

MEDICAL FUTILITY JUDGMENTS: DISCRIMINATING OR DISCRIMINATORY?†

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'It isn't fair, it isn't right,' Mrs. Hutchinson screamed, and then they were upon her.¹

INTRODUCTION

The need to make decisions about medically futile treatment challenges us in several ways.² First, it reveals that medicine's power over death is limited. That revelation threatens our faith in medicine, and erodes the authority that physicians wield because of the belief that they can "do something" about death.³ Second, it reveals that there are limits to what we as a society can do to prolong life and postpone death.⁴ We cannot extend anyone's or everyone's life indefinitely; nor can we afford to act as if we have the ability to do so. Because the demand for life-extending resources exceeds our capacity to provide them, these revelations boil down a simple, unpleasant truth: we must decide who is qualified to receive such resources—and who is not.

If we were honest, we would acknowledge that we have been making decisions of this sort ever since we acquired the capacity to

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¹ SHIRLEY JACKSON, *The Lottery*, in SHIRLEY JACKSON, *THE LOTTERY AND OTHER STORIES* 302 (1982).

² Giles R. Scofield, *Is Consent Useful When Resuscitation Isn't?*, 21 HASTINGS CENTER REP., Nov.-Dec. 1991, at 28, 28-35.

³ JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 207-29 (1984); Jay Katz, *Informed Consent: Must It Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL'Y 69, 87-91 (1994).

⁴ See generally DANIEL CALLAHAN, *SETTING LIMITS* (1987); HENRY J. AARON, *SERIOUS AND UNSTABLE CONDITION* (1991); HENRY J. AARON & WILLIAM B. SCHWARTZ, *THE PAINFUL PRESCRIPTION: RATIONING HOSPITAL CARE* (1984).

prolong life.⁵ That, however, would force us to acknowledge the tragic nature of the choices we are making—and the fact that we are making them.⁶ Tragic choices, simply put, are choices that we need, but do not want to make. We need to make them because we have no choice not to; we do not want to make them because they reveal a seemingly irreconcilable tension between fundamental values, i.e., beliefs that form the basis of social collaboration.⁷ We detest tragic choices because they force us to choose one value at the expense of another, a choice that we would prefer not to make if possible.

Where decisions about medically futile treatment are concerned, making these decisions openly and honestly would force us to acknowledge two seemingly unbearable truths: (1) that decisions about the distribution of some goods, in this instance the *non*-distribution of medical services, entails suffering and death;⁸ and (2) that such decisions are not and cannot be made in ways that are consistent with what it means to preserve life and protect liberty.⁹ Because we would prefer not to admit that we make these choices in ways that deviate from our fundamental values,¹⁰ we search for ways to deny the existence of this conflict, to conceal the nature of the choices we are making, and thereby to convince ourselves and others that this seemingly irreconcilable conflict has been harmoniously resolved.

The need to believe that we are the arbiters of fate, that physicians are not impotent in the face of death, and that we can make these decisions in ways that do not diminish our respect for the values of life and liberty prods us to transform this tragic choice into a decision that does not appear to contradict these fundamen-

⁵ The most obvious example of this fact is in the area of solid organ transplantation. In that arena we decide not only who is medically qualified for such services, but also who, among those who are medically qualified, is going to receive them. RENEE C. FOX & JUDITH P. SWAZEY, *SPARE PARTS* 74-83 (1992); RENEE C. FOX & JUDITH P. SWAZEY, *THE COURAGE TO FAIL* 226-65 (1978); George J. Annas, *The Prostitute, the Playboy, and the Poet: Rationing Schemes for Organ Transplantation*, 74 AM. J. PUB. HEALTH 187 (1985). For a discussion of how scarce resources are distributed among persons with disabilities, see SANDRA J. TANENBAUM, *ENGINEERING DISABILITY* (1986) (discussing the distribution of a prosthesis known as the "Boston Elbow"); Janet F. Haas, *Admission to Rehabilitation Centers: Selection of Patients*, 69 ARCHIVES PHYSICAL MED. & REHABILITATION 329 (1988); Baruch A. Brody, *Ethical Problems in the Placement of Patients*, 3 CURRENT CONCEPTS REHABILITATION MED. 17 (1986).

⁶ GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* 17-28 (1978).

⁷ *Id.* at 18.

⁸ *Id.*

⁹ GUIDO CALABRESI, *IDEALS, BELIEFS, ATTITUDES AND THE LAW* 87-114 (1985).

¹⁰ CALABRESI & BOBBITT, *supra* note 6, at 18.

tal beliefs.¹¹ The need to conceal the truth about this particular choice explains why so many commentators struggle to portray decisions about medically futile treatment as something other than what they are. Thus, we are asked to believe: (1) that futility decisions and rationing decisions are distinguishable,¹² (2) that the doctrine of informed consent does not give patients any legitimate interest of meaningful participation in such decisions,¹³ (3) that physicians can and should be trusted to make such decisions unilaterally,¹⁴ and (4) that denying physicians the right to make these judgments threatens the financial well-being of our health care system and the moral well-being of the physician-patient relationship.¹⁵

While much can and needs to be said in response to these arguments,¹⁶ I intend to address the seemingly limited question of

¹¹ *Id.* Such solutions are called "subterfuges," because they "cover the difficulty and thereby permit us to assert that we are cleaving to both beliefs in conflict." CALABRESI, *supra* note 9, at 88.

¹² Nancy S. Jecker & Lawrence J. Schneiderman, *Futility and Rationing*, 92 AM. J. MED. 189, 192-94 (1992); Howard Brody, *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRICS SOC'Y 875, 875-78 (1994).

¹³ Mark A. Hall, *Informed Consent to Rationing Decisions*, 71 MILBANK Q. 645, 663-64 (1993); J. Chris Hackler & F. Charles Hiller, *Family Consent to Orders Not to Resuscitate*, 264 J. AM. MED. ASS'N 1281, 1281-83 (1990); Stanley G. Schade & Hyman Muslin, *Do Not Resuscitate Decisions: Discussions With Patients*, 15 J. MED. ETHICS 186, 189-90 (1989); Kathy Faber-Langendoen, *Resuscitation of Patients with Metastatic Cancer: Is Transient Benefit Still Futile?*, 151 ARCHIVES INTERNAL MED. 235 (1991); Leslie J. Blackhall, *Must We Always Use CPR?*, 317 NEW ENG. J. MED. 1281, 1283-84 (1987); Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 J. AM. MED. ASS'N 1276, 1279-80 (1990).

¹⁴ See generally Frank J. Marsh & Allen Staver, *Physician Authority for Unilateral DNR Orders*, 12 J. LEGAL MED. 115 (1991); Lawrence J. Schneiderman, *The Futility Debate: Effective Versus Beneficial Intervention*, 42 J. AM. GERIATRICS SOC'Y 883 (1994); Lawrence J. Schneiderman, *Medical Futility and Aging: Ethical Implications*, GENERATIONS, Winter 1994, at 61.

¹⁵ Donald J. Murphy & Thomas E. Finucane, *New Do-Not-Resuscitate Policies: A First Step in Cost Control*, 153 ARCHIVES INTERNAL MED. 1641, 1641 (1993); Donald J. Murphy, *Can We Set Futile Care Policies? Institutional and Systemic Changes*, 42 J. AM. GERIATRICS SOC'Y 890, 890 (1994).

¹⁶ Even though the medical futility debate has been going on for several years, no one has yet come up with an acceptable and workable definition of the term. See, e.g., Robert D. Truog, Allan S. Brett & Joel Frader, *The Problem with Futility*, 326 NEW ENG. J. MED. 1560 (1992); Stuart J. Younger, *Who Defines Futility?*, 260 J. AM. MED. ASS'N 2094, 2094-95 (1988). One hospital was able to adopt a policy on medical futility only by not defining the term. John Z. Sadler & Thomas W. Mayo, *The Parkland Approach to Demands for "Futile" Treatment*, 5 H.E.C. F. 35 (1993). There is no reason to believe that physicians can or do make these decisions objectively, fairly, reliably, and accurately, or in ways that do not reflect bias, prejudice, or subjective considerations. Robert M. Wachter et al., *Decisions about Resuscitation: Inequities among Patients with Different Diseases but Similar Prognoses*, 148 ARCHIVES INTERNAL MED. 2193 (1988). Contrarily, there is considerable reason to be concerned that such decisions are made in a dis-

whether such judgments are discriminatory. The central issue here is whether these decisions discriminate against persons with disabilities,¹⁷ in that the individuals most obviously impacted by a decision to deny care are those whose existence depends on medical life support.¹⁸ Concern that decisions to limit treatment do not discriminate against persons with disabilities extends beyond decisions to limit treatment in individual cases,¹⁹ and embraces societal and governmental decisions to set limits generally to health care.²⁰

criminary manner. J. Randall Curtis et al., *Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders*, 273 J. AM. MED. ASS'N 124, 127-28 (1995). Moreover, the "savings" that are supposed to be generated by denying patients futile care are not as great as we have been led to believe. Joan M. Teno et al., *Prognosis-Based Futility Guidelines: Does Anyone Win?* 42 J. AM. GERIATRICS SOC'Y 1202, 1206 (1994). Finally, while we commonly create exceptions to the rule of informed consent when it is physically impossible to secure the patient's consent, e.g., in an emergency or when the patient is incompetent, nothing indicates that it is impossible for the patient or the patient's surrogate to participate in decisions about medically futile care. The fact that some of these discussions can be difficult and time-consuming, and that some patients may refuse to comply with a physician's judgment, does not justify creating an exception for medically futile treatment. While it is clear that some physicians do not want to have such conversations and believe that patients cannot and should be allowed to participate in them, a physician's preference not to talk does not warrant a policy of disenfranchising patients. Giles R. Scofield, *Medical Futility: Can We Talk?*, GENERATIONS, Winter 1994, at 66.

¹⁷ To be concerned about whether such decisions discriminate against persons with disabilities should also lead to an examination of whether similarly situated persons with disabilities are similarly treated. Thus, if we are concerned with not discriminating against persons with disabilities, are our concerns the same regardless of the person's age, race, or sex? See generally Nora K. Bell, *What Setting Limits May Mean? A Feminist Critique of Daniel Callahan's Setting Limits*, 4 HYPATIA 169 (1989). In other words, even if we do not discriminate against persons with disabilities, discriminating among persons with disabilities in ways that create or sustain prejudicial attitudes and beliefs based on the race, sex, or age of a person with a disability, should cause concern about how and why we are making these choices.

¹⁸ This is the central holding in the trial court opinion rendered in the Baby K case. *In re Baby K*, 832 F. Supp. 1022, 1027-29, *aff'd on other grounds*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). See James Bopp & Richard E. Coleson, *Baby K: Protected at Law*, TRENDS HEALTH CARE, L. & ETHICS, Winter 1994, at 7. Baby K's mother had been counseled about the option of aborting her fetus after prenatal testing revealed the nature of its condition. Interestingly, one of the concerns in the area of genetics counseling is that genetics counselors are conscious of the ways in which their beliefs about persons with disabilities can skew the advice they provide to prospective parents. INSTITUTE OF MEDICINE, ASSESSING GENETIC RISKS 54, 151-56 (1994). If we should be concerned about the ways in which attitudes and beliefs about persons with disabilities can affect decisions about their coming into existence, we should be as concerned about the ways in which such attitudes and beliefs can affect decisions about ending their existence.

¹⁹ Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1666-67 (1993).

²⁰ David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 J. AM. MED. ASS'N 308 (1994); Note, *The Oregon Health Care Proposal and the Americans with*

Of all the questions raised in the debate about medical futility judgments, the question of whether such decisions discriminate against persons with disabilities is the most challenging, because it is the most probing and revealing. It adds to an already tragic choice an additional value, another belief that we wish to maintain as we make these decisions. That belief is that we make these decisions in ways that do not discriminate against persons with disabilities, but that we make them in ways that adhere to what Martha Minow refers to as the "antidiscrimination principle."²¹

While it is fair to assume that each of us does, or should, agree with the view that persons with disabilities should not be discriminated against, it is just as fair to assume that we differ over what it means to discriminate against persons with disabilities. Put another way, even though we agree in principle that we should not make discriminatory decisions, we do not agree on what that means, or what it requires of us.²² To appreciate the nature of the problem, we need first to grasp its enormity.

Implicit in the notion that we should not make discriminatory judgments is the belief that we can divide human judgments into those which are discriminatory, and those which are not. Subsumed within the belief that we can divide human judgments into two such categories is the belief that we can know when we are making discriminatory judgments and when we are not. Taken together, this amounts to believing that we are capable of creating non-discriminatory standards of judgment, of applying them in a non-discriminatory manner—and of knowing when we are acting appropriately and when we are not. In essence, we are saying that we are capable of knowing when our standards for judging and our judgments themselves are and are not the product of bias and prejudice. That is a fairly daunting claim.

I doubt that we can define and hold the line that separates discriminating judgment from discriminatory judgment as ably as we believe we can. Part of my doubt arises from the fact that dis-

Disabilities Act, 106 HARV. L. REV. 1296 (1993); see also Philip G. Peters, Jr. *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491 (1995).

²¹ Essentially, this means that an individual's disability "should play no role in a medical treatment decision about a life-threatening condition independent of that [disability]." MARTHA MINOW, MAKING ALL THE DIFFERENCE 315 n.10 (1990).

²² As Professor Minow says of the antidiscrimination principle, "the meaning of this principle is precisely what is in doubt." *Id.* For an interesting discussion of what it might mean in the context of organ transplantation decisions, see Karen J. Merrikin & Thomas D. Overcast, *Patient Selection for Heart Transplantation: When is a Discriminating Choice Discrimination?*, 10 J. HEALTH POL., POL'Y & L. 7 (1985).

criminating judgment is as much an "art" as it is a "science."²³ Part of it reflects deeper doubts about the notion that we can devise objective, neutral standards for judging, and apply them objectively, accurately, reliably, fairly and impartially. There is little reason to believe that we always can know whether we are deciding appropriately, some reason to believe that we cannot know whether we are doing so, and considerable reason to believe that we act at considerable peril if we refuse to entertain doubt about the empirical or moral correctness of the standards we devise and the judgments we make.²⁴

Acknowledging the fallible nature of human judgment does not prevent us from exercising such judgment; on the contrary, awareness of the fallibility of human judgment is key to our exercising that judgment with the moral attentiveness we must bring to decisions such as these. If our goal is to devise something akin to "non-selective" choosing, that is a futile quest. If it is to convince ourselves that in choosing we do not choose, it is a dangerous one. While I appreciate the desire and need to make these decisions in ways that free us of the anxiety created by having to make them, I believe that we would be better served to remain attentive to the uncertainties and ambiguities of these choices than to conceal, dismiss, or ignore these aspects of human judgment.

I. IT CAN'T BE SO

First, we need to address the notion that decisions about medically futile treatment cannot discriminate against persons with disabilities. This notion arises, I suspect, for two reasons. First, if we conceded the possibility that such decisions might discriminate against persons with disabilities, that would seem to make setting limits to health care impossible. Simply put, if we could not deny a patient medically futile care without running the risk of violating the antidiscrimination principle, then we could not set limits to health care at all; or could do so only by acknowledging that we are violating an inviolable principle.

Second, if we conceded the possibility that decisions to limit treatment might reflect prejudice against persons with disabilities,

²³ As two commentators have observed, "True moral perception or 'discernment' lies in the ability to see how and when strictness is the better course, how and when the deeper wisdom lies in tolerance of exceptions; and that ability once again requires not an abstract grasp of theoretical relations but constructive reflection about the practical lessons of concrete experience." ALBERT R. JONSEN & STEPHEN TOULMIN, *THE ABUSE OF CASUISTRY* 329 (1988).

²⁴ ZYGMUNT BAUMAN, *MODERNITY AND THE HOLOCAUST* (1991).

this would cause consternation among those who have long advocated the unquestionable propriety of forgoing life-sustaining treatment. No one who adheres to the view that a decision to forgo life-sustaining treatment simply upholds a patient's liberty interest is likely to want to wonder whether such a decision might also reflect a bias against persons with disabilities. For reasons such as these, some of us may find ourselves wanting and needing to believe that decisions to limit treatment cannot be regarded as discriminatory. We are just as likely to see arguments being created to support the proposition that what cannot be so is not so.

In this regard, we need to remind ourselves of a basic truth about prejudice. For prejudice to continue, it must be rationalized in a way that prevents us and others from seeing it for the morally stigmatized idea and the morally repugnant practice that it is. The function of a rationalization, after all, is to "inoculate against insight."²⁵ Because the rationalizations used to deflect the claim that decisions about medically futile treatment discriminate against persons with disabilities only support the belief that such decisions *cannot* be discriminatory, we only need see that such decisions *might* be to acquire the insight needed to examine this issue further.

The Americans with Disabilities Act²⁶ (hereinafter ADA), was enacted due to the belief that persons with disabilities are discriminated against, out of the realization that people do hold prejudicial attitudes and beliefs about what it is or must be like to have a disability—to live "like that." A growing body of literature reveals something about the extent to which persons with disabilities are viewed by others with prejudice.²⁷ Assuming that persons with disabilities do encounter prejudice with respect to school, employment, and housing, is it reasonable to suppose that they *cannot* encounter prejudice in the health care setting? To believe that

²⁵ JOAN C. TRONTO, MORAL BOUNDARIES: A POLITICAL ARGUMENT FOR AN ETHIC OF CARE 74-75 (1993) (quoting W.D. BROWN, *Rationalization of Race Prejudice*, 43 J. INT'L. ETHICS 43 (1933)); see also GORDON W. ALLPORT, THE NATURE OF PREJUDICE 334-39 (1979) (discussing the role that repression and rationalization play in creating and sustaining prejudice).

²⁶ Americans with Disabilities Act of 1990. 42 U.S.C. §§ 12101-12213 (1991).

²⁷ See generally LEAH H. COHEN, TRAIN GO SORRY: INSIDE A DEAF WORLD (1994); CAROL PADDEN & TOM HUMPHRIES, DEAF IN AMERICA: VOICES FROM A CULTURE (1988); MICHELLE FINE & ADRIENNE ASCH, WOMEN WITH DISABILITIES: ESSAYS IN PSYCHOLOGY, CULTURE, AND POLITICS (1988); JOSEPH SCHNEIDER & PETER CONRAD, HAVING EPILEPSY: THE EXPERIENCE AND CONTROL OF ILLNESS (1983); HARLAN LANE, THE MASK OF BENEVOLENCE: DISABLING THE DEAF COMMUNITY (1993); JOSEPH SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993).

persons with disabilities cannot encounter prejudice in the health care setting assumes that members of society can compartmentalize their attitudes and beliefs toward persons with disabilities in a way that makes it impossible for such attitudes and beliefs to affect the delivery of health care services to and for persons with disabilities. To state this assumption is to reveal how improbable it is.

One need not ruminate about the possibilities here. There is evidence indicating that health care providers do hold unwarranted beliefs about persons with disabilities,²⁸ and that such beliefs do affect their recommendations with respect to life-sustaining treatment.²⁹ Thus, there is some reason to believe that attitudes and beliefs about persons with disabilities can and do affect decisions about the sort of treatment such persons are to receive, including decisions about medically futile treatment.³⁰

Given that prejudice can affect clinical decisionmaking in this area, we can make this issue a non-issue only if we take the position that the antidiscrimination principle applies to decisions about housing, employment, and schooling, but not to decisions about health care.³¹ There are two problems with this position. First, it amounts to saying that the law will countenance violations of a supposedly inviolable principle. Second, it forces us to reconcile those instances in which the individuals have been able to bring discrimination claims in the health care setting with those in which they have not been allowed to do so.

²⁸ See generally Lindsay Gething, *Judgments by Health Professionals of Personal Characteristics of People with a Visible Physical Disability*, 34 SOC. SCI. & MED. 809, 809 (1992); M. L. Paris, *Attitudes of Medical Students and Health Care Professionals Towards People with Disabilities*, 74 ARCHIVES PHYSICAL MED. & REHABILITATION 818, 818 (1993).

²⁹ Kenneth A. Gerhart et al., *Quality of Life following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS EMERGENCY MED. 807, 808 (1994).

³⁰ As was recently observed in the context of decisions about medically futile treatment:

On what basis do physicians judge that a patient's quality of life is unacceptable if they have not discussed the issue with the patient? [Some researchers] found that immobility was an independent predictor of qualitative futility. However, a patient whose mobility is severely limited may still value continued life. Many studies find that physicians underestimate the extent to which patients believe their lives are worth living. *Physicians who project their own values onto their judgments of what quality of life is not worth living may make inconsistent, arbitrary, and unfair decisions.*

Ann Alpers & Bernard Lo, *When is CPR Futile?*, 273 J. AM. MED. ASS'N 156, 157 (1995) (citations omitted) (emphasis added).

³¹ Indeed, one section of the ADA, 42 U.S.C. 12201 (c), seems to have done just that, since it exempts legitimate underwriting and administering practices in the area of health insurance. Interestingly, the act does not exempt underwriting or claims administering practices from the reach of the act if those practices constitute a "subterfuge."

Legislation enacted to protect persons with disabilities against discrimination has been invoked successfully in the health care setting. For example, a number of cases have held that health care providers may not deny services to persons with AIDS or the HIV infection, on the grounds that such a denial discriminates against persons with disabilities.³² In other instances, denying care to someone because of the nature of his or her disability also has been held improper.³³ If we accept the application of the antidiscrimination principle in these contexts, how can we reject its applicability in cases such as Baby K's?

The distinction seems to lie in whether the treatment in question is related to the disability that the person is suffering from. Thus, where the individual with AIDS or a positive HIV infection status seeks services related to an injured foot (as in *Miller*),³⁴ an ear infection (as in *Glanz*),³⁵ or dental maintenance (as in *Clausen*),³⁶ denying such an individual access to care because he or she has an infectious disease constitutes discrimination because: (1) the person is "otherwise qualified" for treatment, and (2) the only reason the person is denied this treatment is his or her disability. On the other hand, where the treatment in question is directly related to the person's disability, the logic seems to be that a decision to deny the patient treatment does not and cannot give rise to a claim of discrimination.

It takes little imagination to see how useless and pernicious a distinction this is. Consider the case of Baby K, and imagine that Baby K had suffered the breakage or dislocation of a limb, necessitating her hospitalization. Had the hospital refused to treat Baby K's limb on the grounds that she is an anencephalic, she would have had a claim similar to that recognized in the *Glanz*, *Miller*, and *Clausen* cases.³⁷ Instead, she appears for the treatment of a condition—breathing difficulty—that is directly related to her disability—anencephaly. Why is she any less deserving of treatment in the second instance? Why is the first issue an instance of discrimination, yet the second is not? Better stated, on what basis do we

³² *Miller v. Spicer*, 822 F. Supp. 158, 163-66 (D. Del. 1993); *Glanz v. Vernick*, 750 F. Supp. 39, 41-44 (D. Mass. 1990); *State v. Clausen*, 491 N.W.2d 662, 665-68 (Minn. Ct. App. 1992).

³³ *Lyons v. Grether*, 239 S.E.2d 103, 105-06 (Va. 1977) (blind patient who was refused treatment because she refused to remove her guide dog from the waiting room has a cause of action against her physician).

³⁴ *Miller*, 822 F. Supp. at 160.

³⁵ *Glanz*, 750 F. Supp. at 40.

³⁶ *Clausen*, 491 N.W. 2d at 663.

³⁷ See *supra* note 32.

conclude that a decision to deny Baby K the ventilator needed to support her continued existence is not and cannot be the product of prejudice toward persons with disabilities?

II. DISCRIMINATING AMONG? DISCRIMINATING AGAINST?

The difficulty lies in the nature of the antidiscrimination principle itself. If the antidiscrimination principle is supposed to mean that a person's disability "should play no role in a medical treatment decision about a life-threatening condition *independent* of that" disability,³⁸ this gives us no guidance when the medical treatment decision concerns a life-threatening condition that is not and cannot be independent of the disability. To the extent that laws such as the ADA are supposed to enable us to "see the person, and not the disability," they ask us to make a separation that is difficult, if not impossible, to make when the treatment in question concerns medical conditions directly related to the person's disability.³⁹ Our difficulty in knowing how to proceed is compounded, however, by another concern. If the denial of treatment in such instances could be regarded as discriminatory, that would seem to preclude our ever denying a person with a disability the treatment he or she needs to overcome the life-threatening contingencies of living with that disability. Not knowing how to proceed in such instances, and concerned about the possible implications of holding that any denial of disability-related treatment violates the antidiscrimination principle, the courts, understandably, have held that "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say . . . that a particular decision [to deny treatment] was 'discriminatory.'"⁴⁰

Given that we need to make these choices, and that we wish to make them in ways that do not violate the antidiscrimination principle, it is easy to formulate the question that decisions about medically futile treatment force upon us: can we discriminate *among* persons with disabilities (which we must do if we are to use resources prudently) without simultaneously discriminating *against* persons with disabilities (which we must not do if the antidiscrimination principle is to remain inviolate)?

We would like to think that we can do one without the other, but that turns out to be easier said than done. To understand the

³⁸ MINOW, *supra* note 21, at 315 n.10 (emphasis added).

³⁹ Crossley, *supra* note 19, at 1639-66.

⁴⁰ Johnson by Johnson v. Thompson, 971 F.2d 1487, 1494 (10th Cir. 1992) (citing United States v. University Hosp., 729 F.2d 144, 157 (2d Cir. 1984)).

nature of the difficulty, we need to appreciate just how uncertain these decisions are.

III. DECISIONS TO FORGO TREATMENT

When we make a decision to forgo life sustaining treatment, we are interested in knowing two things: (1) whether the patient wants treatment to stop, and (2) if so, when the patient wants treatment to stop.⁴¹ To the extent that courts, scholars and others have grappled with end-of-life decisionmaking, they have focused their attention on knowing *whether* a patient wants treatment to stop, and have largely ignored the equally important question of knowing *when* the patient wants treatment to stop. In so doing, they have created the illusion that there is greater certainty here than is, in fact, the case. Just how uncertain these decisions are becomes clear once we attempt to enter the world of persons with disabilities.⁴²

Because the case of the competent patient seems to present the noncontroversial case,⁴³ we will begin the discussion there. With the competent patient, we need to be concerned both about the potential for bias and prejudice in the test employed to assess the patient's competence, and about the ability and willingness of the person making this assessment to do so reliably, accurately, fairly, and objectively.⁴⁴ We also need to be concerned about how external constraints, such as the availability of financial support needed to make a technologically-dependent life seem worth living, may affect a patient's view of his or her prospects.⁴⁵ We cannot rule out the possibility that such factors may skew the

⁴¹ Sandra Segal Ikuta, *Dying at the Right Time: A Critical Legal Theory Approach to Timing-of-Death Issues*, 5 ISSUES L. & MED. 3, 4 (1989).

⁴² Giles R. Scofield, *Ethical Considerations in Rehabilitation Medicine*, 74 ARCHIVES PHYSICAL MED. REHAB. 341, 344 (1993); Rebecca Dresser & Peter J. Whitehouse, *The Incompetent Patient on the Slippery Slope*, 24 HASTINGS CENTER REP., Jul.-Aug. 1994, at 6, 8.

⁴³ See generally ROBERT F. WEIR, ABATING TREATMENT WITH CRITICALLY ILL PATIENTS 65-105 (1989).

⁴⁴ Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENG. J. MED. 1635 (1988); Loren Roth et al., *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCH. 279 (1977); Morris Freedman et al., *Assessment of Competency: The Role of Neurobehavioral Deficits*, 115 ANNALS INTERNAL MED. 203, 203 (1991); Lawrence J. Markson et al., *Physician Assessment of Patient Competence*, 42 J. AM. GERIATRICS SOC'Y 1074 (1994).

⁴⁵ McKay v. Bergstedt, 801 P.2d 617, 622-23 (Nev. 1990); Thor v. Superior Court, 21 Cal. Rptr. 2d 357 (Cal. 1993). These issues are discussed in Vicki Michel, *Suicide by Persons with Disabilities Disguised as the Refusal of Life-Sustaining Treatment*, 7 HEALTH ETHICS COMMITTEE F. (forthcoming 1995).

decisionmaking process in a way that prejudices the individual in question.

Interestingly, we also need to be certain that the patient knows and means what he or she is saying. One of the difficulties inherent in making decisions with disabled patients who have survived a catastrophic event is that they often cannot know what it is like to live with a disability. Their perceptions about what it might be like to live with a disability are likely to be shaped by others' perceptions and by the messages society sends about the value of a person with a disability, neither of which is necessarily accurate or unbiased.⁴⁶ This makes it difficult to know when it is appropriate to forgo treatment for a person with a chronic disability.⁴⁷ While it is not impossible to make such decisions, they are more uncertain than is commonly believed.

These uncertainties do not disappear when we work with incompetent patients. To the contrary, they become more pronounced. Insofar as our knowing whether the patient would want life-sustaining treatment to cease, matters are complicated by the problematic nature of surrogate decisionmaking.⁴⁸ For our purposes, it is enough to recognize that the degree of confidence in the belief that we are acting in accordance with the patient's wishes and values decreases the less we know about what those wishes and values are. The less we can say that we are acting in accordance with the patient's wishes and values, the more we need to be concerned that someone else's values are being imposed on the patient. At the very least, this should make us wonder whether those values reflect prejudicial attitudes and beliefs against persons with disabilities.⁴⁹

⁴⁶ David R. Patterson et al., *When Life Support is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia*, 328 NEW ENG. J. MED. 506, 508 (1993); Frederick M. Maynard & Andrew S. Muth, *The Choice to End Life as a Ventilator-dependent Quadriplegic*, 68 ARCHIVES PHYSICAL MED. & REHAB. 862, 864 (1987).

⁴⁷ As one physician has observed:

[w]e have programmed our spinal cord injured patients for a lifetime of medical intervention. A patient who did not seek medical treatment would risk being labeled self-destructive, noncompliant, etc. Frequently, patients find physicians and other health care professionals unwilling and unable to talk about the inevitability of death and how to deal with it. When is enough enough? When is it okay to let go of life?

Robert R. Menter, *Aging and Spinal Cord Injury: Implications for Existing Model Systems and Future Federal, State, and Local Health Care Policy*, in SPINAL CORD INJURY: THE MODEL 79-80 (David F. Apple & Lesley M. Hudson eds., 1990).

⁴⁸ See generally ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISIONMAKING* (1989).

⁴⁹ See generally Walter M. Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES L. MED. 131 (1985); Louise Harmon, *Falling Off the Vine: Legal Fictions and the*

Even if we could convince ourselves that we can and do know whether an incompetent would want treatment to stop, can we know *when* he or she would want it to cease? I do not see how we can. The basic difficulty we encounter is that we are trying to make a contemporaneous choice on behalf of someone who is not able to participate in the process contemporaneously. The problem here is obvious. If incompetent patients are to be protected against both a premature and an overdue death, how can we know whether we are providing such protection if we do not and cannot know when they would regard the timing of their death as premature or overdue? If we cannot know when they would want treatment to cease, how can we know that the decision we have made does not discriminate against them, i.e., cause them to die sooner because of the belief that no one would want to live "like that."⁵⁰

For reasons such as these, one criticism made of surrogate decisionmaking—that it may serve to perpetuate prejudice against persons with disabilities—should not be dismissed. We cannot rule out the possibility that such decisions might be discriminatory. If we acknowledge, however, that the decisions we make may discriminate against persons with disabilities, what are the implications? Does this mean that we are precluded from making such decisions altogether? If a decision to forgo treatment might be discriminatory, does that mean that a decision to treat is our only option? Is a decision to treat non-discriminatory?

Herein lies the difficulty. If we cannot know whether and when a patient would want treatment to cease, we also cannot know whether and when the patient would *not* want treatment to cease. The criticisms made of surrogate decisionmaking cut in two directions simultaneously. The criticisms render as uncertain the arguments of those who claim to "know" that the patient would say "yes" as they do the arguments of those who claim to "know" that the patient would say "no." Here again, even if we could know

Doctrine of Substituted Judgment, 100 YALE L.J. 1 (1990); LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 1594-1601 (1988).

⁵⁰ In a recent article, Professor Rebecca Dresser acknowledges that incompetent patients deserve protection from a premature and an overdue death, and further states that the law should "learn more about when death would be the most merciful option for these patients, when extended life would be beneficial for them, and when they themselves would be largely unaffected by the treatment outcome." Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 719 (1994). All of this assumes that we can know these things, and that there are some treatment decisions as to which incompetent patients are largely indifferent. I doubt that we can know any of these things, and doubt that any patient is indifferent as to when he or she dies.

whether the patient would want treatment to stop, no one can claim to know *when* the patient would want treatment to stop. If no one can know what only the patient knows, then anyone who purports to know when the patient would want treatment to stop can only be projecting his or her values and beliefs onto the patient.

This brings us to the next level of difficulty. If it is wrong to base a treatment decision on the belief that no one would, could, or should want to live "like that," it is just as wrong to base a treatment decision on the belief that no one would, could, or should *not* want to live like that. Neither approach respects the person with the disability for the person he or she is; and each enables others to project onto the patient their beliefs about whether living "like that" is appropriate or not. To believe that no one would not want to live "like that" is to assume that all persons with disabilities do, should, or must desire to live as long as is technologically possible. This can be non-discriminatory only if we can know that all persons with disabilities want to live that long (which we cannot), or if we believe that persons with disabilities should have no interest in avoiding a prolonged death (which merely substitutes one bias for another).

Simply put, one perspective asks us to believe that persons with disabilities do not care if they are wrongfully deprived of life, and the other that they do not care if they are wrongfully deprived of liberty. This may explain why persons with disabilities find reason to be attracted to and repelled by what "right-to-die" and "right-to-life" groups bring to end-of-life decisionmaking.⁵¹ Moreover, since no perspective can or does offer reliable guidance on one matter that is of vital importance, i.e., *when* the patient wants treatment to stop, no perspective can offer a definitive answer to what ought to be done in each situation.

At this point, one thing should be clear. Although we wish to respect the antidiscrimination principle, this principle does not give us clear guidance on what we ought to do concerning decisions to forgo life-sustaining treatment. One reason that the principle does not offer such guidance is that we cannot know what we must know in order to determine whether the patient is dying too

⁵¹ David Mathies, *Still Looking for Common Ground: The National Right-to-Life Committee and the Disability Rights Movement*, 14 DISABILITY RAG RESOURCE, Sept.-Oct. 1993, at 42; Marilyn Golden, *Do The Disability Rights and Right-to-Life Movements have Any Common Ground?*, 12 DISABILITY RAG RESOURCE, Sept.-Oct. 1991, at 1. My own experience suggests that persons with disabilities hold a wide range of opinions on this question, which should come as no surprise and should lead us to question anyone who purports to speak for what persons with disabilities want.

soon or too late. To understand the difficulties this presents in the context of medically futile care, we need to turn to the case of Baby K, and examine the "non-discriminatory" decision reached by the trial court.

IV. THE CASE OF BABY K

When faced with the claim that a decision to deny Baby K treatment might discriminate against her on account of her disability, the trial judge concluded that the way to avoid discrimination would be to treat her. While the decision to continue treating Baby K can be grounded in other considerations,⁵² we need to see whether the solution adopted by the trial judge can necessarily be regarded as "non-discriminatory."⁵³

The trial judge's opinion rested on two determinations. The first is that Baby K is "otherwise qualified" to receive ventilator support;⁵⁴ the second is that to deny Baby K such support would discriminate against a person with a disability on account of that disability.⁵⁵ Before analyzing the soundness of the court's conclusion, it is important to acknowledge that there is some merit in the concerns the court raised. As we have already seen, decisions not to render medically futile treatment to patients can reflect prejudicial attitudes toward persons with disabilities, captured in the sentiment that no one could or would want to live "like that." To the extent that such sentiments are cloaked in professional judgments about what physicians can and cannot do for patients, allowing physicians to determine who is "qualified" for treatment enables such attitudes and beliefs to go undetected and uncorrected.⁵⁶ Al-

⁵² Foremost among these would be the mother's desire to have treatment continue. Giles R. Scofield, *Talking about Baby K's Fate*, 9 TRENDS HEALTH CARE, L. & ETHICS 13 (Winter 1994). In stating a preference for family decisionmaking, I am not taking an unqualified stance. Given that there is some latitude of judgment here, I simply think we will experience greater benefits by placing our faith in the family in terms of decision making, rather than allowing such discretion to lie with either the state, the medical profession, or a medical institution.

⁵³ *In re Baby K*, 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993) *aff'd on other grounds*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

⁵⁴ *Id.* at 1027-28.

⁵⁵ *Id.* at 1028-29.

⁵⁶ For example, in an initiative undertaken in Denver, Colorado, it was suggested that a do-not-resuscitate order is automatically entered for patients who have been in a coma for more than 48 hours, on the belief that aggressive treatment for such patients is medically futile. See generally Donald J. Murphy & Thomas E. Finucane, *New Do-Not-Resuscitate Policies: A First Step in Cost Control*, 153 ARCHIVES INTERNAL MED. 1641 (1993). Recently, one of the subcommittees participating in this initiative decided that CPR should not automatically be withheld from such patients, presumably because it is unreasonable to believe that all patients who have been in a coma for more

lowing physicians to decide who is "otherwise qualified" assumes that they are capable of making such decisions in a non-discriminatory fashion, the very capacity for judgment that is in controversy.

The difficulty in the Baby K case lies not in the possibility that a decision to deny Baby K treatment discriminates against a person with a disability. Instead, the difficulty lies in both the solution reached to avoid the claim that Baby K was being discriminated against, and in discerning discriminating from discriminatory judgment. After first concluding that a decision not to treat Baby K would deny her a benefit on account of her disability, the judge concluded that the proper remedy must be to provide her the treatment that the hospital wished to deny her. The reasoning used and the conclusion reached by the judge do not withstand scrutiny.

In deciding that the effort to deny Baby K ventilator support discriminated against her as an individual and against similarly situated persons as a class, the judge held that "the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby *without disabilities* at the parent's request."⁵⁷ This highlights the problem inherent in deciding whether a decision to deny treatment for a condition related to the patient's disability is or is not discriminatory. To conclude that a decision to deny Baby K treatment discriminates against her on account of her disability, one must conclude that she was denied treatment that she would have received if she did not have her disability. However, if she did not have her disability, she would not have needed the treatment in question. That is, if she did not suffer from some form of respiratory distress requiring ventilator support, she would not need ventilator support. It makes no sense to say that she is being denied treatment that would be given to a baby without a disability. This is based on two reasons. First, for such a statement to be true, one has to imagine that the parents of babies without disabilities, i.e., babies who can breathe independently, are asking hospital personnel to place their children on ventilator support, which sounds unlikely. Second, one would have to believe that a decision by the hospital to deny ventilator support to a baby that is capable of breathing independently denies that person a benefit to

than 48 hours cannot recover. Donald J. Murphy & Elizabeth Barbour, *GUIDe (Guidelines for the Use of Intensive Care in Denver): A Community Effort to Define Futile and Inappropriate Care*, 2 NEW HORIZONS 326 (1994).

⁵⁷ *In re Baby K*, 832 F. Supp at 1029 (emphasis added).

which he or she was otherwise qualified, which is ridiculously incongruous. Where the treatment in question is related to the person's disability, the disability itself is what makes the person in need of, i.e., otherwise qualified for, the treatment.

Herein lies the problem. If the antidiscrimination principle requires us to make medical treatment decisions independent of the person's handicap, what are we to do when the treatment decision is necessitated by virtue of the patient's disability? In such an instance, it is impossible to separate the person with the disability from the disabling condition about which a treatment decision must be made. We are not talking about treating a person with AIDS for a foot injury; we are talking about providing ventilator support to someone who is incapable of breathing independently. In the context of individuals such as Baby K, to be otherwise qualified is to be medically qualified for, i.e., in need of, medical treatment.⁵⁸ To set limits to health care, we cannot provide it to everyone who is in need of it; yet to deny individuals in need of care the benefits of treatment is to deny them something for which they are otherwise qualified. Thus, the problem persists.

If we are faced with the circular decision of how to discriminate amongst such persons while at the same time not discriminate against them, we face an impossible task, since the rationing of health care has always required us to decide who does and who does not qualify for medical treatment.⁵⁹ What we seem to want is a way to make these decisions in a way that denies what we know will ultimately be the case: that some will be helped, others will be harmed, and that we cannot dispense scarce medical resources indiscriminately. In short, we wish to deny that the choices we are making are tragic choices. In this context, it is easy to see that denying an individual the possibility of an extended existence constitutes a harm, one that we would like to avoid. Is it necessarily the case, however, that a decision to treat avoids harming the patient?

If we cannot deny the possibility that a decision not to treat is discriminatory, i.e., the result of prejudicial attitudes toward persons with disabilities, can we say that a decision to treat is invariably non-discriminatory? I contend we cannot. In the first place, a decision to provide Baby K with ventilator support results in the denial of other advantages, in this instance, her hospice benefits. If

⁵⁸ This issue has been discussed recently. *Wagner V. Fair Acres Geriatric Ctr.*, No. 94-1275, 1995 WL 107387 (3rd Cir. Mar. 15, 1995).

⁵⁹ See *supra* note 5 and accompanying text for a discussion of the decisions involved in who qualifies for medical treatment.

the litmus test for determining discrimination against a person with a disability is whether such a person is being denied benefits for which he or she is otherwise qualified, then a decision to deny hospice benefits to a disabled, dying person constitutes discrimination. In the context of a patient with a life-threatening condition, one cannot confer one benefit without denying the other.

This means that one can avoid the charge of discrimination only if it is believed that persons with disabilities are never qualified for hospice benefits, or if one "knows" that this person would not consent to such benefits. Since we cannot know what Baby K's wishes would be, we are left only with the first possibility, which amounts to saying that persons with disabilities never qualify for a decent death. While I cannot speak for all persons with disabilities, I suspect that more than a few would find such a standard prejudicial. A wrongful deprivation of liberty is no less wrong than the wrongful deprivation of life.

Yet, how can it be prejudicial to believe that there is nothing wrong with living with a disability, but that it will invariably be regarded as a good thing? While it is common to think of prejudice as consisting of negative beliefs, it also consists of positive beliefs that are not based on actual knowledge or experience.⁶⁰ That aspect of prejudice explains why it is just as prejudicial to believe that no one would not want to live "like that" as it is to suppose that no one would want to live "like that". The key to understanding prejudice is seeing that it consists of the perception, favorable or unfavorable, toward a person, which is not based on actual experience or knowledge.⁶¹ The easiest way to see the difficulties created by indiscriminately endorsing the "positive" perspective of persons with disabilities is to follow this course of action to its logical conclusion.

It is widely held that decisions to withhold and to withdraw life-sustaining treatment are legally and ethically indistinguishable. This implies that no more warrant is needed to withdraw treatment than to withhold it; what makes it permissible to do the one makes it permissible to do the other. Arguably, what makes it impermissible to withdraw treatment also makes it impermissible to withhold treatment. If it is wrong to withdraw treatment out of concern that it perpetuates prejudicial beliefs about what it means to live "like that," then is it not also wrong to withhold treatment if doing so perpetuates such beliefs? If so, then under what circumstances

⁶⁰ GORDON W. ALLPORT, *THE NATURE OF PREJUDICE* 6 (1979).

⁶¹ *Id.*

may a competent person forgo cardio-pulmonary-cerebral resuscitation (CPR)?⁶²

A common result of CPR is an injury to the brain caused by anoxia or hypoxia, total or reduced oxygen flow to the brain.⁶³ This can leave patients with considerable cognitive deficits, or total cognitive deficits, such as in cases where the patient survives resuscitation to live in the persistent vegetative state. Should a competent patient be allowed to refuse CPR?

If we believe that an individual cannot make a truly informed choice about what it would be like to live as a person with a disability without first experiencing what it is like to live "like that," then arguably no one can make an informed decision to refuse CPR. After all, how can someone know what it is like to live with a brain injury until one has suffered a brain injury? If we allow someone to refuse CPR because of the wish not to survive resuscitation with a disability, are we not endorsing prejudicial beliefs about what it means to live "like that?" Indeed, if it is wrong to base a decision to forgo life-sustaining treatment on the belief that no one would want to be "like that," is it not just as wrong not to base such a decision on the belief that no one would want to *become* "like that?"

I use the example of CPR not to make a facetious point,⁶⁴ but to make some telling observations about discriminating judgment and persons with disabilities.⁶⁵ Where tragic choices are con-

⁶² Although it is common to refer to CPR as cardio-pulmonary resuscitation, it is inaccurate and misleading to do so. See generally PETER SAFAR & NICHOLAS G. BIRCHER, *CARDIOPULMONARY CEREBRAL RESUSCITATION* (1988). Because one of the most important aspects of CPR is cerebral resuscitation, i.e., restoring brain function following an episode of anoxia or hypoxia, not mentioning the role CPR plays in restoring brain function conceals this aspect of its use. See generally Paul C. Sorum, *Limiting Cardiopulmonary Resuscitation*, 57 ALB. L. REV. 617 (1994).

⁶³ See generally Risto O. Roine et al., *Neuropsychological Sequelae of Cardiac Arrest*, 269 J. AM. MED. ASS'N 237 (1993).

⁶⁴ In the first place, while there is some value in talking about the values and beliefs we hold concerning what it would be to live "like that," i.e., as a person with a disability, a basic truth is that no one chooses to suffer a catastrophic event. Thus, asking whether one would want to live "like that" may help illustrate our biases and prejudices, both favorable and unfavorable, about persons with disabilities. However, asking whether one would wish to be hurled from a car and into unconsciousness, or from a motorcycle and into high-quadruplegia, brings an equally relevant focus to our discussion. Is it wrong not to want to be in an accident?

⁶⁵ In this context, it is worth noting that the demand for rehabilitative services outstrips their supply, which means that rehabilitation hospitals routinely deny admission to some patients. Janet F. Haas, *Admission to Rehabilitation Centers: Selection of Patients*, 69 ARCHIVES PHYSICAL MED. REHAB. 329, 329 (1988). Despite the importance of cases such as *In re Baby K*, the attention they generate raises questions about whether those who find such cases fascinating are interested in identified, as opposed to unidentified lives. Although we must set limits, this does not mean that we should

cerned, simply following agreed to premises to their logical conclusion can lead to incongruous, even destructive results.⁶⁶ If our goal is to avoid making discriminatory judgments, we will fare no better by treating everyone indiscriminately than we will by not treating them indiscriminately. No single principle or value can answer this question for us, because the exercise of discriminating judgment is a human endeavor, one that cannot and should not be delegated to simplistic notions about what certain principles require us to do under the circumstances. Discriminating judgment is something we do. It is not something that can or should be done for us, no matter how uncomfortable we may feel about the choices we make or the need to make them. It is precisely because the antidiscrimination principle leaves us in doubt that we must proceed as confidently as we can under conditions of moral and empirical uncertainty.

Next, prejudice towards persons with disabilities differs from other forms of prejudice in one significant respect. Where matters of race and sex are concerned, the discrimination at issue is based on conditions of birth, and on categories that are largely immutable. While some persons are born with disabilities, anyone can acquire a disability during life. Indeed, many of us are likely to be disabled for some portion of our lives.⁶⁷ Thus, this is one area of life in which it is possible and probable for each of us to fall into the category of persons who are the victims of prejudice and discrimination. There is no "us" and "them," or "I" and "other" in this situation. As the disabled community believes, being able-bodied is a temporary existence. Once we see that persons with disabilities are not different persons with special needs, but that persons with disabilities represent needs in which each of us and all of us have an interest,⁶⁸ we will be able to see what lies at the core of this tragic choice: that in deciding about "them" we are deciding about ourselves. Just as we cannot deny that we are choosing, we cannot deny that we are choosing for and about ourselves.

be indifferent as to the impact this has on persons with disabilities. Likewise, it is absurd to suppose that the decision in the Baby K case represents a victory for persons with disabilities. While persons with disabilities are not interested in dying prematurely, just as they are not interested in dying "too late," they seem united in their interest to have access to the sort of care that will enable them to enjoy a meaningful life. To the extent that we allow our focus on what constitutes a "good death" for such persons to distract us from what constitutes a "good life" for them, we do a disservice.

⁶⁶ CALABRESI & BOBBITT, *supra* note 6, at 70.

⁶⁷ INSTITUTE OF MEDICINE, *DISABILITY IN AMERICA* (1991).

⁶⁸ Irving Kenneth Zola, *Toward the Necessary Universalizing of a Disability Policy*, 67 MILBANK Q. 401, 420-22 (1989).

V. WHAT OR HOW TO DECIDE?

I opened this paper with the closing lines of Shirley Jackson's chilling short story entitled *The Lottery*. This story captures the essence of our fear, namely that the way in which we choose who lives and who dies might be unfair and unjust—and that we might not see it as such. We are right to be concerned about this. The question we face is how best to address that concern.

Where end-of-life decisionmaking is concerned, it is doubtful that we will ever be able to make these decisions in ways that free us from any doubt about the manner in which we choose. It is probably better for us to make these decisions while understanding the perilous nature of the endeavor in which we are engaged than to attempt to make them as if there could be no doubt about the propriety of the choices we make.

Our problem is both simple and complex. Death does not discriminate, but we do. We discriminate in the sense that the choices we make affect how, where, and when we and others die. The moral question runs deeper than whether we can discriminate among persons with disabilities while at the same time not discriminate against them. It boils down to whether we can make decisions affecting everyone without adversely affecting anyone. Given that we must make these choices, and that they will adversely affect everyone (some more than others), the choice we face is whether we should pretend that we can and do make these decisions without violating inviolable principles. The choice we face, as in all tragic choices, is between honest or dishonest decisionmaking.

Instead of focusing solely on what choice we should make, we must focus our attention on *how* to decide, by choosing a decision-making process that will enable us to aspire to the values that make us the type of society we wish to be, and avoid becoming the sort of society we wish not to be.⁶⁹ To do that, we must acknowledge the possibility that we may be wrong and that we cannot know for certain whether we are right or wrong. The only way we can take our fallibility seriously is if we remain open to the possibility of error, which means that we must be highly attuned to the choices we are making, the fact that we are making them, and how and why we are

⁶⁹ "[I]t is in choosing that enduring societies preserve or destroy those values that suffering and necessity expose. In this way societies are defined, for it is by the values that are foregone no less than by those that are preserved at tremendous cost that we know a society's character." CALABRESI & BOBBITT, *supra* note 6, at 17. One such process is outlined in Alexander M. Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340, 364-76 (1974).

making them. The only way to do that is by deciding them openly and honestly. For it is only by being open and honest with ourselves and others about the choices we make, that we can make these decisions as we must, and not as we must not, even though they are choices that we do not wish to make.⁷⁰ As Jay Katz and Alexander Morgan Capron have observed:

One cannot, of course, ignore the possibility that the complex and hard choices, often involving life and death, which have to be made in the catastrophic disease process have in the long run a less devastating impact on the members of society and its institutions if they are arrived at by "low visibility" rather than "high visibility" decisionmaking. We have concluded that obscuring the bases for decision can only lead to fear and misunderstanding and, most important, to abuse, particularly of those groups within society who are traditionally the objects of neglect and mistreatment.⁷¹

The question we face is not whether we can bear making these decisions openly and honestly, but whether we can afford not to.

⁷⁰ "We want to live, but we cannot. We want [individuals] to be equal, but they are not. We want suffering to end, but it will not. Honesty permits us to know what is to be accepted and, accepting, to reclaim our humanity and struggle against indignity." *Id.* at 26.

⁷¹ JAY KATZ & ALEXANDER M. CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* 3 (1975).