public accommodation is simply irrelevant. The "specific prohibitions" following the general prohibition, however, implicitly recognize a public accommodation's freedom to enforce eligibility requirements for its services, so long as those criteria do not screen out or tend to screen out persons with disabilities. If a public accommodation's imposition of eligibility criteria have a screening out effect, that imposition will be deemed a form of discrimination unless the criteria are shown to be necessary for the provision of the goods or services offered.284 Thus, conceptually, this analysis closely resembles the analysis of whether a Title II plaintiff meets the public entity's essential eligibility requirements for receipt of the relevant benefit.285

Factual differences between a state's Medicaid program and a hospital, however, would lead to different arguments regarding whether the "probability of benefit" criterion effectively imposed by a futility policy should be deemed "necessary for the provision of the . . . services" offered by a hospital. While a state Medicaid program defending a futility policy would likely point to its dire need to make allocation decisions designed both to control costs and to maximize the health benefits provided to the Medicaid population, a hospital defending its futility policy may or may not be able to make a similar claim. Hospitals reimbursed on a fee-for-service basis286 for patient care cannot convincingly raise a cost-saving justification for the policy, for the hospital itself will not capture the bulk of any cost savings that flow from withholding futile care. Instead, these savings will accrue to the third-party payer responsible for the patient from whom care is withheld.287 As a result, the hospital would have difficulty arguing that the resource conservation sought by a cost-conscious futility policy288 is necessary to its provision of services.289

285. See supra Part III.C.4.a (discussing the essential eligibility criteria for qualification); accord Peters, supra note 101, at 512.
286. Under fee-for-service reimbursement, the relevant unit of payment is each service, procedure, or supply provided to a patient. Traditionally, most payers have reimbursed hospitals and physicians on this basis. See Thomas Bodenheimer & Kevin Grumbach, Reimbursing Physicians and Hospitals, 272 JAMA 971, 971, 975 (1994).
287. Of course, to the extent that a patient is not covered by a third-party payer, a hospital is not likely to be fully compensated for treatment provided and therefore would benefit from any cost savings. Likewise, if reimbursement by a third-party payer does not fully cover the hospital's costs of providing care, as may often be the case with Medicaid patients, the hospital again may benefit from limiting futile care and thereby minimizing the shortfall in its reimbursement.
288. This Article focuses on a futility policy like that proposed by Murphy & Finucane, supra note 19, for the primary purpose of controlling costs. A hospital also could adopt a futility policy based primarily on concerns regarding professional authority and professional morale. This change in the policy's purpose would change the ADA analysis, and at first blush, it is difficult to imagine how a hospital would convince a court that a futility policy with those goals would be "necessary" to the provision of the hospital's services.
289. A hospital defending a futility policy could raise a "stewardship" argument as to why
By contrast, a hospital that participates in managed care plans and is compensated on a capitation basis for large numbers of its patients would be able to make a more compelling argument that the cost savings from a futility policy are indeed necessary to its provision of services. Because a capitation system of reimbursement provides the hospital with a flat sum per enrollee to pay for all care provided to the covered population, the hospital bears insurance risk, giving it the incentives to make what are effectively rationing decisions designed to maximize the health of its capitated patient population. This incentive to maximize patient welfare arises not only from the hospital's ethical commitment to patient care and distributive justice, but also from the hospital's potential malpractice exposure if the care it provides to any individual patient falls short of the standard of care expected from hospitals. Thus, if a

the hospital should be concerned with controlling costs that other parties ultimately bear. See Miles, supra note 3, at 514. Again, however, even if a court acknowledged such an interest on the hospital's part, it seems unlikely that a futility policy fulfilling the hospital's stewardship obligations would be deemed "necessary" to the hospital's provision of services.

290. Hospitals have played an important role in the rapid development of integrated delivery systems in the 1990s. This "alphabet soup" grab bag of organizational structures is characterized by the integration of health care providers, administrators, and insurers and the sharing of insurance risk among the various players. See generally Mark A. Hall, Managed Competition and Integrated Health Care Delivery Systems, 29 Wake Forest L. Rev. 1 (1994). For a description of some of the organizational structures in which hospitals might be involved, see Jonathan P. Weiner & Gregory de Lissovoy, Razing a Tower of Babel: A Taxonomy for Managed Care and Health Insurance Plans, 18 J. Health Pol'y, Pol'y & L. 75 (1993).

291. Under a capitation reimbursement scheme, a provider is reimbursed by a single payment for each plan participant's entire treatment needs during a set time period, usually a month or a year. Capitation payment is most often used in the context of managed care. See Bodenheimer & Grumbach, supra note 286, at 971, 976 (explaining capitation reimbursement).

News accounts of institutions' development of cost-conscious futility policies have identified the growing trend of hospital participation in managed care networks as one impetus for that development. See Gianelli, supra note 4.

292. Cf. Randall A. Bovbjerg, The Medical Malpractice Standard of Care: HMOs and Customary Practice, 1975 Duke L.J. 1375, 1414 (arguing for imposition of standard of care that recognizes capitation-based HMOs' incentive to make trade-offs designed to maximize the health of the whole patient population over the health of an individual patient); Morreim, supra note 101, at 917 n.110 (describing the fundamental objective of many health plans as "maximiz[ing] the health of the covered population as a whole").

It should be noted that fee-for-service reimbursement and capitation payment are methods of payment that lie on opposite ends of a continuum reflecting the extent to which a health care provider bears a risk that the costs of providing care will exceed the payment received therefor. Intermediate points on the continuum of methods of hospital reimbursement include per diem payments and diagnosis related groups (DRG) payments, the method of hospital reimbursement used by the Medicare program. For an illuminating explanation of the extent to which hospitals bear risk under different reimbursement schemes, see Bodenheimer & Grumbach, supra note 286, at 971, 975-76. To develop fully the argument presented in the text would require a breakdown of a hospital's various sources and methods of reimbursement.

293. In this respect, a hospital's futility policy may be supported by a consideration
hospital could show that its futility policy will result in significant cost savings, a hospital heavily dependent on capitation or another form of prospective payment would be able to argue with some force that it must be able to limit care providing minimal or no benefit to individual patients in order to be able financially to provide care of proven benefit to all its patients.

Therefore, the strength of a hospital's argument that its adoption of a probability of benefit criterion is necessary to its provision of services may depend in part on the hospital's particular reimbursement arrangements. A hospital that functions purely or primarily as a health care provider and does not bear significant insurance risk with respect to the cost of caring for its patients likely would have a difficult time convincing a court of the necessity of a futility policy. By contrast, a hospital that bears substantial financial risk as a result of its participation in managed care plans—as many hospitals increasingly do—would be able to make a much stronger argument.

2. "Reasonable Modifications" Under Title III

Title III of the ADA specifically provides that a public accommodation's failure to make reasonable modifications to its policies, when such modifications are necessary to afford its services to individuals with disabilities, will be deemed discriminatory unless "the entity can demonstrate that making such modifications would fundamentally alter the nature of such ... services . . . ." As discussed above, the modification of a futility policy most likely to afford life-sustaining treatment to persons with severe disabilities would be to allow individualized assessment of each patient to determine the potential for benefit in light of the patient's own valuation of her life and any benefits achievable by an extension thereof. Challengers of the hospital futility policy would argue

294. The ADA puts the burden on the defendant to demonstrate the necessity of the eligibility criteria. 42 U.S.C. § 12182(b)(2)(A)(ii) (Supp. V 1993). Thus, the hospital would have to demonstrate the cost savings that would flow from a futility policy. These savings may well be insignificant, as discussed above. See supra text accompanying notes 238-39.

295. Cf. Lantos, supra note 13, at 869 (discussing linkage between the adoption of prospective payment systems in the early 1980s and the emergence of the futility debate). As discussed above in part III.C.4.a, however, a claim of necessity would be weakened to the extent that the hospital limits only life-sustaining treatment and does not attempt to limit other treatments that provide minimal or no benefit. See supra text accompanying notes 240-43.

296. Another factor that a court might consider as part of this analysis of necessity is whether the hospital operates on a for-profit or not-for-profit basis. Any savings reaped as the result of a not-for-profit hospital's futility policy would be legally required to be reinvested to somehow further the institution's not-for-profit mission. The savings enjoyed by a for-profit hospital, by contrast, could conceivably benefit only the hospital's investor-owners.


298. See supra text accompanying note 246.
that because the hospital, through its physicians, already engages in ongoing medical assessment of each of its patients, the proposed modification would not fundamentally alter the nature of the hospital's services or be overly burdensome. Essentially, the modification would require additional communication with the patient or surrogate about matters not entirely medical in nature and potentially would impose some additional cost for those patients provided with life-sustaining treatment as a result of the individualized assessment. In response, a hospital could argue that the modification would pervert medical practice by deflecting medicine's focus from patients' health and turning medicine into a vehicle for serving patients' personal desires. A hospital's ability to convince a court that this perversion would work a fundamental alteration in the hospital's services, however, seems questionable.

Moreover, a hospital's defense of its futility policy against modification seems weaker than a state Medicaid program's corresponding defense because the hospital cannot convincingly claim the deference that courts frequently accord a government's policy decisions allocating scarce resources; this is simply not a role traditionally played by hospitals. Similarly, a hospital cannot point to overarching federal regulation of its operations, as a state Medicaid program could, to justify limiting the reach of disability discrimination law. Instead, challengers of a hospital's futility policy could argue with some force that courts should be particularly suspicious of any discrimination flowing from private policies allocating vital societal resources, particularly when those decisions are motivated by private, rather than public, fiscal concerns.

Despite the appeal of this argument, however, a hospital defending a futility policy against modification may, as a practical matter, benefit from the traditional reluctance of courts to "second-guess" decisions requiring the exercise of medical judgment. So, in recent disability discrimination cases involving hospitals' relations with HIV-infected health care workers, courts have deferred to hospitals' assessment of the threat to patient safety posed by those workers. The same strain of deference is evident in the

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299. For this reason, the burden of the proposed modification would arguably be less in the context of the hospital futility policy than in the context of the Medicaid futility policy, because the state Medicaid program is itself not ordinarily involved in direct patient care. Consequently, the state Medicaid program would need to add some sort of new level of administrative review if the proposed modification were implemented.

300. This additional cost, however, may or may not fall on the hospital, as discussed in part III.D.1 above.

301. Challengers would be in danger of overstating this point because, as a practical matter, the conditions of participation imposed on hospitals by the federal Medicaid program function as federal regulation of those hospitals. Those conditions include requirements with respect to both the physical characteristics of the institution (e.g., adequate ventilation systems and staffing) and the policies and practices of the institution. See, e.g., 42 C.F.R. § 482.41(c)(4) (1994) ("proper ventilation, light, and temperature controls"); id. § 482.23(b) (staffing of nursing services); id. § 482.21 (quality assurance program requirements); id. § 482.12 (governing body requirements).

so-called Baby Doe cases from the mid-1980s, in which the courts effectively refused to intervene in cases involving nontreatment decisions for newborns with disabilities. Thus, a hospital may be able to play a "defer to medical judgment" card in substitution for the "defer to government policy choices" card available to the State.

In sum, considering the validity of a hospital's futility policy under the ADA introduces a few analytical variations on our discussion in Part III.C of a Medicaid futility policy. Some of these variations lend strength to challengers' arguments, others support a hospital's arguments defending the policy. Ultimately, however, the foregoing discussion has failed, to my mind, to provide conclusive or compelling arguments either for or against the legality, as a matter of disability discrimination law, of cost-conscious futility policies like the one Murphy and Finucane propose. Rather, the question seems to be quite a close one.

Where does that leave us? On a practical level, it suggests that a careful court, called on to decide an ADA challenge to the legality of either type of futility policy, will need to focus intently on the specific factual setting in which the challenge arises and will face a complex, difficult decision. Specific variables that could significantly influence the court's decision would include: (1) the definition of futility employed and the extent to which quality of life judgments inhere in that definition; (2) the degree of individualization built into the implementation processes of the policy; and (3) the ability of the policy maker to quantify cost savings substantial enough to render the futility policy essential to the policy maker's program goals. On a more theoretical level, as I will argue in the next Part, it leaves us with questions about the wisdom of relying primarily on disability discrimination law to determine the legitimacy of health care allocation decisions.

IV. RESERVING JUDGMENT AND ASKING QUESTIONS

At this point in an article, a reader normally might expect to find the author's recommendation as to how a court should resolve an ADA challenge to a cost-conscious futility policy implemented by either a state Medicaid program or a hospital, along with an analysis of the bases for that recommendation. But, as the preceding heading suggests, I am reluctant to proclaim an answer to the questions raised in Part III. My reluctance stems primarily from two sources.

First, as a practical matter, the arguments put forward in Part III regarding the invalidity of a futility policy demonstrate the fact-specific nature of the inquiry that the ADA requires. This fact specificity is both the beauty and the bane of the ADA. The Act's standards, expressed in general
terms, encourage a court to engage in a richly textured analysis of a challenged action and its context and to weigh competing interests in a manner both progressive and pragmatic. At the same time, however, this fact specificity often renders elusive any certainty regarding compliance with the Act’s directives. Even minor factual variations with respect to the types of treatments and patients affected by a futility policy, the policy’s development and implementation, and the policymaker’s motivations and financial situation could significantly affect a court’s factual and hence legal analysis. While Murphy and Finucane’s proposal contains sufficient factual detail to serve as a convenient springboard for analyzing the disability discrimination issues cost-conscious futility policies raise, it remains merely a proposal—without the rich contextual surroundings that an actual, implemented policy would present. Thus, any “conclusion” with respect to the validity of either hypothetical policy discussed in Part III would be so riddled with caveats as to provide little resolution.5

Second, advancing a conclusion as to the validity or invalidity of the hypothetical futility policies might be mistaken for an indication of satisfaction with the sufficiency of legal analysis of statutes and caselaw for addressing the ethically problematic nature of cost-conscious futility policies. I am not so satisfied. In other words, I do not think that we should sanguinely believe that if a judge hearing an ADA challenge to a futility policy were to listen to the parties’ legal arguments, carefully consider the law, and render a conscientious decision thereon, the question of such policies’ tolerability would be settled. Instead, to my mind, a considerable part of the value of the arguments developed in Part III stems from how well they illuminate the extent to which legal analysis can depend on our understanding of the meaning of the end of life, of persons’ interests in how they die, of the goals of medicine, and of how to balance justly the interests of an individual against the interests of the community. Because the ADA analysis inevitably raises, but does not begin to resolve, these more fundamental issues, disability discrimination law (at least as it currently exists) fails to resolve fully the issues that cost-conscious futility policies raise.5

304. I hasten to add, however, that I do not believe that the hypothetical nature of the policies discussed in part III renders that part’s analysis worthless. Indeed, I would hope that the discussion might prove valuable to advocates framing their arguments regarding futility policies and to a court hearing and considering those arguments.

305. I distinguish between the question of a futility policy’s tolerability—i.e., whether society should find it ethically acceptable—and the question of a futility policy’s soundness as a policy choice—i.e., whether it effectively advances societal goals without imposing undue societal costs. I allude to the latter question in the Introduction to this Article. Of course, the two questions overlap to some extent.

306. Of course, if we cannot resolve these more fundamental issues, we may be thankful that the ADA provides some mechanism—however imperfect—for negotiating some resolution to the debate over futility and rationing. This seems to be Haavi Morreim’s view when she writes about Baby K:

[1] It is very difficult to draw limits w.r.t. . . . egging fundamental questions. We
Consequently, the arguments presented in Part III lead not to a conclusion, but to a recognition of the need for further and deeper thought and research about some of the issues that futility policies raise, but that the ADA fails to answer. I divide these issues into two groups: issues regarding the demands and meaning of justice in health care resource allocation, and issues regarding the interests of persons near the end of life. While full consideration of these issues lies beyond the scope of this Article, I will describe briefly some of the questions raised.

A. Questions About Justice

First, the possible implementation of a cost-conscious futility policy, whether by a state Medicaid program or by a hospital, raises thorny questions about the justice of limiting the treatment resources available to some critically ill and severely disabled patients in order to increase the treatment resources available to other patients. Does an allocative futility policy comport with our conception of distributive justice in the health care context?507

Of course, even phrasing the question in terms of “our conception of distributive justice” belies the question’s complexity, for despite the abundance of ink spilled on the question of justice in health care resource allocation, little consensus has been achieved.508 For beginners, should we adopt a utilitarian perspective on the justness of health care allocation decisions, effectively endorsing a scheme that maximizes the health benefit that a population receives from the application of health resources?509 If so, does a futility policy further the goal of such maximization?510 Or, by...
contrast, does justice require a more egalitarian approach to the allocation of health care resources, based on the ethical premise that factors other than cost-effectiveness—for example, the immeasurable value of each human life—should direct allocative decisions? From this perspective, one could argue that because the remaining life of a patient for whom physicians deem CPR futile is equally precious as the remaining life that other patients enjoy, the futility judgment reflects no ethically relevant difference between these groups of patients that would allow life-sustaining treatment to be withheld from the former group, while being provided to the latter.

Thus, a prerequisite to any judgment as to the acceptability of a futility-based rationing scheme is a richer, more complete discussion of how our society can ration health care justly in light of the special needs and interests of persons with disabilities. A few scholars have begun this dialogue, but achieving societal consensus on these difficult questions remains a distant, yet important, goal.

Moreover, any assessment of the measure for quantifying health benefit. Possible candidates include number of lives saved, life-years saved, and quality-adjusted life years saved (QALYs). See Elhauge, supra note 193, at 1512-13 (noting that these choices reflect underlying policy decisions about health care priorities).


312. See Peters, supra note 101, at 536-37 (noting how quality of life assessments reduce the value of remaining life).

313. See, e.g., Morreim, supra note 101; Orentlicher, supra note 8 (outlining specific methods of rationing health care under the ADA); Peters, supra note 101 (exploring the extent to which federal disability law limits effectiveness criteria as a tool to ration health care). In his thoughtful article, Professor Peters examines the disability rights implications of using medical effectiveness measures in rationing care and concludes that such a rationing scheme poses "a value choice... between maximizing benefits from scarce resources and presuming equal worth—a choice between utility and equality." Id. at 540. Ultimately, Peters concludes that effectiveness measures based on empirically based criteria like survival rates should be found not to violate disability rights legislation. By contrast, effectiveness measures that take quality of life into account should, in most cases involving life-extending care, be found to violate the principle of equal worth embodied by the ADA. Peters qualifies this conclusion, however, by suggesting that "in extreme cases" the presumption of equal worth should yield to utility concerns. He describes these extreme cases as typically possessing three characteristics:

First, the patient's quality of life is so poor that the net benefit to the patient from life-extending treatment is open to question. Second, the patient's cognitive function is so severely impaired that the nonhealth benefits of being alive are unlikely to be significant.... Third, the anticipated costs of life-extending care are extraordinary. Patients in a persistent vegetative state meet all three criteria.

Peters, supra note 101, at 541.

314. Some commentators have responded to the elusiveness of moral consensus on these points by suggesting that health resources could be ethically allocated by allowing individuals to choose among competing health care plans, each of which articulates its own health maximization policy. Under this approach, each person could choose to be subject to the rationing scheme most consistent with his or her own moral philosophy. See, e.g., Elhauge, supra note 193, at 1456; cf Ezekiel J. Emanuel, The Ends of Human Life: Medical Ethics in a Liberal Polity (1991) (envisioning a liberal communitarian system of community health
justness of a particular scheme must take into account not only its theoretical acceptability, but also the issues that implementation of a rationing scheme raises.315

Probing these justice issues, however, may prompt confrontation of a related question: How should we respond if we were to conclude both that a cost-conscious futility policy satisfies the demands of justice and that it effectively discriminates based on disability under the ADA because it devalues the lives of persons with severe disabilities? In other words, if our sense of justice conflicts with the statutorily created rights of individuals or groups, which should prevail?316 Although courts have acknowledged the need to keep disability discrimination law within "manageable bounds," that judicial recognition has not focused specifically on how to resolve clashes between communitarian demands for collective justice for group members and rights-based demands for equal treatment of specific group members.317

B. Questions About Dying

On a deeper level, cost-conscious futility policies also raise questions regarding the interests of persons near the end of life. As a result, any attempt to assess the legitimacy of these policies by using only existing legal tools would be severely impoverished, for it would fail to consider the

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315. See Daniels, supra note 82.

316. As some commentators have suggested, this question may be moot: The very ambiguity of the ADA as it applies to health care allocation schemes may allow a court sufficient leeway to decide an ADA challenge to a cost-conscious futility policy consistent with the court's own conception of justice. See Peters, supra note 101, at 509 (reasoning that the legal tests erected by the ADA "correspond only obliquely to the underlying ethical question . . . [but] fortunately, the terms 'necessary' and 'essential' are sufficiently elastic to permit judicial consideration of the important ethical issues").

317. For suggested guidelines on interpreting the ADA "[t]o ensure a reasonable balance between the rights of persons with disabilities and the need of society to use its limited health care resources wisely," see Orentlicher, supra note 8, at 312. Dr. Orentlicher proposes that the following five ethically relevant criteria be considered: (1) likelihood of benefit; (2) duration of benefit; (3) degree of benefit; (4) cost; and (5) number of people who will benefit. While acknowledging some of the difficulties in applying these criteria, Dr. Orentlicher does not recognize a fundamental ambiguity that emerges when these criteria are applied to a futility policy: Who gets to decide what counts as a "benefit"?
nature of dying and persons' interests therein. Admittedly, the law's failure to account adequately for the nature of dying is unsurprising and a natural reflection of our society's failure to do so. By and large, contemporary American culture and medicine, rather than contemplating and accepting dying, fear and shrink from it. As a result, the process of dying for most Americans has become a process not of "go[ing] gentle into that good night," but of simultaneous isolation and invasion— isolation from loved ones and familiar places and invasion by medical technology attempting to prolong life. In response to what some have come to see as a dehumanizing and intolerable situation, some movements are occurring in our society towards the development of more accepting and humanistic attitudes and practices toward dying.

But suggesting that persons near the end of life—persons whose physical and perhaps mental being is profoundly compromised—develop an accepting attitude towards dying may or may not fit easily with examining our treatment of the dying as a question of disability discrimination law. The ADA pursues the integration and equal treatment of persons with disabilities, but it seems that integration and equal treatment are primarily the concerns of the living, not the dying. The paramount concerns of the dying seem more likely to lie in receiving compassionate and respectful care and achieving some level of spiritual or philosophical resolution. If, therefore, we conceive of the ADA as being concerned primarily with promoting independence and protecting individual rights, the ADA may appear largely irrelevant to advancing a

318. Here I am referring not solely to the minutes or hours immediately preceding a determination of death, but of the process of a person's final decline from life. In fact, if we were to focus solely on the immediate dying process, studies suggest that most patients who die in hospitals or long term care institutions do so as a result of a choice to discontinue treatment. See Marni J. Lerner, Note, State Natural Death Acts: Illusory Protection of Individuals' Life-Sustaining Treatment Decisions, 29 Harv. J. on Legis. 175, 176 (1992). Persons for whom such a choice is made may thus be allowed to go gently.


320. For an intelligent and sensitive account of the physical processes by which dying most often occurs and a gentle critique of medicine's unwillingness to accept dying, see Sherwin B. Nuland, How We Die (1993); cf. Michael M. Burgess, The Medicalization of Dying, 18 J. Med. & Phil. 269 (1993) (discussing the medicalization of dying in the context of the debate over active euthanasia).

321. Two prime illustrations of this phenomenon are the importation of the hospice movement from England to the United States and the popularity of Final Exit, a book written in 1991 by Derek Humphrey as a "how-to" book for persons with terminal illnesses who seek to end their own lives. For a description of the hospice movement's ethic of compassion and care for a dying patient, see Courtney S. Campbell et al., Conflicts of Conscience: Hospice and Assisted Suicide, 25 Hastings Center Rep., May-June 1995, at 35, 36-37. The precursor to this burgeoning interest in understanding death was the publication of On Death and Dying in 1970 by Elizabeth Kubler-Ross. This book was widely read and its description of the "seven stages of dying" has become part of popular culture. See also Stephen Levine, Who Dies? (1982).

322. Cf. John D. Banja, Does the Americans with Disabilities Act Protect Persons in the
dying person's interests. If, on the other hand, we conceive of the ADA's philosophical base as being the acceptance of persons with disabilities and their inclusion in the community, compassionate caring for the dying may be exactly the kind of "accommodation" the ADA calls for.\textsuperscript{323}

Another potential problem exists with applying the ADA to persons who become disabled as they approach the end of their lives. Congress's legislative findings describing persons with disabilities as "a discrete and insular minority"\textsuperscript{324} show that many persons without disabilities in the United States tend to view and treat most persons with disabilities as being somehow "other"—as existing on the other side of an unbridgeable divide. This concept of persons with disabilities as a discrete and insular minority seems less apt, however, when we consider the sort of "creeping disability" that flows, often gradually and almost imperceptibly, from the progression of chronic illness and infirmity. In these cases, the boundary between persons with disabilities and those without may not be so clear.\textsuperscript{325}

The potential inaptitude of applying the ADA to persons who become disabled as, and because, they are approaching the end of life lies not only in the difficulty of describing these persons as part of a "discrete" minority. It also flows from the probability that, shrink as they might from death, most Americans will not view a dying person as "other" in the same way they do persons who are more stereotypically "disabled." In other words, while we can deny to ourselves that we will experience an injury or illness that will leave us with a chronic disability, we cannot deny that we will die. And for many Americans today, death comes after a period of chronic illness that most often disables a person before killing her.\textsuperscript{326} Thus, when

\textsuperscript{Persistent Vegetative State?, 8 J. Head Trauma Rehab. 108 (1993) (arguing that the ADA is not properly applicable to persons in a PVS because of their inability to "interface with their environment").}

\textsuperscript{323}. I am indebted to Wendy Parmet for pointing this out to me. \textit{Cf}. Michael B. Laudor, Disability and Community: Modes of Exclusion, Norms of Inclusion, and the Americans with Disabilities Act of 1990, 43 Syracuse L. Rev. 929, 939 (1992) (advocating the interpretation of the ADA based on communitarian values and a norm of inclusion).


\textsuperscript{325}. Unbridgeable in the sense that, although most persons may rationally be aware of their own potential for becoming disabled, they do not authentically recognize that blindness, deafness, quadriplegia, or impaired mental functioning could someday be "theirs."

\textsuperscript{326}. \textit{Cf}. Ruth Colker, Bi: Race, Sexual Orientation, Gender, and Disability, 56 Ohio St. L.J. 1 (1995) (coining the term "bi-abled" to describe individuals who are neither disabled nor able-bodied).

we see the face of a person who is declining toward death—the sort of person to whom a futility policy might be applied—we should know that most of us are likely to wear that face some day in the future. In light of our recognition that we are likely to grow old (we hope) and that we will all die, the danger that we will discriminate invidiously against persons who occupy our future position seems slighter and thus the application of the ADA to policies impacting those persons seems less necessary. By raising these questions, I do not mean to suggest that the concerns embodied in disability discrimination law are irrelevant to the situation of persons near the end of life, but to highlight the inappropriateness of adopting a “one size fits all” approach to applying disability rights legislation in this context. Dying is a transformative process; hence, we should recognize that during the process an individual’s interests may undergo a profound change. By extension, we ought also recognize that our obligation to the dying person, both individually and as a society, may similarly change. Aside from disability discrimination issues, the imposition of a futility-based rationing scheme would raise other concerns. These concerns flow from the personal importance that many, if not most, individuals attach to how they die. Ronald Dworkin suggests that this significance attached to the process of dying may be understood as the importance to a person that his death be appropriate in light of the values by which he lived his life. From this perspective, a person’s attempt to influence how he dies should not be seen merely as one more opportunity to exercise autonomy, but as a person’s ultimate opportunity to express and conform his behavior to the values he believes most important to his life. Accordingly, depriving some dying persons of the option to seek life-sustaining treatment deemed futile may be a far more serious affront to their personal dignity than any other interference with autonomous choice in the medical realm.

In a related vein, Margaret Pabst Battin expresses concern about attempts to use standardization to produce efficient results when dying patients are involved:

The wish to have a “death of one’s own” ought to be

330. Id. at 211-12. An example that Dworkin gives is of a person who fights to stay alive in order to experience an important family milestone:

The aim of living not just until, but actually for, an event has very great expressive power. It confirms ... the critical importance of the values it identifies to the patient’s sense of his own integrity, to the special character of his life. If his has been a life rooted in family, if he has counted, as among the high peaks of his life, family holidays and congresses and celebrations, then stretching his life to include one more such event does not merely add to a long list of occasions and successes. Treating the next one as salient for death confirms the importance of them all.

Id. at 212.
recognized... because since it is not like other medical processes, there is no compelling reason for it to be any one, uniform way. ... Dying is different, and it is not morally appropriate for a system governed by principles of efficiency to impose a standard expectation of how this final period of an individual's life should play itself out.331

Of course, the imposition of a cost-conscious futility policy would not completely standardize how persons die. It, however, could be seen as one step down the road of a standardization process, for the policy would remove one option available to persons seeking to die in a way that seems right to them: the option of continuing to fight as long as possible even though the "experts" deem it futile.332

Thus, adoption of cost-conscious futility policies challenges not only our conception of disability discrimination, but also our understanding of why the way we die matters and how profoundly having some control over how we die implicates our humanity. Discussions of futility policies also raise a series of distinct, but related, questions: How are we to understand existence in a persistent vegetative state? What are our obligations to persons in a PVS, and what, if any, are their own interests in continuing or discontinuing their existence? One could argue that persons completely lacking consciousness and sentience can have no interests one way or the other.333 Dworkin, however, suggests that in some cases it may be in the best interests of a patient—if we view the patient as the person who has lived the entire life and not merely as the organism currently existing in an insentient state—to be kept alive as long as possible, even in an unconscious state.334

So we see that applying a futility policy to limit a dying patient's

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332. John Lantos has noted that denying a critically ill patient treatment on the grounds of futility may block the therapeutic power of hope:

If hope itself is therapeutic, then there is no such thing as false hope and, at least for a competent or conscious patient, no reason for a patient to accept a doctors' [sic] assessment that further treatment would be futile. Put another way, accepting a futility assessment might validate it, while denying the futility assessment might refute it.

Lantos, supra note 13, at 870.
333. Cf. In re Peter, 529 A.2d 419, 424-25 (N.J. 1987) (reasoning that test balancing benefits and burdens of continued treatment is inapplicable to a person in a PVS, because such a person does not experience any benefits or burdens).
334. Dworkin, supra note 329, at 212-13. He writes:

For such people, contemplating themselves in [a permanently unconscious state], integrity delivers a very different command. The struggle to stay alive, no matter how hopeless or how thin the life, expresses a virtue central to their lives, the virtue of defiance in the face of inevitable death. It is not just a matter of taste on which people happen to divide, as they divide about surfing or soccer. None of us wants to end our lives out of character.

Id. at 213.
treatment options poses difficult questions: Should disability discrimination law even apply in this context? Do futility policies, by limiting the choices of a dying patient, pose too great an affront to our humanity? And—to tie the two themes together—how might the importance of choice to a dying person inform our consideration of a futility policy's implications from a disability discrimination perspective?

Clearly, tackling the questions highlighted in this Part is not a job exclusively for lawyers. Instead, the task of addressing cost-conscious futility policies' problematic nature calls for an interdisciplinary approach, in which the law's focus on rights should be supplemented by what other fields of inquiry have to offer regarding the demands of justice and the meaning of dying. While undertaking to answer these questions is far beyond the scope of this Article, they are questions that we ought to consider carefully. In the meantime, we should recognize that disability discrimination law provides only an incomplete and inadequate tool for advising us to embrace or to reject cost-conscious futility policies.

V. CONCLUSION

The concept of medical futility, which originally developed in the medical literature as a basis for allocating between physician and patient decisional authority regarding end-of-life treatment, is increasingly appearing in discussions regarding possible methods of containing medical costs by limiting treatment. This use of medical futility as a rationing mechanism, whether by a state Medicaid program or by a hospital, raises concerns regarding its impact on persons with severe disabilities near the end of life. This Article considers how the applicability of the Americans with Disabilities Act to cost-conscious futility policies might be analyzed. After developing arguments that proponents and challengers of such policies could raise, however, this Article ultimately concludes that the very arguments available under the ADA demonstrate the inaptness of disability discrimination law for thoroughly responding to the concerns that futility policies raise. Instead, to answer these concerns fully, our society should focus on more fundamental questions regarding the demands of justice in health care resource allocation and the nature of dying and the interests of dying persons, questions calling for an expansion of the dialogue beyond the bounds of law.