FUTILITARIANISM, EXOTICARE, AND COERCED ALTRUISM: THE ADA MEETS ITS LIMITS†

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I. INTRODUCTION

The case of Baby K has raised, more starkly than any scenario to date, the question of whether health care can be limited without discriminating against the handicapped. Baby K was an anencephalic infant born with no brain except a brain stem, permanently unconscious, and virtually certain to die. Baby K's mother, insisting that all life is precious, demanded that the Virginia hospital where she was born provide all possible care, including mechanical ventilation in an intensive care unit (ICU), whenever her condition deteriorated. After reluctantly complying for many months,[1] the hospital requested court permission to refuse such heroic care in the event the infant again developed respiratory distress while in the nursing home where she eventually resided. Aggressive care is futile, the hospital argued, because it can never render Baby K conscious or significantly prolong her life.

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[1] *In re* Baby K, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). Although Baby K's mother was aware of her condition prenatally, Baby K was placed on a respirator at birth in order to provide the mother with more time to come to terms with the devastation of her infant's condition. 832 F. Supp. at 1025. After three days, hospital personnel began urging the mother to designate K as "DNR"—do not resuscitate—but the mother refused. After continued discussion failed to produce agreement, an ethics committee was consulted. It recommended that if still further discussion could not resolve the matter, the hospital should seek court adjudication—which the hospital did, some six months into the controversy. Meanwhile, after spending her first month and a half on a respirator, K's condition stabilized enough for her to be transferred to a nursing home. She subsequently developed respiratory distress requiring hospitalization on several occasions, but returned to the nursing home after her condition stabilized. *Id.* Baby K died of cardiac arrest on April 5, 1995. By then she was known to the world by her name, Stephanie Harrell. Marylou Tousignant & Bill Miller, *Death of 'Baby K' Leaves a Legacy of Legal Precedent*, WASH. POST, Apr. 7, 1995, at B3.

The Eastern District Court of Virginia ruled against the hospital, primarily on two grounds. First, the Emergency Medical Treatment and Active Labor Act (EMTALA) states that when a patient seeks care, the hospital must initially determine whether an emergency medical condition exists (i.e., whether the patient will suffer serious impairment of bodily functions or organs if immediate medical attention is not provided). If an emergency condition does exist, the hospital must stabilize that patient to avert material deterioration in his or her condition prior to any transfer to another facility. The hospital conceded that when Baby K presents with respiratory distress, she will indeed suffer serious deterioration unless she receives ventilatory support, but argued that such treatment nevertheless should not be mandated because it is futile. The court rejected that argument: EMTALA contains no exceptions for futility and, in any event, a ventilator can indeed alleviate K's acute respiratory distress.[2]

The Fourth Circuit upheld the decision solely on EMTALA grounds,[3] never reaching the district court's more prominent argument that refusing care to this infant would constitute discrimination against the disabled, proscribed by Section 504 of the 1973 Rehabilitation Act[4] and by the Americans with Disabilities Act (ADA).[5] The district court argued that if life support would not be denied to a person on grounds of his race, neither should it be denied to Baby K because of her mental handicap. The hospital's futility argument fails here too, the court reasoned, because life support is commonly provided to other patients with grim prognoses such as cancer or AIDS. If these patients would receive ventilator care, then so must Baby K.

The disability issues in this case are among the most difficult

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[2] In addition to the EMTALA and discrimination concerns, the district court briefly discussed the Child Abuse Amendments of 1984, which it said were not relevant here since the case did not involve the Virginia Child Protective Services. Moreover the court dismissed the hospital's appeal to Virginia Medical Malpractice Act (exempting physicians from providing care they deem medically or ethically contraindicated), noting that it did not wish to intrude into state malpractice standards. *Id.* at 1029-30. The court also noted that when parents disagree about continuing life support, as in this case (K's father was largely uninvolved but did not want heroic care for K), the benefit of the doubt should favor life. *Id.* at 1031.

[3] 16 F.3d 590 (4th Cir. 1994).

[4] 29 U.S.C.A. § 794(a) (West Supp. 1993). Section 504 reads: "No otherwise qualified individual with a disability . . . shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . ." *Id.*

[5] 42 U.S.C. §§ 12102 to 12213 (Supp. IV 1993).

questions we must face if we wish both to broaden access to health care and to avert bankrupting ourselves in the process.[6] On the one hand, our finite funds must do as much good as possible while avoiding the bottomless pit of expenses inherent in trying to meet literally every need and desire of every citizen. On the other hand, any attempt to trim low-yield expenditures is almost certain to affect the disabled more adversely than other citizens, since these people often have a shorter life span, or respond less favorably than other patients to medical treatments.[7]

The potential tradeoffs between costs and disabilities can be considered on two levels. In a broad perspective, we can ask whether the health care system as a whole should attempt to reap the greatest possible benefit for each dollar, determining which services to buy for whom according to a cost-benefit or cost-effectiveness priority scheme. The state of Oregon has constructed such a priority system, prompting considerable discussion.[8]

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[6] As David Hadorn pointed out, "the 'D-word' [for disability] threatens to replace the 'R-word' (for rationing) as the most feared epithet in the field of resource allocation." David C. Hadorn, *The Problem of Discrimination in Health Care Priority Setting*, 268 JAMA 1454, 1454 (1992).

[7] James V. Garvey, *Health Care Rationing and the Americans With Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?*, 68 NOTRE DAME L. REV. 581 (1993); Hadorn, *supra* note 6; David Orentlicher, *Rationing and the Americans With Disabilities Act*, 271 JAMA 308 (1994); Philip Peters, *Health Care Rationing and Disability Rights*, 70 IND. L. REV. 491-547 (1995).

[8] The Oregon plan attempts to ensure that all citizens have access to health care and, as an integral part, reorganizes Medicaid spending to seek the greatest benefit for the money spent. The plan forswears one kind of rationing—a patient-based rationing in which expenses are limited by denying Medicaid eligibility to large numbers of patients—in favor of a treatment-based rationing that attempts to determine which medical services provide the greatest benefit for their cost. Through a multistage process involving public meetings, phone surveys, and meetings of health planning committees, the state developed (and then considerably revised) a priority list in which the most effective (and cost-effective) treatments receive the highest priority, and more marginal treatments receive lower rankings. Depending on actuarially based estimates of the cost of providing the particular services at each priority level on the list, and depending also on the amount of funding allocated for health care by the legislature each year, a line is drawn. Above that line services are funded, and below it, they are not.

For further discussion, see RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND (Martin A. Strosberg et al. eds. 1992); *Ethics And Alternative Health Care Systems Forum*, 17 J. MED. PHIL. 1-97 (1992); Norman Daniels, *Is the Oregon Rationing Plan Fair?*, 265 JAMA 2232 (1991); David M. Eddy, *What's Going on in Oregon?*, 266 JAMA 417 (1991); David M. Eddy, *Oregon's Methods: Did Cost-effectiveness Analysis Fail?*, 266 JAMA 2135 (1991); David M. Eddy, *Oregon's Plan: Should It Be Approved?*, 266 JAMA 2439 (1991); David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-effectiveness Meets the Rule of Rescue*, 265 JAMA 2218 (1991); Harvey D. Klevit et al., *Prioritization of Health Care Services: A Progress Report by the Oregon Health Services Commission*, 151 ARCHIVES INTERNAL MED. 912 (1991).

Baby K raises the tradeoff on a second, narrower level. She forces us to consider whether in certain extreme cases we can rule out heroic care as a waste of resources. In other words, it is not necessary to rank all forms of medical care according to their medical and economic value, as the Oregon plan tries to do, in order to consider whether at least some kinds of care at the fringes should be ruled out. Baby K, with no mental function and the grimmest prognosis, is the paradigm of such a possibility. If we cannot resolve this case, neither can we manage more complex cases. This narrower question is the focus of this Article.

The debate has a certain intractable character. On one side of the question, the hospital, its *amici*, and many commentators argue that aggressive care for patients like Baby K is futile.[9] *Quantitatively*, it is futile because an anencephalic like Baby K will die soon no matter what physicians do. *Qualitatively*, it is futile because they will never be conscious or enjoy any form of human experience.[10] It is a life so profoundly diminished that it bears little resemblance to human personhood.[11] On this view, which I have decided to call "futilitarianism," physicians need not offer costly, futile care to patients or their families, nor even accede to overt demands for it.[12] There is no significant benefit for the patient,[13] it serves no valid

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[9] *See 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. (1994). *See also* G.J. Annas, *Asking The Courts To Set The Standard Of Emergency Care—The Case Of Baby K*, 330 NEW ENG. J. MED. 1542 (1994).

[10] Schneiderman, Jecker, and Jonsen introduced the distinction between quantitative and qualitative futility. *See* Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990).

[11] Indeed, some commentators would argue that Baby K and others who permanently lack consciousness are not persons at all. *See* Joseph F. Fletcher, *Four Indicators of Humanhood: The Enquiry Matures*, HASTINGS CENTER REP., Dec. 1974, at 1; Michael Tooley, *Abortion and Infanticide*, 2 PHIL. PUB. AFF. 37 (1972).

[12] *See generally* Leslie J. Blackhall, *Must We Always Use CPR?*, 317 NEW ENG. J. MED. 1281 (1987); Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512 (1991); Donald J. Murphy, *Do-Not-Resuscitate Orders: Time for Reappraisal in Long-term-Care Institutions*, 260 JAMA 2098 (1988). *But see* Robert D. Truog et al., *The Problem With Futility*, 326 NEW ENG. J. MED. 1560 (1992) (criticizing this view).

[13] *See* J. Chris Hackler & F. Charles Hiller, *Family Consent to Orders Not to Resuscitate: Reconsidering Hospital Policy*, 264 JAMA 1281 (1990); Lawrence J. Schneiderman, *The Futility Debate: Effective Versus Beneficial Intervention*, 42 J. AM. GERIATRIC SOC'Y 883 (1994).

Some cases suggest that aggressive life support for the terminally ill or permanently unconscious patient is not a prolongation of life, but of dying. *See, e.g.*, American Acad. of Pediatrics v. Heckler, 561 F. Supp. 395, 400 (D.D.C. 1983); *In re* Doe, 418 S.E.2d 3, 6 (Ga. 1992); *In re* Guardianship of L.W., 482 N.W.2d 60, 72 n.15 (Wis. 1992).

medical goals,[14] it can violate the integrity of the medical profession,[15] and physicians would be poor stewards[16] to waste scarce resources on clearly hopeless causes. A gentler version of futilitarianism argues that more pressing needs for limited resources must be met before such extraordinary expenditures can be justified.[17]

Opposing futilitarianism is a vitalism holding that all life is infinitely precious, regardless of its quality.[18] On this view, futilitarians are simply wrong to suppose that keeping patients like Baby K alive holds "no benefit." Life is of infinite intrinsic value, not merely an instrumental value toward some further life goals. Therefore, it is wrong for members of the medical community to impose their definition of "benefit" on others by denying life support to those whose lives they personally deem unworthy of living.[19] These patients are fully as human as anyone else, and any attempt to save resources by singling them out is blatant discrimination.[20]

Significantly, the debate is marked by a futility of its own. Each side makes presumptions about the moral status of profoundly diminished life, presumptions that can neither be defended nor defeated because they are at the core of each side's moral views.[21]

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[14] HOWARD BRODY, THE HEALER'S POWER 173-185 (1992) [HEREINAFTER BRODY, POWER]; Howard Brody, *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRIC SOC'Y 875 (1994) [hereinafter Brody, *Futility*].

[15] *See* BRODY, POWER, *supra* note 14; Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. A Physician's Professional Conscience*, 44 HASTINGS L.J. 1241 (1993); Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276 (1990).

[16] Miles, *supra* note 12.

[17] *See, e.g.*, Orentlicher, *supra* note 7. For a useful discussion of the conceptual and empirical problems of futilitarianism, see Truog et al., *supra* note 12.

[18] Baby K's mother is joined by other people who, as family of patients who were dying or in a persistent vegetative state, insisted on unrelenting medical support for their loved ones. *See, e.g.*, Daniel Avila, Letter to the Editor, *Withdrawing Treatment In The Persistent Vegetative State*, 331 NEW ENG. J. MED. 1382 (1994). For a useful summary of the cases of Helga Wanglie, Baby Rena, Baby L, Jane Doe, Joseph Finelli, and Teresa Hamilton, see Daar, *supra* note 15; Bethany Spielman, *Collective Decisions About Medical Futility*, 22 J.L. MED. & ETHICS 152 (1994).

[19] Articulating, though not entirely defending, this view, see generally Loretta M. Kopelman, Letter to the Editor, *Rationing and the Americans With Disabilities Act*, 271 JAMA 1903 (1994); Robert M. Veatch & Carol M. Spicer, *Medically Futile Care: The Rule of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15 (1992).

[20] One need not go to this extreme of vitalism in order to argue that futilitarianism is dangerous. *See, e.g.*, Gilbert Meilaender, *Terra es animata: On Having a Life*, HASTINGS CENTER REP., July-Aug. 1993, at 25.

[21] For further discussion of these points, see E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33.

The futilitarian can only conclude that preserving K's life is of "no benefit" by flatly denying the vitalist view that life *per se* is of infinite value, regardless of its quality, thus begging the very question at issue. Baby K's intermittent respirator treatments do, after all, keep her alive when she would otherwise have died. To declare her continued survival to be of no value presupposes that quality of life supersedes longevity, the very point K's mother denies.

Reciprocally, the vitalist can insist that this infant, whose level of function is below that of even very primitive animals, warrants fully the same level of moral respect and medical attention as every other human being. This position necessitates a presumption that the only or most important factor of moral significance is to be alive[22] and to possess a human set of chromosomes. Why this combination should be morally decisive is left a mystery.[23]

The rest of society is involved in this debate, like it or not. If society is to be able to draw reasonable fiscal limits on health care expenditures, the discrimination challenge must be answered. It will not suffice to assert that "we must draw limits somewhere, so they might as well be here." Our society has a serious history of discrimination against disabled citizens, and we need to ensure that the limits we draw will respect, rather than abuse, the vulnerability of disabled persons. And yet, we cannot permit a virtually endless array of disabilities to convey an unlimited claim on societal resources.

As we address this issue, we must take care not to beg the central questions, nor simply to "declare victory and go home," as futilitarians and vitalists can both be accused of doing. We must get beyond their endlessly circular debate. Equally important, any credible response to this challenge must reflect the realities of clinical medicine. That is, it must be based on a clear picture of what discrimination would actually look like in the context of health care—a very different environment from the worlds of employment, education, transportation, and the like, which the an-

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[22] A number of commentators advocate a "cortical" definition of death that would actually declare death in Baby K and others who have permanently lost consciousness. For further discussion, see Amir Halevy & Baruch Brody, *Brain Death: Reconciling Definitions, Criteria, and Tests*, 119 ANNALS INTERNAL MED. 519 (1993); Robert M. Veatch, *Brain Death and Slippery Slopes*, 3 J. CLINICAL ETHICS 181 (1992); S.J. Youngner, *Defining Death: A Superficial and Fragile Consensus*, 49 ARCHIVES NEUROLOGY 570 (1992).

[23] The debate essentially parallels the equally intractable abortion debate regarding the moral status of the fetus. One side insists that even the tiniest zygote is fully human because it has a full set of chromosomes, while the other argues that humanness and moral personhood require more than forty-six pairs of genes. *See* Morreim, *supra* note 21.

tidiscrimination laws commonly envision. In health care, after all, a disability or illness is often the very reason for seeking treatment; in other situations, it can be the factor that renders treatment impossible. Accordingly, Part II of this Article will explore how discrimination might look in the medical context.

Part III will show why society can permissibly restrict exotic medical care for patients like Baby K without running afoul of the ADA. Several arguments will be developed.

First, the purposes of the ADA, as expressed in its preamble, arguably do not apply to extreme situations such as that of Baby K. If disability law is to help citizens participate more fully in their community, it obviously does not encompass individuals who are utterly incapable of "participation" in human social life.

Second, the law's protections apply only to "eligible" or "qualified" individuals. In health care, the criteria for "eligibility" for a medical service are equivalent to "medical indications" for treatment. These are ordinarily established by the medical community and acknowledged by the judiciary as medicine's professional standards of care. Important questions arise concerning whether or when some nonmedical authority may permissibly intervene in medical standards.

Third, although the ADA requires those who provide services or programs to make "reasonable accommodations" to include a disabled person, it does not expect them to go beyond reasonableness into undue burdens or hardships. In the context of health care, the cumulative costs of meeting the needs, not just of one individual with costly demands, but of everyone else similarly situated, can exact an undue toll on other citizens by inordinately raising the cost of care. These costs can be found excessive on two grounds.

Foremost, the ADA is based not just on values of a collective societal obligation to help the less fortunate among us, but on a coerced private altruism that requires private citizens to use their own money to make up for others' misfortunes that they in no way caused. If the public generosity extracted through taxes should be limited, such coerced private altruism should be even more restrained.

Additionally, once we recognize that concessions to Baby K cases logically commit us also to support a wide array of costly marginal treatments for patients with comparably dismal prognoses, the financial costs can quickly become prohibitive. And so can the opportunity costs as it forecloses other projects people value.

Fourth, the ADA does not require programs to "fundamentally change" their essential character in order to accommodate a disabled individual. When health plans must divert vast portions of their limited resources to cover "exoticare" for disabled patients, they may no longer be able to provide basic care for the main group of their subscribers. If providing basic care was the initial and legitimate purpose of the health plan, then such a change would be fundamental.

This change, in turn, may trigger a *fifth* ADA-based caveat. Providers of a program or service are not required to endanger the health or safety of others in order to accommodate the disabled. If large numbers of people no longer receive basic care in order to provide exoticare to a minority, it is virtually certain that some of them will suffer adverse effects, as some diseases may not be diagnosed as quickly or treated as effectively.

Sixth, decisions under these circumstances to limit some of the care available to disabled people cannot be said to be based "solely" on their disabilities. Other exceptions such as the allowance for insurance risk rating can also play an important role.

Part IV will propose a legislative resolution. Once it is established that citizens should not be forced to provide unlimited care, while also recognizing that limits can nevertheless be set in wrongful and discriminatory ways, it is important to define limits as precisely and defensibly as possible. One promising approach is to renovate an existing piece of legislation.

The Child Abuse Amendments of 1984 (the Act), the last vestige of the old "Baby Doe" regulations,[24] require that any child pro-

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[24] During the early 1980s, the Reagan administration, reacting to a case in which an infant with Down's syndrome was denied a simple but life-saving surgical procedure, attempted to ensure that newborns were not discriminatorily denied medical care. In a series of regulations issued by the Department of Health and Human Services, the administration created toll-free hotlines for anonymous tipsters to turn in suspected cases in which infants were denied essential care; sent squads of federal investigators to look into the cases identified on the hotline; and generally created an atmosphere in which neonatologists believed they were legally forced to administer all potentially life-prolonging medical care to all infants, regardless of their prognosis or quality of life.

The original regulations were struck down, but eventually the Child Abuse Amendments of 1984 were passed. They apply, not to hospitals or physicians, but to child protective services. They require, not medical care, but procedures for investigating alleged instances of abuse and neglect, including medical neglect. For further discussion, see Bowen v. American Hospital Ass'n, 476 U.S. 610 (1986); American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983); Marcia Angell, *The Baby Doe Rules*, 314 NEW ENG. J. MED. 642 (1986); John Lantos, *Baby Doe Five Years Later: Implications for Child Health*, 317 NEW ENG. J. MED. 444 (1987); Loretta M.

tective service receiving federal funds must establish procedures for investigating alleged cases of abuse and neglect, including medical neglect. Significantly, the Act explicitly identifies three kinds of situations in which withholding or withdrawal of medical treatment does not constitute neglect: when the infant is irreversibly comatose, terminally ill, or in a probably-terminal condition in which continued medical treatment is inhumane. These limits, appropriately adapted, could represent a reasonable limit on the level of care that providers and payers are obligated to furnish. Those who want a richer level should be free to purchase it if they wish. But at least under these narrowly drawn conditions, those who provide or pay for medical care should be free to refuse without any accusations of discrimination.

II. THE ADA: ITS BASIC PURPOSE AND SPECIAL CHARACTER IN MEDICAL CARE

A. *The ADA*

The first major initiative to protect the disabled against discrimination was the 1973 Rehabilitation Act. It states in Section 504: "No otherwise qualified individual with a disability . . . shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."[25] In 1990, the Americans with Disabilities Act (ADA) extended its protections to private settings. It encompasses employment (Title I), public services such as transportation (Title II), public accommodations and services operated by private entities (Title III), and miscellaneous provisions covering areas such as telecommunication services (Title IV).[26]

The ADA defines disability as any "physical or mental impairment that substantially limits one or more of the major life activities," or a record of such impairment, or "being regarded as having such an impairment."[27] These major activities include "caring for one's self, performing manual tasks, walking, seeing, hearing,

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Kopelman et al., *Neonatologists Judge The "Baby Doe" Regulations*, 318 NEW ENG. J. MED. 677 (1988).

[25] 29 U.S.C.A. § 794(a).

[26] 42 U.S.C. §§ 12101-12213. Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 L. MED. & HEALTH CARE 331 (1990); Garvey, *supra* note 7, at 595-603; Orentlicher, *supra* note 7; Amir Halevy & Baruch Brody, *Acquired Immunodeficiency Syndrome and the Americans With Disabilities Act: A Legal Duty to Treat*, 96 AM. J. MED. 282-88 (1994); Hadorn, *supra* note 6.

[27] 42 U.S.C. § 12102(2). *See also* Hadorn, *supra* note 6, at 1454; Lawrence O. Gos-

speaking, breathing, learning, and working,"[28] and also including any "physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more . . . body systems."[29] The list of conditions includes, but is not limited to, "such contagious and noncontagious diseases and conditions as orthopedic, visual, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV [human immunodeficiency virus] disease (whether symptomatic or asymptomatic), drug addiction, and alcoholism."[30] Explicit exceptions, however, are made for active drug users, people who engage in socially unaccepted sexual or other behaviors such as homosexuality, and certain specified social and environmental conditions.[31]

The ADA, unlike Section 504, explicitly encompasses health care providers, listing the "professional office of a health care provider, hospital, or other similar service establishment" in its definition of "public accommodations" in Title III.[32] Arguably, health maintenance organizations (HMOs) and similar managed care organizations (MCOs) would likewise be included because they not only administer the funding of health care benefits, but also arrange to deliver the care itself. In exchange for a single annual or monthly premium, the MCO agrees to provide all necessary care

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tin, *The Americans With Disabilities Act And The U.S. Health System*, 11 HEALTH AFF. 248, 248-49 (1992).

[28] 28 C.F.R. § 36.104 (1992).

[29] 28 C.F.R. § 35.104 (1992).

[30] *Id.*

[31] *See, e.g.*, 42 U.S.C. § 12114. *See also* Parmet, *supra* note 26, at 332, 337.

[32] 42 U.S.C. § 12181(7)(F). The ADA's exact implications for physicians are uncertain. It is not clear, for instance, whether or when a physician can refuse to care for a patient with HIV. It seems well established that a physician cannot refuse to provide a service which he is capable of performing, which he ordinarily would provide, and which the patient needs and will benefit from, solely because of the patient's HIV infection. *See generally* Halevy & Brody, *supra* note 26.

And yet, if the physician acts as an independent contractor in a hospital, rather than providing care in his office, his conduct may not be covered by the ADA. In a case decided by the United States District Court for the Northern District of California, a deaf woman who served as her husband's surrogate decision maker sued her husband's physician and the hospital because their failure to provide an interpreter made communication difficult. Aikins v. St. Helena Hosp., 843 F. Supp. 1329 (N.D. Cal. 1994). Among other findings, the court determined that the ADA did not apply to the physician, so long as he was rendering services at the hospital rather than in his office. The ADA applies to places of public accommodation, rather than to persons, and there is an implicit requirement of ownership or control. Because the physician "lacks the power to control hospital policy on the use of interpreters, [the court held] that [the doctor was] not a proper defendant under the ADA." *Id.* at 1335.

for subscribers. Thus, it necessarily must contract with physicians, hospitals, and other appropriate providers to render services. In many cases, the patient actually looks to the MCO, rather than specifically to the physician, for care.[33]

The status of health insurance companies is somewhat less clear, since they only distribute money and do not in any sense "provide" the care. Where health coverage is provided as a benefit of employment, the insurer's actions may be covered under Title I, though it is not entirely clear which sections of the ADA might cover insurers that are not workplace benefits.[34]

Fortunately, we need not belabor the question here. Insurers and HMOs are plainly covered, since they are expressly permitted to engage in risk rating so long as it is not a subterfuge for invidious discrimination against the disabled.[35] Beyond this, the provisions of Title I resemble those of Title III closely enough that, whether we are considering a hospital's refusal to provide mechanical ventilation to a Baby K or an insurer's or HMO's refusal to pay for it, the ADA analysis will be substantially the same.

The question before us in this Article concerns whether or when insurers, health care providers, HMOs, or society as a whole can refuse to provide costly or heroic care on the ground that the patient's disability—his illness—renders the care medically contraindicated or futile. It is therefore necessary to understand the distinctive way in which disabilities can figure into medical decision making and examine the circumstances under which refusal of care on grounds of an illness or disability might, or might not, constitute legally and morally unacceptable discrimination.[36]

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[33] Boyd v. Albert Einstein Med. Ctr., 547 A.2d 1229 (Pa. Super. 1988); Independence HMO, Inc. v. Smith, 733 F. Supp. 983 (E.D. Pa. 1990).

[34] In *Pappas v. Bethesda Hospital Ass'n*, a benefits administrator who denied health coverage to a hospital nurse's disabled family members was found not to be a direct agent of the employer, and hence not open to liability under Title I of the ADA. Pappas v. Bethesda Hosp. Ass'n, 861 F. Supp. 616, 618-19 (S.D. Ohio 1994). Neither was the administrator liable under Title III, since that part of the ADA covers *places* of accommodation—the plaintiff did not at any time enter the administrator's office building, and neither was she physically deterred from entering the hospital building. *Id.* at 619-20. The court noted, however, that "neither the U.S. Supreme Court nor the Sixth Circuit has interpreted the scope of Title III." *Id.* at 620.

[35] 42 U.S.C. § 12201(c).

[36] It is striking to note how many commentators point out the difficulty of interpreting the ADA, particularly in the context of medical treatment. *See* Marshall B. Kapp, *Futile Medical Treatment: A Review of the Ethical Arguments and Legal Holdings*, 9 J. GEN. INTERNAL MED. 170, 175 (1994); Garvey, *supra* note 7, at 600; Parmet, *supra* note 26, at 339; Orentlicher, *supra* note 7, at 310-12.

B. Disabilities in Health Care

The courts have been remarkably unhelpful in sorting out the special features of discrimination in the health care setting. At one end of the spectrum, the United States District Court for the Eastern District of Virginia insisted that Baby K should receive whatever treatment any other patient would receive, regardless of her anencephaly.[37] Clearly, there are circumstances in which this judgment, taken to its logical extreme, would make no sense. If, hypothetically, Baby K lacked cochlea or other standard anatomical features in her ears, it would make no sense to provide her with a cochlear implant. Hearing requires not just aural anatomy, but a brain cortex with which to process sound vibrations into a conscious hearing experience. In this case, the disability itself would render the treatment utterly pointless.

At the opposite end, some other courts seem to presume that it is almost impossible in principle to engage in discrimination in the medical context. In *United States v. University Hospital, SUNY*,[38] the Second Circuit argued:

> [S]ection 504 prohibits discrimination against a handicapped individual only where the individual's handicap is unrelated to, and thus improper to consideration of, the services in question. As defendants here point out, however, where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to, the need for services. Defendants thus argue, and with some force, that the "otherwise qualified"

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[37] *In re Baby K*, 832 F. Supp. 1022, 1027-28 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

[38] 729 F.2d 144 (2d Cir. 1984). In this case, an infant suffered from multiple anomalies including myelomeningocele (spina bifida), microcephaly (very small head), hydrocephalus (excessive fluid within the cranium), "weak face" (impaired ability to suck and take nourishment), a malformed brain stem, and spasticity. There was also a very high risk that she would be severely retarded and, therefore, unable to interact with her environment or with other people. *Id.* at 146.

This case was one of several so-called "Baby Doe" cases in which infants with Down's syndrome or other congenital defects had been denied treatment for anomalies that were easily treatable, but life-threatening if untreated. In some cases, the treatment involved a simple surgical repair of a malformation in the gastrointestinal tract. A duodenal atresia, for instance, is a blockage of the duodenum (connecting the stomach and small intestine) that is easily repaired by surgically removing the blocked area and connecting the two severed ends at the base of the stomach and the top of the small intestine. A tracheo-esophageal fistula is an area in which the trachea and esophagus share a common pathway in such a way that food can travel to the lungs and compromise respiration. Again, surgical repair is relatively easy. In each of these Baby Doe cases, the surgery was foregone not because there was some specific contraindication, but because it was deemed that the child's underlying problem (Down's or whatever) was so unacceptable that he would be better off dead.

> criterion of section 504 cannot be meaningfully applied to a medical treatment decision.[39]

The court went on to observe that:

> Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent, breaks down. Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation . . . to determine whether a decision to treat . . . was based on a "bona fide medical judgment."[40]

These points were reiterated with approval in *Bowen v. American Hospital Association*[41] and echoed in *Johnson by Johnson v. Thompson.*[42] Similarly and almost prophetically, Judge Gerhard Gesell, in *American Academy of Pediatrics v. Heckler,*[43] decried the government's position that Section 504 "requires doctors and parents to undertake heroic measures to preserve for as long as possible, despite expense and a prognosis of certain death within months, the life of an anacephalic [*sic*] lacking all or part of the brain and with no hope of ever achieving even the most rudimentary form of consciousness."[44]

Realistically, both sides have a bit of the truth, yet both sides significantly miss the mark. A disability is typically a chronic illness, biological anomaly, or other impairment that is ordinarily a focus

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[39] *Id.* at 156.

[40] *Id.* at 157. Note that the expression "(un)related to" plays a crucial role in these passages. On one level, one might say that having Down's syndrome is unrelated to having another condition, such as a tracheo-esophageal fistula. That is, Down's syndrome can occur without any such fistula, and the medical character and consequences of each can be investigated and treated quite independently. On the other hand, the two are, as a matter of fact, quite related. For reasons not entirely understood, Down's syndrome is often accompanied by other anomalies, including heart disease and an increased susceptibility to acute leukemia. Very likely a given individual with Down's syndrome would not have a fistula if he or she did not have the underlying genetic anomaly. In this way, someone who wants to use the Down's syndrome as an excuse for not treating such a fistula or repairing a heart defect might correctly argue that the two are not unrelated.

[41] 476 U.S. 610 (1986).

[42] 971 F.2d 1487 (10th Cir. 1992). The Tenth Circuit suggested that the "otherwise qualified" language of the Rehabilitation Act makes little sense in the medical context because it would require the plaintiff to "prove that, in spite of the birth defect, he or she was 'otherwise qualified' to receive the denied medical treatment. Ordinarily, however, if such a person were not so handicapped, he or she would not need the medical treatment and thus would not 'otherwise qualify' for the treatment." *Id.* at 1493.

[43] 561 F. Supp. 395 (D.D.C. 1983).

[44] *Id.* at 402.

for medical attention. Sometimes, the medical question solely and directly concerns whether or not to provide treatment for this disabling condition. A tumor might be so large, for instance, that the surgeon judges it to be inoperable. Additionally, when AZT first emerged as an effective but extremely costly treatment for acquired immune deficiency syndrome (AIDS), there was some discussion of whether the nation could afford to provide the drug for the rapidly growing number of patients who might benefit.

In many instances, however, the underlying disability is accompanied by one or more secondary conditions. These instances, in turn, can be subdivided. First, the existence of the disability may substantially alter the benefits or harms associated with treating the secondary condition. It thus represents a medically significant comorbidity. For instance, a patient with a major respiratory impairment such as cystic fibrosis (CF) may be unable to withstand the hazards of general anesthesia. Similarly, the long-term anticoagulant therapy normally recommended for patients with deep venous thrombosis would be clearly contraindicated in an autistic patient exhibiting aggressive self-mutilation behaviors. In these cases, the disability—CF, autism—may medically preclude treatment of the secondary condition. The disability is both relevant to and the very reason for the denial of treatment.

Second, there are cases in which the disability is not at all the focus of treatment decisions. It is incurable or already being treated as much as possible, as where the patient is permanently blind or irreversibly demented with Alzheimers. It thus represents a "baseline condition" that cannot itself be directly modified. Here, the question of whether to treat a secondary condition is sometimes the question of whether the patient's quality of life, given the baseline condition, can be significantly changed or helped by the secondary treatment. As noted above, a cochlear implant could not help an anencephalic to hear, even if it could restore the aural anatomy.

In these cases the question may be, not whether treating the secondary condition will improve the baseline condition, but whether the patient's baseline condition is so dismal that life itself is no longer a benefit. In this last set of cases, the secondary condition may be a life-threatening problem that is allowed, even embraced, as a means to let the patient die without the necessity of actively terminating his life. In the days before antibiotics, pneumonia was sometimes called the "old man's friend" because it permitted death to end an ill and debilitated life that the patient no longer cherished. Similarly, patients who are terminally ill from cancer or other illness can request do-not-resuscitate (DNR) orders to ensure that, if heartbeat or respiration ceases, resuscitative treatment will be withheld so that they can die peacefully.[45]

C. Discrimination in Health Care

Within this richer account of disabilities and secondary conditions, several possibilities exist for wrongful or invidious discrimination.

First, a physician or other health care provider might base his medical judgment on inaccurate facts. Factual inaccuracy *per se* does not represent discrimination, but when the alleged "facts" are simply the product of presumptions or prejudices rather than empirical investigation, discrimination can occur. For example, it would be easy—but wrong—to assume that a liver transplant is contraindicated for (i.e., wasted on) an alcoholic. However, evidence indicates that recovering alcoholics' survival following transplant is roughly the same as other recipients', and that they are usually unlikely to return to drinking.[46]

Analogously, physicians and parents withheld simple life-saving surgeries from infants with Down's syndrome in the so-called Baby Doe cases of the 1980s.[47] Rather than being founded on factually sound assessments of the infants' projected quality of life, the judgments in these cases were largely based on biased, unfounded assumptions about the lives and potential of retarded people. In the case of Baby Jane Doe,[48] an infant with multiple anomalies including myelomeningocele,[49] microcephaly,[50] hydrocephalus, "weak face,"[51] malformed brain stem, and spasticity, physicians pre-

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[45] Arguably, this is what occurred in the Baby Doe cases. A minor anomaly—such as duodenal atresia or tracheo-esophageal fistula—was used as a vehicle to allow a baby to die. It was done not because the atresia or fistula rendered life not worth living, but because it provided a vehicle for allowing death when the underlying disability, such as Down's syndrome, was deemed to render life not worth living.

[46] *See generally* Carl Cohen et al., *Alcoholics and Liver Transplantation*, 265 JAMA 1299 (1991); Kenneth R. McCurry et al., *Resource Utilization and Outcome of Liver Transplantation for Alcoholic Cirrhosis: A Case-Control Study*, 127 ARCHIVES SURGERY 772 (1992).

[47] *See supra* note 24.

[48] United States v. University Hosp., SUNY, 729 F.2d 144 (2d Cir. 1984).

[49] Myelomeningocele, also known as spina bifida, involves congenital malformations of the spinal column that, depending on how high the lesion is, can impair ambulation, bowel and bladder control, and other functions.

[50] Microcephaly is a condition where a child is born with a very small head.

[51] "Weak face" describes the impaired ability of the infant to suck and take nourishment.

dicted "an extremely high risk that the child would be so severely retarded that she could never interact with her environment or with other people."[52] This child ultimately survived. "Now a ten-year-old named Keri Lynn, Baby Jane Doe is not only a self-aware little girl, who experiences and returns the love of her parents, she also attends a school for developmentally disabled children."[53]

Second, discrimination can enter through irrational reasoning. Ordinarily, it is appropriate for a surgeon to not offer surgery when a patient's comorbidity renders the procedure so much riskier that the probable harm now outweighs any chance of benefit. However, when a patient is certain to die without surgery, and has at least a remote chance to live if he does receive the surgery (e.g., someone with an end-stage heart disease requiring transplant), it would be irrational to deny the procedure on grounds of mortality risk. There may be other reasons to deny such a surgery, as where the patient's quality of life is likely to be miserable if he survives, or if there is a shortage of facilities and this patient's prospects are much smaller than other patients'. But in a patient who *will* surely die without treatment, it makes no sense to deny treatment on the ground that it *might* take his life.

Third, discrimination can enter through inappropriate values. A decision to let someone die, based on the value judgment that persons of a particular race or gender are inherently inferior, would violate fundamental social values of equality among human persons. Although we can identify some fairly clear examples of bogus values, this area probably presents the greatest room for con-

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[52] *University Hosp.*, 729 F.2d at 146.

[53] B.D. Colen, *What Ever Happened to Baby Jane Doe?*, HASTINGS CENTER REP., May-June 1994, at 2.

Another example of factual inaccuracy concerns L.W., a 79-year-old man with a long history of chronic undifferentiated schizophrenia who suffered a heart attack. Later that same week, his physicians declared that he had entered into a persistent vegetative state (PVS) and determined that it would be appropriate to withdraw life support if he did not improve within a month. The Supreme Court of Wisconsin later upheld the decision to forego such treatment for him. *In re* Guardianship of L.W., 482 N.W.2d 60, 60 (Wis. 1992). However, two justices, one in a concurrence and another in a dissent, pointed out that the diagnosis of PVS had been made prematurely. *Id.* at 76 (Ceci, J., concurring); *id.* at 78 (Steinmetz, J., dissenting). In current medical practice, the persistence of a vegetative state cannot be ascertained any earlier than three months after the patient's loss of consciousness. This discrepancy does not necessarily entail that the physicians reached an inappropriate conclusion. But one can say, at the least, that it was not based on a fully correct appraisal of the facts.

See also Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (first of two parts)*, 330 NEW ENG. J. MED. 1499 (1994); Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (second of two parts)*, 330 NEW ENG. J. MED. 1572 (1994).

troversy in discussions about discrimination. Baby K provides a case in point. Vitalists insist that her life is every bit as precious as any other human being's, while many futilitarians would deny that someone who is irreversibly unconscious can properly be said to be a person at all, or to have interests of the sort that moral values are designed to protect.[54] As argued below, the fundamentally irresolvable character of this normative issue[55] can play an important role in limiting our duties to accommodate the disabled.

III. LIMITS ON DUTIES TOWARD THE DISABLED

For many observers, the most disturbing aspect of the Baby K case is its potential to drain society of untold resources, for what most people would deem no good purpose. She is obviously disabled, and if disability law really requires that she be provided with the same level of treatment that anyone without this disability would receive—as suggested by the Eastern District Court of Virginia—we may find ourselves overwhelmed by medical bills. And yet, as discussed above, it is very difficult to draw limits without begging fundamental questions. We cannot simply assert that her care is "futile" or that it is "obviously too extravagant," because the vitalists can simply assert the contrary.

Rather, we must look directly at the disability law, focusing on the ADA, and discern, point by point, how its provisions can permit us to draw credible limits on our collective obligations to aid the disabled. We will look mainly at five such provisions: the preamble stating its intent, its provisions regarding eligibility requirements, its relief from the threat of undue burdens, its exemption from making fundamental changes, and its bypass for measures that would endanger the safety of others.

A. *Preamble: Basic Purposes of the Law*

The first of the five provisions represents not a decisive argument, but a worthwhile observation before moving on to the more substantive arguments below. Neither the Rehabilitation Act nor the ADA was intended as platforms from which to demand unlimited heroic medical care for patients who are permanently unconscious. These laws aim to recognize that people with disabilities often are not permitted to fully participate in society or to make

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[54] *See* Fletcher, *supra* note 11; Tooley, *supra* note 11. The same questions arise regarding other patients who are persistently in a vegetative state, as for instance Helga Wanglie. *See* Spielman, *supra* note 18.

[55] Morreim, *supra* note 21.

the contributions of which they are capable. As noted in the ADA's introductory statements:

> [I]ndividuals with disabilities . . . have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of 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.[56]

Accordingly, the disability laws are intended to remove obstacles, ensure evenhanded treatment, and reduce adversities needlessly created by ignorance and prejudice.[57] The Rehabilitation Act says that taxpayers' money must not be used in ways that are unfair to the disabled, while the ADA broadens the mission by asserting that society as a whole should not mistreat or underestimate the capabilities of those with physical or mental impairments. The ADA's avowed goal is to "assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals"[58] by forbidding discrimination against the disabled.[59] In so doing, the objective is to displace stereotypical generalizations regarding classes of people with decisions based upon individual qualifications.[60]

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[56] 42 U.S.C. § 12101(a)(7).

[57] The Tenth Circuit, ruling in a case featuring infants with meningomyelocele, approvingly quoted the Supreme Court's language in *Bowen*:

> "'[N]either the language, purpose, nor history of [section] 504 reveals an intent to impose an affirmative-action obligation' on recipients of federal financial assistance. . . . [N]othing in the legislative history . . . even remotely suggests that Congress contemplated the possibility that 'section 504 could or would be applied to treatment decisions[ ] involving defective newborn infants.'"

Johnson by Johnson v. Thompson, 971 F.2d 1487, 1494 (10th Cir. 1992) (quotations omitted).

Similarly, the Supreme Court has enunciated that the purpose of § 504 is to "assure evenhanded treatment and the opportunity for handicapped individuals to participate in and benefit from programs receiving federal assistance," but not to ensure precisely equal treatment or outcomes. Alexander v. Choate, 469 U.S. 287, 304 (1985).

The Second Circuit has similarly stated: "Section 504 simply insures the institution's even-handed treatment of a handicapped applicant who meets reasonable standards so that he or she will not be discriminated against solely because of the handicap." Doe v. New York Univ., 666 F.2d 761, 775 (2nd Cir. 1981).

[58] 42 U.S.C. § 12101 (a)(8); *see also* Parmet, *supra* note 26, at 340.

[59] The Act states that discrimination should be eliminated "in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services." 42 U.S.C. § 12101(a)(3).

[60] *Id.*

Baby K does not fit into this rationale. It is meaningless to speak of her "opportunities" or of her "participation" in society. Heroic medical care could extend her life, but being alive made no further difference in her own life. Admittedly, the vitalist would argue that such a life is difference enough. And yet, to the extent that actual legislative intent is relevant in interpreting the scope of a law, the vitalists seem to have gone far afield.

B. *"Qualified," "Eligible"*

An important caveat throughout the legislation and litigation of disabilities law is that the disabled individual must first show that he is actually qualified or eligible[61] for the particular service, benefit, privilege, etc., that he is requesting.[62] It is not discrimination to refuse to hire a blind person, or even a diabetic,[63] as a motor vehicle driver.[64]

The Supreme Court first made this clear in *Southeastern Community College v. Davis.*[65] In ruling that a community college did not have to accept a deaf woman as a nursing student, the Court pointed out that an "otherwise qualified person is one who is able to meet all of a program's requirements in spite of his handicap."[66] That is, the person must be fully capable of meeting all the appropriate standards, so that the handicap is fundamentally unrelated to, and therefore an improper consideration of, the position or services in question.[67] The Court went on to note that although a school may not exclude someone on an assumption that the bare existence of the handicap disqualifies him or her from functioning, Davis's inability to hear could endanger patients and require

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[61] The Rehabilitation Act uses the expression "otherwise qualified." This language was dropped in the ADA, but the essence of the requirement remains the same: the individual cannot claim that he has suffered invidious discrimination if he is not legitimately eligible for the service or benefit or job in the first place. Hadorn, *supra* note 6, at 1457.

[62] The ADA states that it is discriminatory to impose "eligibility criteria that screen out or tend to screen out an individual with a disability . . . from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered." 42 U.S.C. § 12182(b)(2)(A).

[63] Chandler v. City of Dallas, 2 F.3d 1385 (5th Cir. 1993).

[64] An individual is qualified "if he or she is capable of meeting the essential performance or eligibility criteria for the particular position, service, or benefit. Thus, a person with a disability is not protected unless he or she is otherwise qualified to hold the job or to receive the service or benefit." Gostin, *supra* note 27, at 249.

[65] 442 U.S. 397 (1979).

[66] *Id.* at 406.

[67] United States v. University Hosp., SUNY, 729 F.2d 144, 156 (2d Cir. 1984).

inordinate revisions in the normal school curriculum.[68]

In medicine, however, to be "qualified" or "eligible" for services is not like being qualified for a particular job or education curriculum, or being eligible to receive federal financial assistance. To be qualified for medical services is to have an illness or injury that needs, and can be helped by, medical care. In other words, a person is qualified if treatment is "medically indicated" for him under these conditions.

Criteria of medical indication are, in essence, the medical standard of care. And in the U.S. legal system, that standard is ordinarily a set of collective professional judgments about which interventions are likely to help under what conditions, without creating an unacceptable risk of harm. In medicine, unlike virtually any other profession, physicians are permitted by law to set their own standard of care unilaterally. When injured patients sue physicians, courts determine whether their care was negligent by examining the practices of other physicians under similar circumstances.[69]

The disabilities cases fundamentally challenge this pattern. On one side of the Baby K case, physician groups vigorously argued that the courts must not use these cases to interfere with medical judgment[70]—much as the Supreme Court itself held in *Bowen*.[71]

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[68] *Davis*, 442 U.S. at 409-10. Similar rulings have emerged in other education cases. The Second Circuit, for instance, has held that a medical school did not have to ignore the disability (in this case, a history of serious mental illness) nor bypass other applicants who were more qualified for its limited number of spaces. Doe v. New York Univ., 666 F.2d 761, 780 (2nd Cir. 1981). *See also* Wynne v. Tufts Univ. Sch. of Med., 976 F.2d 791 (1st Cir. 1992).

[69] Customary or prevailing practice is not the only way to set medical standards. Variations have been carved out for local differences in practices and resources, for members of various subspecialties, and for reputable minorities. However, all these variations still appeal, empirically, to physicians' actual medical practices. J.H. KING, THE LAW OF MEDICAL MALPRACTICE 38-75 (2d ed. 1986).

Complete deviations from physician-set standards are real but rare. In *Helling v. Carey*, for instance, the Washington Supreme Court held that although physicians did not routinely test patients under age forty for glaucoma, they should. Helling v. Carey, 519 P.2d 981 (Wash. 1974). That ruling was intensely controversial and, indeed, was effectively overturned by subsequent legislation.

[70] *See, e.g.*, Amicus Brief for the American Academy of Pediatrics and Society of Critical Care Medicine, *In re* Baby K, 16 F.3d 590 (4th Cir.) (Nos. 93-1899, 93-1923, 93-1924), *cert. denied*, 115 S. Ct. 91 (1994). See also the Virginia statute stating:

> Nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate. However, in such a case, if the physician's determination is contrary to the terms of an advance directive of a qualified patient or the treatment decision of a person designated to make the decision under this article, the physician

Indeed, in its petition to the Fourth Circuit to rehear the case *en banc*, the Virginia hospital challenging the requirement to care for Baby K pointed out that such a mandate actually conflicts with Medicare and Medicaid regulations that require physicians to provide care only when it is medically necessary, according to recognized professional standards.[72] Similarly, the federal Emergency Medical Treatment and Active Labor Act (EMTALA), upon which the circuit court based its ruling, expressly requires physicians to provide care according to recognized professional standards.[73] Those standards are created by physicians.

Opponents challenge the prerogative of physicians to define for all patients what will count as a benefit. As noted above, the most profound dispute surrounding Baby K concerns whether life is invariably a benefit, regardless of its quality. On this alternate view, physicians can and historically have insinuated discrimination into their medical standards. Therefore, at least when the care of the disabled is at stake, these observers believe that medical standards of care should be subjected to societal or judicial oversight.

We can address this dispute with several steps. First, we must acknowledge that, quite independently of the disabilities cases, physicians are no longer permitted to set the standard of care as independently as they have in the past. In bygone days of lavish reimbursement for health care services, the prevailing practices of physicians were the product partly of scientific research, but partly also of theoretical speculation, fashions set by local medical leaders, fears about potential liability if new technologies were not rapidly adopted, easy availability of reimbursement even for tests and treatments whose effectiveness and best uses were not scientifically documented, and a technological imperative holding that it is better to do too much than too little.[74]

> shall make a reasonable effort to transfer the patient to another physician.

VA. CODE ANN. § 54.1-2990 (Michie 1994).

[71] The Court admonished that "Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children." Bowen v. American Hosp. Ass'n, 476 U.S. 610, 647 (1986). *See also* American Acad. of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983).

[72] Hospital Petition For Rehearing, *In re* Baby K, 16 F.3d 590 (4th Cir.) (Nos. 93-1899, 93-1923, 93-1924), *cert. denied*, 115 S. Ct. 91 (1994).

[73] *Baby K*, 16 F.3d at 593-94.

[74] Edward T. Wong & Thomas L. Lincoln, *Ready! Fire! . . . Aim!: An Inquiry Into Laboratory Test Ordering*, 250 JAMA 2510 (1983); John F. Burnum, *Medical Practice A La Mode: How Medical Fashions Determine Medical Care*, 317 NEW ENG. J. MED. 1220 (1987); David B. Reuben, *Learning Diagnostic Restraint*, 310 NEW ENG. J. MED. 591 (1984);

With the relentless rise of health care costs over the past three decades, insurers, businesses, governments, and others who pay the costs have inserted considerably more oversight over the delivery of care. These payers are imposing their own, often independently constructed, proprietary guidelines to determine which care is medically necessary and thereby reimbursable.[75] The result is a growing array of discrepancies between what physicians do and what payers cover. Prominent examples concern new technologies, such as autologous bone marrow transplant for breast cancer.[76]

On one side, patients may be told by their physicians that the treatment is widely practiced and judged to be a benefit. On the other side, they may be told by their insurers that the practice is unsupported by scientific data and is therefore experimental—not part of the standard of care. In a sense, both sides are right. The medical standard of care is very much a matter of physicians' professional judgments and practices. But increasingly, it is also appropriate to expect that those practices will be guided more systematically by scientific data than they have in the past.

In a second step to address the standards issue, we must yield considerable deference to physicians' judgments about what the standard of care should be, including their evaluations of what is to count as a benefit or a harm. Laws governing the medical profession's licensure and prescription power are premised on the idea that the tests and treatments of medicine can be dangerous as well as helpful, and that people with special knowledge and skills should pass judgment on who should receive which of these interventions. These laws imply that with their highly specialized training, physicians are more capable than others of determining when an intervention will do harm and when it will do good. And that,

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David A. Grimes, *Technology Follies: The Uncritical Acceptance of Medical Innovation*, 269 JAMA 3030 (1993).

As a result of these varying factors, physicians' actual practices might not always match what they would endorse on more careful reflection. *See generally* Joseph H. King Jr., *In Search of a Standard of Care for the Medical Profession: The "Accepted Practice" Formula*, 28 VAND. L. REV. 1214 (1975).

[75] *See generally* E. HAAVI MORREIM, BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS (1991).

[76] *See, e.g.*, Fuja v. Benefit Trust Life Ins. Co., 18 F.3d 1405, 1406 (7th Cir. 1994); Harris v. Blue Cross Blue Shield, of Missouri, 995 F.2d 877, 878 (8th Cir. 1993); Nesseim v. Mail Handlers Ben. Plan, 792 F. Supp. 674, 674 (D.S.D. 1992), *rev'd* 995 F.2d 804 (8th Cir. 1993); Pirozzi v. Blue Cross-Blue Shield of Virginia, 741 F. Supp. 586, 587 (E.D. Va. 1990); Thomas v. Gulf Health Plan, Inc., 688 F. Supp. 590, 591 (S.D. Ala. 1988).

in turn, presupposes that they are authorized to employ definitions of "harm" and "good" when they make those judgments.

Indeed, it would be impossible in principle to establish any standard of care if physicians were not permitted to bring in definitions of harm and benefit. To judge that a procedure is medically indicated in a particular situation is, after all, to judge that it is more likely to benefit than harm the patient. These judgments cannot be made without presuming specific concepts of benefit and harm.

Beyond this, it is widely recognized that all professions—medicine in particular—are in part defined by their commitment to a particular set of values defining their service to the community. On this view, to foreclose the prerogative of physicians to define their own values, including medical benefits and harms, is to deny their status as professionals.[77]

In a third step, however, we must acknowledge that this necessity for profession-governed definitions of benefit and harm does not preclude some measure of social oversight. Part II identifies several ways in which medical practice can be discriminatory, such as the factual ignorance implicit in underestimating the capabilities of people with Down's syndrome. And as noted just above, the strongest and most pervasive current challenge to physicians' standard-setting comes from payers. This challenge, too, arises mainly on factual grounds, as payers point out the dearth of outcomes data underlying physicians' prevailing practices.

Where medical standards of care are demonstrably based on inaccurate or inadequate factual premises, a good case can be made for some form of societal monitoring. In a number of cases, the judiciary has shown considerable deference to the opinions of physicians, public health officials, and the like, concerning whether a disabled person is qualified for a particular service.[78] However, that deference is not absolute. Medical views can and

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[77] Howard Brody, M.D., argues that medicine as a profession cannot be practiced without a deep commitment to a particular set of values.

> The moral value at stake here is the internal integrity and coherence of a professional practice and the maintenance of its internal standards of excellence. . . . Someone who calls himself a physician, but who is constantly willing to compromise on valid modes of treatment in order to satisfy the wishes of each patient, is a fraud.

BRODY, POWER, *supra* note 14, at 176.

[78] Such deference encompasses physicians' opinions concerning the safety hazards that someone's disability might pose for other persons. *See, e.g.*, School Bd. v. Arline, 480 U.S. 273 (1987); Bradley v. University of Tex. M.D. Anderson Cancer Ctr., 3 F.3d 922 (5th Cir. 1993), *cert. denied*, 114 S. Ct. 1071 (1994); United States v. University

should be corrected when they are clearly wrong.[79] At the same time, societal oversight must be limited. As suggested in Part II, discrimination cases sometimes hinge not on factual errors, but on value judgments. It is common for futilitarians to argue that, because physicians should be empowered to make some value judgments about harm and benefit and because there is a fairly widespread view within the medical community that the care of patients like Baby K is not a benefit, physicians should be permitted to refuse to provide heroic care.

In fact, however, in this area there is not really a medical, any more than a moral, consensus. As Judge Gesell noted in ruling against the original Baby Doe regulations, "as even the most cursory investigation by the Secretary would have revealed, *there is no customary standard of care* for the treatment of severely defective infants."[80] While many physicians do deem it medically and morally wrong to deliver heroic care to those who will never be conscious, others accede to families' wishes either out of respect for their autonomy or from fear of litigation, and at least some others hold a vitalist commitment to life.

Equally important, the moral status of diminished lives, just like the moral status of the fetus in the abortion debate, is inherently unresolvable. It concerns our most basic assumptions about the scope of morality, assumptions that form the basis of further moral reasoning but which cannot themselves be defended.[81]

Accordingly, it becomes clearer why the futilitarian argument is unsound. The most effective argument is not that physicians can deny care because they—or society at large—have reached this consensus. Rather, it is because *we can never possibly achieve a consensus* that we cannot endorse coercion by either side. Where the dispute concerns fundamental values rather than facts, neither side can rationally command the moral high ground, nor should they coercively grab it. Although physicians are rightly empowered in many other realms to make judgments that both define and balance benefits and harms, they cannot appropriately extend that authority into this fundamentally different kind of issue. But neither do vitalist families have any moral basis on which to coerce provid-

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Hosp., SUNY, 729 F.2d 144 (2d Cir. 1984); Doe v. New York Univ., 666 F.2d 761 (2d Cir. 1981).

[79] Glanz v. Vernick, 756 F. Supp. 632, 638 (D. Mass. 1991). *See also Doe*, 666 F.2d at 776 (stating that the court will show deference absent proof that the institution is doing nothing more than denying an education to handicapped people).

[80] American Acad. of Pediatrics v. Heckler, 561 F. Supp. 395, 400 (D.D.C. 1983).

[81] Morreim, *supra* note 21.

ers to engage in actions which the providers personally deem cruel, wasteful, or otherwise wrong.

In sum, the discrimination laws' eligibility requirement permits physicians considerable leeway to determine which medical interventions will benefit which patients. Unfounded assumptions and factual errors underlying these standards should be corrected, but only in clear cases should this be done outside the profession. The esoteric nature of medical science will preclude such outside correction in most instances. At the same time, physicians cannot appeal to medical science to determine that a patient's life—his very existence—is somehow "medically contraindicated." It is here that controversies should be resolved, not by professional declaration, but by societal negotiation.

It is one thing to suggest that physicians and families should not coerce one another into conduct they deem morally offensive. But where providers are willing to deliver maximal care to a patient in a profoundly diminished state, we must inquire whether other people, such as fellow subscribers to an HMO or insurance policy or taxpayers in society as a whole, are obliged to pay for that care.[82] Disability law requires that we help disabled individuals, but it limits that obligation. One need not bear an undue burden in accommodating the handicapped; an institution or program need not change its fundamental nature; and the health and safety of others should not be endangered. These caveats will be explored in the next three sections.

C. *"Reasonable Accommodations," "Undue Burdens"*

Employers, those proffering public accommodations (including health care), and others covered by the ADA must make reasonable accommodations or modifications to permit the disabled to participate in society.[83] This duty, however, is not unlimited.

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[82] In this Article, we will not consider the question of whether disability law forces physicians to personally render care they deem inappropriate, because our focus is mainly on the limits of society's obligation to fund costly care for the disabled. The question regarding physicians' obligations is important, and is addressed in other forums. Perhaps the most prominent example concerns physicians' obligations to care for patients with HIV infection. *See, e.g.*, Glanz v. Vernick, 756 F. Supp. 632 (D. Mass. 1991); Halevy & Brody, *supra* note 26; Richard M. Ratzan & Henry Schneiderman, *AIDS, Autopsies, and Abandonment*, 260 JAMA 3466 (1988); Abigail Zuger & Steven H. Miles, *Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations*, 258 JAMA 1924 (1991).

[83] Title I, which governs employment, speaks of "reasonable accommodation[s]," 42 U.S.C. § 12111(9), while Title III, which governs public accommodations speaks of "reasonable modifications." 42 U.S.C. § 12182(b)(2)(A)(ii).

These entities need not endure undue hardship or unreasonable burdens in order to accommodate the disabled.[84]

But such concepts are vague, and once again the circular dispute between the futilitarians and vitalists looms. One side argues that spending hundreds of thousands of dollars to keep an anencephalic alive is obviously, wildly unreasonable, while the other side insists that if such expenditures are reasonable for anyone, they are reasonable for everyone. We must avoid this circle if we are to find defensible limits to societal expenditures for the disabled. In this subsection, we will first examine relevant parts of the ADA. Then, we will consider factually what burdens are likely to be imposed if we grant strong rights to heroic care to anyone with a disability. Finally, we will consider when, and why, such burdens might be considered "undue."

1. Law

Title I of the ADA, which covers employment and thereby probably also much health insurance, defines "undue hardship" in terms of several factors that may be considered: "the nature and cost of the accommodation needed," "the overall financial resources of the facility or facilities involved in the provision of the reasonable accommodation," "the effect on expenses and resources, or the impact otherwise of such accommodation upon the operation of the facility," "the overall financial resources of the covered entity," and similar factors.[85]

Title III, governing public accommodations (including health care providers) states that these providers need not endure an "undue burden" as they make "reasonable modifications" to accommodate the disabled.[86] This section of the Act does not offer further definition, but subsequent regulations largely mirror Title I. Factors to consider in determining whether a burden is undue include: "The nature and cost of the action needed," "[t]he overall financial resources of the site or sites involved," "[i]f applicable,

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[84] Under Title III, the purveyor of public accommodations must make reasonable modifications, "unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden." 42 U.S.C. § 12182(b)(2)(A)(iii).

See also Bradley v. University of Tex. M.D. Anderson Cancer Ctr., 3 F.3d 922 (5th Cir. 1993), *cert. denied*, 114 S. Ct. 1071 (1994) ; Doe v. New York Univ., 666 F.2d 761 (2d Cir. 1981); Barth v. Gelb, 2 F.3d 1180 (D.C. Cir. 1993); Gostin, *supra* note 27, at 250; Kapp, *supra* note 36, at 175; Parmet, *supra* note 26, at 335.

[85] 42 U.S.C. § 12111(10)(A) and (B).

[86] 42 U.S.C. § 12182(b)(2)(A)(ii) and (iii).

the overall financial resources of any parent corporation or entity," and so forth.[87] Title III does provide some additional help by noting that an entity will not be found to be in violation where it "can demonstrate that the removal of a barrier . . . is not readily achievable."[88] "Readily achievable," in turn, is determined according to such factors as "the nature and cost of the action needed," "the overall financial resources of the facility or facilities involved," and "the effect on expenses and resources, or the impact otherwise of such action upon the operation of the facility."[89]

2. Burdens

The reasonableness of a particular accommodation can only be determined with a full and accurate description of its scope and costs. This is particularly important in the case of medical treatment, since it can be so very costly. Significantly, medical needs are not like job openings or hotel rooms or other typical realms where disability accommodations must be made. An employer may have just one job opening, and if a disabled applicant is hired he may build a wheelchair ramp or change some office arrangements. But that accommodation does not carry any further implications, since that employer may have no more job openings, or disabled applicants, for a considerable time. In medicine, however, the numbers of patients and the range of their needs are virtually endless, and whatever is done for one patient has potentially vast implications throughout the system.

Baby K, for example, received a respirator for respiratory distress. If her heart had failed, however, she might have needed a left ventricular assist device or even an organ transplant.[90] They, too, could stave off her death a while longer. And now for the broader implications. This level of accommodation, once provided for Baby K, can hardly be denied to others in comparably disastrous condition. People in persistent vegetative states, and octogenarians with advanced dementia, would deserve at least as much. At that point, we can hardly deny at least that level of care to people who are conscious and suffering—for instance, women with advanced breast cancer, whose only hope is an unproven but promising bone marrow transplant.

After all, *denying comparable care to any of these others would be*

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[87] 28 C.F.R. § 36.104 (1992).

[88] 42 U.S.C. § 12182(b)(2)(A)(v).

[89] 42 U.S.C. § 12181(9).

[90] Annas, *supra* note 9, at 1544.

blatant discrimination. The most basic rules of fairness require that persons who are similarly situated must be treated similarly.[91] Moreover, in the context of providing medical care for the needy, similarity should not be based on the patient's technical diagnosis. It would be irrational to deny a respirator to the demented octogenarian while granting it to Baby K, simply because one patient has anencephaly while the other has Alzheimers. They both are in respiratory distress and will die without the help. Neither is it significant that a mechanical ventilator is the particular treatment needed. If extra corporeal membrane oxygenation (ECMO) would yield the better opportunity for survival, and if survival is the goal, then ECMO rather than the ventilator could be required (at a cost of approximately $100,000 per week).

Exact diagnoses and medical technologies are not the important factors, then, but rather the prognoses and the prospects of helping the patient through medical intervention. If two patients, for whatever reason, are equally likely to suffer death or substantial deterioration in their condition—or if they even hope that a new technology might reverse an otherwise permanent illness or disability—and if some sort of treatment offers each a comparable chance of averting or delaying that death or deterioration, then those treatments would equally be required for both. With this move, the area of concern has expanded from a limited number of end-of-life situations to virtually any health need that might be answered by some exotic new technology.

By direct implication of mandating endless respirator care for anencephalic, terminally ill Baby K, we have embraced the farthest reaches of what I will call "exoticare": virtually any cost for virtually any level of care must be shouldered for virtually any patient who has even the smallest chance of surviving or benefitting, even for a short time. If ventilators in intensive care units are required for an anencephalic's dismal prognosis, then the same unlimited care is equally mandatory for every other patient with a similar or better prognosis.

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[91] This principle of formal justice was acknowledged quite explicitly by the Fourth Circuit. Sheppard & Enoch Pratt Hosp. v. Travelers Ins. Co., 32 F.3d 120 (4th Cir. 1994). The plaintiff contended that because two consulting physicians within the health plan had disagreed about the length of her psychiatric hospitalization, the plan was arbitrary in opting for one physician's recommendation over the other's. *Id.* at 122-23. The Fourth Circuit rejected this argument. The charge of inconsistency applies not to this situation, but to "inconsistent applications of the Plan to members suffering from the same or similar ailments." *Id.* at 126.

3. Undue burdens

Once we recognize this, it follows that even if we accept the vitalist belief that life is precious regardless of its quality, the exoticare entailed by mandating unlimited treatment under the wide array of circumstances such as Baby K's would constitute an undue burden, an unreasonable accommodation, from those who pay for her treatment. The cost is not just one treatment for one patient. It is a vast array of costly care for a vast array of patients.

The unreasonableness of the accommodation is found in three factors: [a] the sheer cost of such care; [b] the imposition of coerced private altruism; and [c] the infringing of private values.

[a] *Cost.* The cost of such exoticare for such a wide array of people would assuredly be staggering. While it is beyond the scope of this Article to provide detailed documentation, the vastness of the expenditures will be obvious to anyone with a passing acquaintance with health care economics.[92] They would inevitably result in markedly higher health premiums or reductions in coverage. Arguably, such extraordinary expenditures are not required by disability law. The Equal Employment Opportunity Commission (EEOC) defines an "unacceptable" change in coverage or premiums to be one that would

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

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[92] Capron argues that the cost of care in so-called "futility" cases is not really prohibitively high. In one study, out of the $8.9 million spent on the care of "futile" patients, only about $1 million might reasonably have been expected to be saved by earlier withdrawal of ventilator care. Alexander M. Capron, *Medical Futility: Strike Two,* HASTINGS CENTER REP., Sept.-Oct. 1994, at 42, 43. Similarly, another study argues that cost savings by changing management of care at the end of patients' lives are not likely to be substantial. 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, 543 (1994).

Two replies may be made. First, as argued above, our concerns are not restricted to literal end-of-life situations. Patients in PVS can live for many years, for example, and are not included in these figures. More importantly, once we recognize that the relevant area encompasses virtually any exotic treatment for virtually any patient's need, we have gone well beyond anything resembling the so-called "futility" cases.

Second, even if the costs for a particular kind of care for a particular group of patients are not unbearable for society as a whole, they can be for the small hospital or payer that must actually provide or pay for the care.

plans offered by other employers in the community.[93]

We must also acknowledge who actually pays for exoticare. Rarely is it "society" per se, except in the case of federal insurance plans such as Medicare. More often, it is particular insurers, MCOs, hospitals, and individuals. In some cases, those entities may find their resources devastated by even a single, very expensive case. A small hospital or HMO, for instance, may be unable to afford endless intensive care of one anencephalic or patient in PVS. Small businesses may find that just one ill employee or dependent can cause their next year's experience-rated insurance premiums to rise prohibitively high.

Even here we must delve deeper. Third-party payers, businesses, and governments are basically just intermediaries. Ultimately, the money comes from private individuals who pay premiums either directly through their pockets, or indirectly through taxes, consumer prices, and the diminution of wages and other employee benefits that inevitably accompanies a rise in health premiums.[94] Baby K's funding came from the other members of her Kaiser plan.[95]

The costs are not only monetary. Members may be inconvenienced as the rising cost of exoticare for the neediest subscribers results in longer waits for their own care, or a reduced availability of their favorite providers or treatments. A costlier hypertension drug, for instance, may be dropped from an HMO's pharmaceutical formulary, even though it has fewer annoying side effects than its cheaper alternatives. And as such changes emerge, morale among those subscribers may dim, a factor that has been acknowledged by at least one court to be a significant burden in disabilities litigation.[96]

[b] *Coerced Private Altruism.*

Next, we must acknowledge a peculiar feature of the ADA. It coerces private altruism. This law does not merely forbid people to erect barriers to handicapped persons, or require the removal of

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[93] EEOC, *Interim Guidance on Disability-Based Distinctions in Health Care Plans* [June 8, 1993], Accommodating Disabilities (CCH), at 140,027.

[94] U.E. Reinhardt, *Reorganizing the Financial Flows in American Health Care*, 12 HEALTH AFF. 172-93 (Supp. 1993).

[95] *See* Carol J. Castaneda, *Baby K—now Stephanie—turns 2*, USA TODAY, Oct. 13, 1994, at 3A.

Some $700,000 spent to support Helga Wanglie, a woman in a persistent vegetative state, came from fellow subscribers in her HMO. *See* Steven H. Miles, *Interpersonal Issues in the Wanglie Case*, 2 KENNEDY INST. ETHICS J. 61, 65 (1992).

[96] Barth v. Gelb, 2 F.3d 1180, 1189-90 (D.C. Cir. 1993).

such barriers. It goes beyond, holding that neglect—defined partly as a failure to help the disabled—can likewise impede these citizens' participation in society. Hence, the ADA includes an affirmative obligation placed on employers, public accommodations, and the like to make accommodations to aid these people.[97] Employers, for example,

> may be required to institute significant and even expensive accommodations, as long as they do not undermine an essential job function or pose an 'undue hardship' on the employer. Although the 'undue hardship' concept is a flexible one, it was clearly meant to place far more than a *de minimis* obligation on employers.[98]

This requirement is not a general tax levy placed on all citizens, as with welfare programs to help the indigent. It is placed on particular private individuals who happen to have certain encounters with the disabled. Additionally, it is not merely the usual requirement that people refrain from causing new injuries, as where the Occupational Health and Safety Administration (OSHA) requires employers to go to sometimes great lengths to ensure that the workplace does not harm workers. Rather, this body of law can find fault with someone for failing to expend enough of his private resources to overcome the misfortunes that someone or something has inflicted on a complete stranger. It is coerced private altruism, then, when an individual employer or restaurateur is expected to spend his own money to build a ramp to accommodate the person whose paraplegia was caused by a diving accident twenty years ago.[99]

Even if justified as a necessary vehicle of social solidarity, this coerced private altruism must be carefully restricted. Since its burdens fall on those who did not cause the problem they are expected to remedy, and since those burdens are not shared by the rest of the community, it is especially important that such duties be

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[97] The ADA "actually imposes significant specific affirmative obligations on numerous sectors of society. . . . At many points, the ADA goes well beyond traditional antidiscrimination law by imposing explicit obligations upon institutions in order to benefit the disabled." Parmet, *supra* note 26, at 335. *See also* Kapp, *supra* note 36, at 175.

[98] Parmet, *supra* note 26, at 335; Peters, *supra* note 7.

[99] Physicians, for example, may recognize that many deaf patients need sign interpreters for adequate communication. However, the cost of such signing can be higher than the physician's earnings for the care of that patient, particularly in the case of uninsured or Medicaid patients. The cost falls on the physician as an individual, not on "society," even though the physician did nothing to cause the deafness. *See* David A. Ebert & Paul S. Heckerling, *Communication With Deaf Patients: Knowledge, Beliefs, and Practices of Physicians*, 273 JAMA 227, 229 (1995).

limited. Indeed, Feinberg notes that only two states in the U.S. require citizens to rescue people in distress, and even those duties are severely limited.[100]

The Supreme Court has explicitly noted other contexts in which altruism, even publicly funded, is not required. In upholding laws that deny federal funding for abortions, the Court explained that a woman's freedom of choice does not carry with it

> a constitutional entitlement to the financial resources to avail herself of the full range of protected choices. Although government may not place obstacles in the path of a woman's exercise of her freedom of choice, it need not remove those not of its own creation, and indigency falls within the latter category.[101]

[c] *Infringing Private Values.*

Perhaps more fundamentally, a rise in health care expenditures means that less money is available to spend on other kinds of priorities, including those outside health care entirely. An important dimension of this debate concerns the importance of respecting widely diverging values. Where vitalists are able not just to command the freedom to act on their beliefs, but also to conscript others' money to fund their choices, they prevent those people from using that money for their own values and goals, whether educating their children or buying a home.

Perhaps even more important, some people will find these expenditures to be profoundly morally objectionable. Baby K's exoticare did not just diminish the funds available for others, it also required scarce resources such as intensive care unit (ICU) beds and nursing time. The consequences could be disastrous if some otherwise viable patient is denied a needed ICU bed, or a transplant organ, because the last one available is taken by some patient who is permanently unconscious.

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[100] According to Feinberg:

> Until joined recently by Minnesota, the only American state to enact a criminal bad samaritan statute of the European type was Vermont, whose criminal code now provides that "A person who knows that another is exposed to grave physical harm shall, to the extent that it can be rendered without danger or peril to himself or without interference with important duties owed to others, give reasonable assistance to the exposed person unless that assistance or care is being provided by others." [VT. STAT. ANN. tit. 12, § 519 (1973).] Even the Vermont law only slaps the wrist of the bad samaritan, creating a mere misdemeanor and imposing only a $100 fine.

JOEL FEINBERG, THE MORAL LIMITS OF THE CRIMINAL LAW: HARM TO OTHERS 127 (1984).

[101] Harris v. McRae, 448 U.S. 297, 316 (1980); *see also* Maher v. Roe, 432 U.S. 464 (1977).

In other areas like this that are marked by a profound, unresolvable moral controversy, there is precedent for refusing to conscript money for purposes that a significant number of people find to be seriously immoral. One example is the Hyde amendment, which forbids federal money to be used for elective abortions.[102] In essence, the law recognizes that a large number of citizens believe abortion to be murder, and that using tax money to fund it can amount to forcing these people to be accomplices to a moral outrage.[103]

In the case of exoticare for patients with anencephaly or PVS, many citizens find morally abhorrent the prospect of watching an otherwise viable person die or deteriorate for lack of resources. They find it shocking to spend millions of dollars to preserve biofunction in unconscious, dying patients while so many of our people lack the most basic health care, housing, and sustenance. If our objective in these difficult areas is to respect citizens' diverging viewpoints, we must draw stringent limits on the amount of funding that we conscript from unwilling citizens to fund exotic health care.

D. *Fundamental Changes in Programs*

Employers, schools, or other ADA-covered entities need not fundamentally or substantially change the nature of their programs.[104] As noted above, in *Southeastern Community College v. Da-*

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[102] The *Harris* Court traced the history of Congress's prohibition on the use of federal funds to reimburse "the cost of abortions under the Medicaid program except under certain specified circumstances." *Harris*, 448 U.S. at 302. Commonly know as the Hyde amendment, the then-current version, named after its original sponsor, Representative Hyde, provided:

> "[N]one of the funds provided by this joint resolution shall be used to perform abortions except where the life of the mother would be endangered if the fetus were carried to term; or except for such medical procedures necessary for the victims of rape or incest when such rape or incest has been reported promptly to a law enforcement agency or public health service."

Id. at 302 (quotation omitted).

[103] The explicit rationale for the Hyde amendment has been articulated differently—namely, as a choice by the state to favor childbirth with the financial incentive of covering this service while not covering abortion services. *See Harris*, 448 U.S. at 315; *Maher*, 432 U.S. at 464. However, it can be argued that the respect-for-values rationale described in this Article, though less openly discussed, is at least as important. Without it, it is difficult to explain the statute upheld in *Harris*, which denied funding for medically necessary abortions right alongside elective abortions.

[104] Title III, concerning public accommodations, prohibits as discriminatory a

> failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals

vis,[105] a nursing school was not required to accept a deaf applicant, in part because the need for special supervision and waiving of course requirements would have altered the nursing school's curriculum too much. The bare fact that a particular approach is traditional does not mean that it is forever enshrined, of course. But in this case, the school's requirements were reasonable and there was no reasonable expectation that they should change.[106]

Similarly, in *Wynne v. Tufts University School of Medicine*,[107] the First Circuit found that a medical school was not wrong for failing to offer a student with cognitive deficits an alternative to a multiple choice exam for his biochemistry course. The school had made a persuasive case that it had "considered alternative means, their feasibility, cost and effect on the academic program, and came to a rationally justifiable conclusion that the available alternatives would result either in lowering academic standards or requiring substantial program alteration."[108]

In *Bradley v. University of Texas M.D. Anderson Cancer Center*,[109] the Fifth Circuit ruled that a hospital could lawfully reassign an HIV-infected surgical technician to other kinds of work in the institution. The institution could not accommodate him in his prior work except by moving him away from surgery and placing another technician in his place—a fundamental redefinition of essential roles, and therefore not required by the law.

This exemption becomes vital when we recall an important point from the preceding section. Once exoticare is granted to one patient with a grim prognosis, we must do the same for all others with a similar prognosis demanding comparably extraordinary care. Once this is granted, the fundamental nature of the health plan supporting their care will almost certainly be changed.

Health plans underwritten by insurers and HMOs do not ordinarily hold themselves out to ensure the most exotic interventions

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> with disabilities, *unless the entity can demonstrate that making such modifications would fundamentally alter the nature* of such goods, services, facilities, privileges, advantages, or accommodations.

42 U.S.C. § 12182(b)(2)(A)(ii) (emphasis added); *see also* Alexander v Choate, 469 U.S. 287, 306-09 (1985); Southeastern Community College v. Davis, 442 U.S. 397, 405 (1979); Wynne v. Tufts Univ. Sch. of Med., 976 F.2d 791, 794-95 (1st Cir. 1992); Doe v. New York Univ., 666 F.2d 761, 775 (2nd Cir. 1981); Garvey, *supra* note 7, at 608; Gostin, *supra* note 27, at 250.

[105] 442 U.S. 397 (1979).

[106] *Id.* at 413-14.

[107] 976 F.2d 791 (1st Cir. 1992).

[108] *Id.* at 793.

[109] 3 F.3d 922 (5th Cir. 1993).

for the most desperate circumstances. Rather, they purport to provide something much broader in concept and more modest in intensity: basic care for the covered population as a whole.[110] If a health plan is required to provide exoticare on the massive scale implied by the Baby K case, subscribers would have substantially less access to the "basicare" they thought they had purchased. If more nurses must be dedicated to intensive care for demented octogenarians with new organ transplants, fewer nurses will be available for ordinary office visits or routine hospitalizations. If more physicians are specialists caring for anencephalics on ECMO, fewer primary care physicians will be available, even though the same number of subscribers will continue to need primary care. If more of the pharmaceutical budget is spent on high-cost life-saving drugs, less of it will be available to offer a broad variety of choices for more common maladies like hypertension, arthritis, and asthma. In short, subscribers could expect to wait longer for rou-

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[110] There are several approaches to defining that product. On a superficial level, these financiers purport to cover "medically necessary care"—care that is ordinary and reasonable, according to the usual standards of the medical profession. As noted above, this definition is somewhat inadequate. Physicians' actual practices can reflect local custom, litigation fears, and the like, more than a thoughtful and well-researched judgment of the profession. For this reason, health plans are introducing their own, sometimes conflicting, guidelines of care.

A better description of many health plans' fundamental objective, then, might be to maximize the health of the covered population as a whole. *See* Peters, *supra* note 7, at 514-33. *See generally* David M. Eddy, *Principles for Making Difficult Decisions in Difficult Times*, 271 JAMA 1792 (1994); David M. Eddy, *Broadening the Responsibilities of Practitioners: The Team Approach*, 269 JAMA 1849 (1993); L.I. Sederer, *Managed Mental Health Care and Professional Compensation*, 12 BEHAVIORAL SCI. L. 367, at 375 (1994). Such an approach could encompass a rich level of coverage, but would stop short of treatments that are highly unlikely to succeed, or promise little or no improvement for the patient, or whose cost greatly outweighs any benefits. Diverting resources away from such population-oriented care toward exoticare would fundamentally change the health plan's objective.

In a third option, health plans might be seen to ensure basic care. Basic care aims to prevent or cure illness, ameliorate pain, reverse or minimize dysfunction, and the like. It refers to interventions that are genuinely likely to achieve these ends—not to care that is experimental, highly unlikely to benefit, or prohibitively costly relative to benefits. This third concept differs somewhat from the population-oriented approach. In that approach, some kinds of care genuinely helpful for individuals might in principle be sacrificed to the greater good, where, for instance, someone with an unusual disease can benefit from a treatment that is nevertheless costly. Individuals who sign up for plans promising basic care expect to receive at least some modicum of services for themselves as individuals in need, even if it does not absolutely maximize the welfare of the group.

Although the latter two approaches differ in some details, they are fairly close in scope. Both demand effectiveness of care and reject marginal interventions at high expense.

tine appointments and have substantially fewer choices of providers, tests, and treatments.

Throughout, the health plan has changed from one offering quality basicare for everyone to a heavy emphasis on exoticare for the few. For most health plans, this change would be fundamental. HMOs, for example, were conceived in the belief that preventing illness and minimizing excessive costly care such as inappropriate hospitalization could help more people to live healthier lives at lower cost. Ordinary indemnity insurance is likewise conceived as a way to make affordable the kind of care that most citizens want in order to ensure that they can live healthy, productive lives. Few people purchase insurance in order to ensure that their bodies will be perpetuated indefinitely after they have lost all consciousness and human function. To the extent that these conceptions constitute the nature of the insurance or HMO products being sold,[111] a switch to emphasize exoticare over basic care would be a fundamental change of the kind not required by disabilities law.

There is one caveat, easily addressed. The ADA exempts programs from fundamentally changing their nature, but only if that nature is acceptable in the first place. Thus, if a school states that the accommodations necessary to accept a handicapped student would require basic alterations in its curriculum, that curriculum must be acceptable on its own merits. In *Davis*, the Supreme Court noted that the bare fact that certain curricular requirements are traditional does not entail that they must be perpetuated for all time. Advances in technology might one day permit participation in certain activities by persons who currently cannot partake. Hence, "situations may arise where a refusal to modify an existing program might become unreasonable and discriminatory."[112] But for now, this nursing school need not accommodate this deaf applicant. Nursing is an important service, and the requirements for providing quality, safe nursing care for patients cannot be modified enough to allow this person's participation.

In the case of health insurers and managed care organizations, this caveat is plainly satisfied. Providing ordinary care for large numbers of people is a legitimate goal. It does not inherently discriminate against the handicapped, because they too need basic

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[111] The claim that most insurance and HMO products offer basicare does not preclude some health plans' truly being designed around exoticare. If a plan is so conceived and advertised, then there would be no problem if it spent the bulk of subscribers' premiums on costly care for the few rather than ordinary care for the many.

[112] Southeastern Community College v. Davis, 442 U.S. 397, 412-13 (1979).

care. Indeed, many handicapped people could be most adversely affected by a shift from basicare to exoticare, since they are far more likely than nondisabled people to need frequent, ongoing care for their conditions. To be quadriplegic is not just to need a wheelchair. It is to be at substantially higher risk for urinary tract infections, stasis ulcers, and a host of comorbidities that often accompany their immobility.

E. Health and Safety of Others

In a further exception to requirements for accommodating the handicapped, programs are not expected to expose other people to significant health and safety risks.

> Nothing in this subchapter shall require an entity to permit an individual to participate in or benefit from the goods, services, . . . of such entity where such individual poses a direct threat to the health or safety of others. The term "direct threat" means a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.[113]

This provision has been invoked in the employment setting, where an employee with a contagious disease endangers other people. The Supreme Court has held that a contagious disease such as tuberculosis can constitute a handicap, the significance and accommodation of which must be determined in a case-by-case manner according to such factors as the nature, duration, and severity of the risk.[114] In *Bradley v. University of Texas M.D. Anderson Cancer Center*,[115] the Fifth Circuit found that a hospital could rightly exclude an HIV-infected surgical technician from his work in the operating room on grounds of the risk it posed for patients.[116] The same court ruled that the city of Dallas could permissibly exclude two workers—one with insulin-dependent diabetes and the other with impaired vision—from jobs requiring a significant amount of driving. These conditions present an unacceptable risk that such persons could injure themselves or others.[117]

From previous sections it should already be evident that a shift

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[113] 42 U.S.C. § 12182(b)(3); *see also* School Bd. v. Arline, 480 U.S. 273 (1987); Bradley v. University of Tex. M.D. Anderson Cancer Ctr., 3 F.3d 922 (5th Cir. 1993), *cert. denied*, 114 S.Ct. 1071 (1994); Chandler v. City of Dallas, 2 F.3d 1385 (5th Cir. 1993); Parmet, *supra* note 26, at 332, 339.

[114] *Arline*, 480 U.S. at 287-88.

[115] 3 F.3d 922 (5th Cir. 1993), *cert. denied*, 114 S.Ct. 1071 (1994).

[116] *Id.* at 925.

[117] Chandler v. City of Dallas, 2 F.3d 1385, 1397 (5th Cir. 1993).

from basicare to exoticare also presents dangers of harm. If subscribers to an HMO have fewer primary care physicians, fewer nurses delivering ordinary care, and a narrower range of tests and treatments, it is virtually certain that some of them will develop more illnesses, experience more exacerbations of chronic illnesses, and, as a population, enjoy less health care than they would have had if resources had been focused on basicare instead of being diverted to exoticare.[118]

Even without precise data, one can reasonably conclude that a shift from basicare to exoticare will likely endanger the health and safety of ordinary subscribers in the plan. If we presume that routine health care actually does what it is supposed to do—foster health, reduce illness, and ameliorate pain and dysfunction—then a serious reduction in ordinary care will quite surely result in at least some harm to the safety and well-being of a significant number of people.

By implication, health plans need not risk such harms to their members in order to accommodate the exotic needs of a limited number of patients. The decision to provide costly care for someone with a very bleak prognosis entails, by implication, a commitment to provide the same expensive level of care to everyone else with a similarly bleak prognosis. To do otherwise, as noted above, would be arbitrary and discriminatory. If this commitment, fully arrayed, would significantly diminish the care available to other subscribers, then the health plan need not provide such care to this lone individual.

F. Other Arguments

There are other arguments showing how health plans can legitimately avoid providing extraordinary care to patients with little hope of extended survival or of participating in human life in any fashion beyond continuing one's bare existence. For example, disabilities law specifies that decisions denying disabled persons par-

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[118] The actual impact of providing exoticare to Baby K-type patients could be relatively easy to measure, particularly within HMOs and other health plans which have a defined list of subscribers and a fixed budget. A survey of the patient population in the plan could determine roughly the number of patients with dire conditions and the costs of exoticare for them. Standard epidemiological techniques can project the health needs of the rest of the population, while historical and concurrent data can calculate roughly whether subscribers in a particular plan would wait longer for physician appointments, whether their illnesses last longer or develop more complications, and the like, after a switch from basicare to exoticare.

ticipation cannot be based "solely" by reason of the disability.[119] If there are other, legitimate reasons for excluding this person, the law may not be violated.[120] Once we tally up the costs and the impact on other subscribers in this health care setting, it is clear that a denial of exoticare is not based solely on the individual patient's handicap.

Another argument notes that the ADA explicitly permits health insurers to engage in risk rating, so long as it is not used as a subterfuge for invidious discrimination against the disabled.[121] There are several justifications for this caveat. Insurers need to have some advance projection of their outlays in order to set premiums at an adequate level so that all who are entitled to compensation can receive their due.

Beyond this, there are limits on the extent to which people who already have a compensable problem, or whose risks are known to be substantially higher than normal, can fairly tap the resources of people who simply want to be prudent in planning for future contingencies. Indeed, this latter notion logically underlies the ADA's explicit permission for differential premiums based on risk. After all, an insurer need not charge differential premiums in order to cover all its high-risk people; it would need only to know how many high-risk subscribers there are in order to set a sufficiently high rate that could then be uniform for all subscribers. Permitting differential premium costs requires the further premise that people at unusually high risk are not entitled to expect unlimited subsidization from their fellow subscribers. This allowance is a potentially powerful entree for cost considerations to limit the extent to which the disabled can make claims on common

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[119] Bowen v. American Hosp. Ass'n, 476 U.S. 610, 630 n.15 (1986); Johnson by Johnson v. Thompson, 971 F.2d 1487, 1493 (10th Cir. 1992); Doe v. New York Univ., 666 F.2d 761, 775 (2nd Cir. 1981); Gostin, *supra* note 27, at 251.

[120] Tucker notes that "to violate Section 504 an employer or program administrator must have no *legitimate* reason for rejecting a disabled individual; the *sole* reason for that rejection must be an unfounded or unjustifiable response to the disability." B.P. TUCKER, FEDERAL DISABILITY LAW 45 (1994).

Similarly,

> Section 504 simply insures the institution's even-handed treatment of a handicapped applicant who meets reasonable standards so that he or she will not be discriminated against solely because of the handicap. But if the handicap could reasonably be viewed as posing a substantial risk that the applicant would be unable to meet its reasonable standards, the institution is not obligated by the Act to alter, dilute or bend them to admit the handicapped applicant.

Doe, 666 F.2d at 775.

[121] 42 U.S.C. § 12201(c); Gostin, *supra* note 27, at 253; Orentlicher, *supra* note 7, at 310; Parmet, *supra* note 26, at 340.

resources.[122]

Other arguments could be added, but at this juncture the basic point is established: While the claims of the disabled for adequate health care must be taken very seriously, some demands cross over into an exotic level of care that is neither morally nor legally mandatory, nor even desirable. One more task remains. We must at least begin to identify the point at which basicare becomes exoticare. That is, we need some description of the kinds of care that providers and payers can legitimately refuse to provide.

IV. DRAWING LIMITS

It is morally right, perhaps even required, for citizens in an affluent society to help members in need. Current disability law begins with an injunction against inflicting gratuitous harms and disadvantages to those who are less able to participate in the community. The ADA, however, is also affirmative, and we should actively enhance those members' opportunities. Likewise, access to basic health care arguably should be universal, because ill health brings a great price to virtually all human projects.

However, there must be limits on such obligations. This need for limits initially appears economic, but ultimately it, too, is moral. To say that a particular helping effort costs too much is to acknowledge that we value other things and that resource limits do not permit us to do everything we want.[123]

Courts already permit health care providers and payers to enforce limits. A variety of courts have agreed that government insurers are not required to fund every conceivable medical benefit.[124] Other cases acknowledge that insurance plans can set and enforce

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[122] Note, however, that at the same time, it could under some interpretations threaten to undermine the protections the disability laws are designed to convey. *See* Gostin, *supra* note 27, at 353; Parmet, *supra* note 26, at 340.

[123] The moral questions go deeper. When one group demands support from others, coercion looms. One's liberty to act according to his own values is threatened, not only as his financial freedom to pursue his own alternative projects is curtailed, but also where he may be forced to support actions that he finds morally objectionable. Thus, the nonvitalist does not just resent his money being taken to support indefinitely and extravagantly the life of an anencephalic; he may find deeply abhorrent the prospect of an otherwise salvageable person being denied needed intensive care because the last bed is already occupied by a Baby K.

[124] *See generally* Alexander v. Choate, 469 U.S. 287 (1985); Harris v. McRae, 448 U.S. 297 (1980); Maher v. Roe, 432 U.S. 464 (1977); Doe v. Devine, 703 F.2d 1319 (D.C. Cir. 1983), *aff'g* 545 F. Supp. 576 (D.D.C. 1982); Matthews v Shalala, No. 93 Civ. 1408, 1993 U.S. Dist. LEXIS 13434 (S.D.N.Y. Sept. 27, 1993); Duquette by and through Duquette v. Dupuis, 582 F. Supp. 1365 (D.N.H. 1984). Congress' own implementation of its Medicare programs, through the Health Care Finance Administration, likewise

limits on coverage.[125] Courts have further conceded that other patients' competing needs can be a legitimate reason for institutions to limit the care they provide for a given individual.[126] And at least some courts have indicated that the state has less interest in preserving the lives of patients who are permanently unconscious than it does where the patient has some chance of returning to cognitive life.[127]

Given the precedent set by the Baby K case, however, further limits need to be specified. The Fourth Circuit noted that EMTALA, the law requiring emergency treatment for anyone who wants whatever level of care is necessary to avert significant medical deterioration, contains no exceptions.[128] The care must be given regardless of the patient's prognosis, regardless of cost, and, by further implication, perhaps even regardless of the potential harm to other patients competing for the same resources. The hospital's duty to keep treating ends only when the patient is medically stable, or dies despite all efforts. Any other limits, said the court,

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draws limits. Heart transplants, for instance, are to be made available only under limited conditions. *See* Peters, *supra* note 7, at 522.

[125] *See generally* Barnett v. Kaiser Found. Health Plan, Inc., 32 F.3d 413 (9th Cir. 1994); Harris v. Blue Cross Blue Shield, of Missouri, 995 F.2d 877 (8th Cir. 1993); Nesseim v. Mail Handlers Ben. Plan, 995 F.2d 804 (8th Cir. 1993); Loyola Univ. of Chicago v. Humana Ins. Co., 996 F.2d 895 (7th Cir 1993); Harris v. Mutual of Omaha Cos., 992 F.2d 706 (7th Cir. 1993); Farley v. Benefit Trust Life Ins. Co., 979 F.2d 653 (8th Cir. 1992); McGee v. Equicor-Equitable HCA Corp., 953 F.2d 1192 (10th Cir. 1992); McLeroy v. Blue Cross/Blue Shield of Oregon, Inc., 825 F. Supp. 1064 (N.D. Ga. 1993); Arrington v. Group Hospitalization & Med. Serv., 806 F. Supp. 287 (D.D.C. 1992); Thomas v. Gulf Health Plan, Inc., 688 F. Supp. 590 (S.D. Ala. 1988); Madden v. Kaiser Found. Hosps., 552 P.2d 1178 (Cal. 1976); Gee v. Utah State Retirement Bd., 842 P.2d 919 (Utah App. 1992).

[126] Davis v. Johns Hopkins Hosp., 622 A.2d 128 (Md. 1993); Jersey City Med. Ctr. v. Halstead, 169 N.J. Super. 22, 404 A.2d 44 (1979). In the field of education, it is similarly acknowledged that an institution facing many candidates competing for a very limited number of slots can legitimately look for those who are the most qualified, even if that means passing over a qualified (though somewhat less) handicapped applicant. Doe v. New York Univ., 666 F.2d 761 (2nd Cir. 1981).

[127] *See, e.g., In re* Quinlan, 355 A.2d 647, 70 N.J. 10 (1976). The Wisconsin Supreme Court recently suggested: "We stress the unique status of individuals in a persistent vegetative state, and the fact that this opinion is strictly limited to persons in such a condition." Furthermore,

> "If a prognosis of permanent unconsciousness is correct . . . continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible." . . . Patients in a persistent vegetative state are on a completely different footing than patients with other disabilities.

In re Guardianship of L.W., 482 N.W.2d 60, 72 n.15 (Wis. 1992) (quotation omitted).

[128] *In re* Baby K, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

must be drawn by Congress.[129]

The ADA may or may not be as demanding as EMTALA. The law is seriously unclear and, although many commentators argue that it should not be interpreted as an endless obligation to provide exoticare for anyone demanding it, the fact remains that at least one court has judged otherwise.[130]

Therefore, it seems essential to propose some limits that Congress might enact. Fortunately, existing legislation is readily available, needing only a few adaptations. In the 1980s, the Reagan administration issued the Baby Doe regulations alluded to above.[131] After some public instances in which infants with Down's syndrome or other anomalies were denied simple lifesaving treatments, a series of regulations was issued to ensure that handicapped infants would not be denied necessary care. These were interpreted by physicians to require every possible medical intervention for every infant, regardless of prognosis and regardless of the pointless pain and prolongation of dying that the such care sometimes would cause the infant and his family.[132] A series of court adjudications repudiated virtually the whole series of Baby Doe regulations,[133] but one piece of legislation did survive, namely, the Child Abuse Amendments of 1984.[134]

This law applies only to child protective service agencies, and requires them to have procedures for identifying and intervening in cases of medical neglect, on pain of losing federal funding if they do not. Significantly, the law identifies three specific scenarios in which a failure to provide treatment does not constitute medical neglect:

> (1) The infant is chronically and irreversibly comatose; or
> (2) The provision of treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
> (3) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under

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[129] *Id.* at 596.

[130] *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). .

[131] *See supra* note 24 and accompanying text.

[132] Angell, *supra* note 24; Lantos, *supra* note 24; Kopelman et al., *supra* note 24.

[133] Bowen v. American Hosp. Ass'n, 476 U.S. 610 (1986); United States v. University Hosp., SUNY, 729 F.2d 144 (2d Cir. 1984); American Acad. of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983).

[134] Child Abuse Prevention and Treatment Act Amendments, Pub. L. No. 98-457, 4 U.S.C.C.A.N. 2918 (1984).

such circumstances would be inhumane.[135]

In other words, a failure to provide lifesaving medical care does not constitute neglect if the infant is permanently unconscious, or clearly dying, or, in a recognition of medical uncertainty, almost certainly dying and also suffering because of the treatment itself. These limits on the definition of medical necessity, suitably adapted, could provide a legislative basis for limiting the level of care that citizens could demand, whether under the ADA, EMTALA, or any other law that requires citizens to furnish health care for one another.

The first adaptation would expand the scope of the definition to encompass all patients, not just infants. Second, it would extend beyond social service agencies. Particularly, such a measure would exempt both providers and payers from being coerced to continue medical care under the three conditions specified.

More specifically, providers—whether physicians, clinics, hospitals, nursing facilities, or others—would be free to refuse to provide heroic care under these conditions, though they would still be free to offer it if they wished. The important feature is that patients and families could not sue for malpractice, abandonment, wrongful death, or on any other grounds if providers refuse to extend exoticare under these specified conditions. Ordinary care to ensure the patient's comfort and dignity would still be owed, but aggressive measures to prolong life would not.

Likewise payers, whether insurers, HMOs, or self-insured businesses, would be free to stipulate that their policies do not fund heroic care under these conditions. This adaptation might actually be the most important of all. So long as payers continue to reimburse exoticare, families are easily enabled to demand it, and providers cannot easily refuse it. When the money is cut off, refusals are far easier. But again, this does not preclude any payer from offering coverage for extended life support, even under these extreme conditions. Indeed, one could easily envision a market arising for the sale of insurance-riders, or richer health plans, to fund exoticare. Just as "Medi-gap" policies are available for Medicare recipients to cover their out-of-pocket expenses, so might various religious groups, right-to-life groups, and others with similar values band together to purchase "exoticoverage."

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[135] Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878 (1985).

V. CONCLUSION

Disabilities laws mark an important step forward in society's recognition that all citizens are of value, and that all warrant respect and consideration. However, if we are to respect those who contribute as well as those who receive, and if we are also to help those whose less obvious needs compete with those who demand extraordinary help for extraordinary needs, we must draw limits. Such limits will undoubtedly seem harsh at times, because inevitably they will refuse help to some of those who ask for it.

But the alternative is worse. The unlimited care and cost posed by those who demand exoticare at common expense threatens to deplete society's good will right alongside its resources. Fortunately, a careful reading of existing law, combined with modest adaptations of other law, can reasonably ensure that fellow citizens with disabilities will be invited and helped to join the community, while assuring those who extend the hand that their efforts will be kept within the bounds of reason and respect.