Medical Decision-Making for Children: A Struggle for Autonomy

Erin A. Nealy

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I. INTRODUCTION

"I did it because I loved my son, all right?," the father shouted to reporters after he was arrested. 'I loved my son, all right? I love my wife.' These were the words spoken by 23-year-old Rudy Linares, moments after he kept hospital staffers at bay with a .357-caliber handgun while he tearfully removed his comatose son from life support and let him die. This incident, along with numerous others, vividly illustrates the controversy and resulting debate over when medicine can agonizingly postpone death rather than prolong and sustain life.

The sickness or loss of a loved one, though a common experience, is never easy. The situation is particularly poignant and difficult when a

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2. Id.
child is involved. Medical treatment for minors is often the most difficult of medical decision-making because "[f]alling as they do somewhere between adult humans and animals in terms of their capacities, but normally having from the moment of conception the potential to become adults, children constitute a category of living things unlike any other from the standpoint of the moral and conceptual problems that their treatment raises." Thus the task of deciding what limitations, if any, should be placed on the rights of children’s parents, health care providers, or government officials in making decisions about a child’s health care is both controversial and emotionally charged. Usually, all these interests converge, and medical treatment is provided accordingly. It is when these interests conflict, however, that complex legal and ethical issues arise, and the answers to solve these issues are never clear and never simple.

One recent example serves to illustrate the complex issues that arise when there are questions concerning what medical treatment is most appropriate and in the best interests of a sick child. This paradigmatic controversy involved a struggle between a mother and a hospital over an infant girl known as "Baby K." Baby K was born with a congenital condition known as anencephaly. Anencephaly is a defect in which the brain stem is present but the cerebral cortex is rudimentary or absent. There is no treatment that will cure, correct, or ameliorate this affliction. Since most anencephalic infants die within days of their birth, hospital medical personnel urged Ms. H, the baby’s biological mother, to permit a “Do-Not-Resuscitate Order” (DNR) for Baby K that would allow medical personnel to discontinue any mechanical ventilator treatment. This decision was based on the fact that no treatment existed for Baby K’s anencephalic condition, “[b]ecause agressive treatment would serve no therapeutic or palliative purpose” and “ventilator care was medically unnecessary and inappropriate.”

Despite this advice, Ms. H continued to request ventilator care for Baby K. In response to Ms. H’s request, the hospital consulted a three-person ethics committee, composed of a family practitioner, a psychiatrist, and a minister. The committee’s recommendation to the hospital was that the ventilator treatment should end because the care was “futile” and, if the mother refused to follow the advice, that the hospital should seek guidance on how to resolve the conflict through the appropri-

6. It is a standard procedure in most hospitals that a patient be given Cardiopulmonary Resuscitation (CPR) unless there is a written DNR order in the patient’s chart. The entry of a DNR order on a child’s medical chart is a prohibition against heroic and extraordinary efforts at resuscitation. *See generally* John M. Luce, *Ethical Principles in Critical Care*, 263 JAMA 696, 697 (1990).
7. *Baby K*, 16 F.3d at 592-93.
ate legal channels. When Ms. H subsequently rejected the committee’s recommendation, the hospital eventually moved to appoint a guardian ad litem to represent the best interests of Baby K.

Both the guardian ad litem, and Mr. K, Baby K’s biological father, shared the hospital’s position that ventilator treatment should be withheld from Baby K. The hospital then instigated an action for declaratory and injunctive relief in federal district court to allow it to refuse to provide the medical treatment that it deemed medically and ethically inappropriate. The unresolved issue was whether or not the hospital should be forced to provide, upon demand of the parents, medical treatment that it determined to be futile and medically inappropriate. Furthermore, the question remained whether Ms. H was really looking out for Baby K’s best interests, or whether a court-appointed guardian was a more objective proponent of Baby K’s interests.

This story, and others like it, presents the highly controverted issue of who ultimately makes the decisions for a severely ill infant or child. In such cases, medical personnel have come to the difficult decision that aggressive medical treatment for an infant or child is futile. The provision of care is characterized as medically, and in some instances ethically, inappropriate for the patient, yet a family member disagrees and continues to request the disputed treatment.

At this point the legal system is often called upon to resolve the controversy. The debate flourishes around the following questions: whether there is a point at which certain medical treatments are to be considered futile and whether standards can be articulated to determine such a point; whether federal laws permit courts to order health care personnel to provide medical care believed to be inappropriate and futile; whether the statutes implicated in such situations were intended to interfere with a physician’s medical judgment or ethical responsibilities; and finally, who is best able to make decisions regarding what treatment would be in the best interests of the child involved.

This comment addresses these questions. Part II explores the various models for conceptualizing the idea of futility and proposes a framework for a discussion of these decisions. Part III analyzes the applicable federal law that influences judicial decision-making in this area. Part IV discusses the struggle between the various decision-makers and the ethical and moral issues implicated by decisions of this sort. Part V concludes that medical professionals should ordinarily defer to the wishes of the parents in treatment decisions for minors; however, they should not be ordered by courts to provide medical care generally acknowledged by the

8. Id. at 593.
9. See infra notes 157-60 and accompanying text for a discussion on the resolution of the case by the Fourth Circuit, and its narrow holding based on an application of the Emergency Medical Treatment and Labor Act.
medical profession to be futile and medically, as well as ethically, unsound.

II. FRAMEWORK FOR FUTILITY DECISIONS

Futility is the term used when physicians seek to limit the lengths to which they must go to sustain the lives of patients, children or adults, who have lost the ability for conscious, interactive, and meaningful functioning. Thus, decisions regarding futility are steeped in moral and social dilemmas. The case of Baby K exemplifies the competing interests between the physician and the parents that form the bases of the controversy. It is certainly troubling to consider foregoing life-sustaining treatment for a severely ill child or adolescent. Society views young people as vulnerable and in need of protection from the harsh realities of life. In such situations, ending the life of children before it barely has begun seems tragic, unfair, and unnatural to the adults who must participate in this kind of decision-making.

The case of Baby K also reflects the ability of medical technology to prolong life in the absence of obvious benefit to seriously ill patients. While case law and living wills enunciate the right of the competent adult to make decisions concerning life-sustaining treatment, these lines become blurred when dealing with minors because of the need for surrogate decision-makers to act in the best interests of the child. Whoever the decision-maker may be, a general overview of futility is needed to understand the framework from which these difficult medical decisions are made.

A. FUTILITY DEFINED

Futility is not easily defined. One medical ethicist commenting on a futility case in the adult decision-making context described it as “care that does not accomplish its immediate purpose.” Many other commentators have suggested that treatment is medically futile whenever physicians, patients, or surrogate decision-makers deem that medical intervention (1) is useless or ineffective; (2) fails to offer a minimum


quality of life or modicum of medical benefit;\textsuperscript{15} (3) cannot possibly achieve the patient's goals;\textsuperscript{16} or (4) does not offer a reasonable chance of survival.\textsuperscript{17} At the very least, there is a point at which further treatment is medically useless. It is at this point that further treatment also becomes ethically problematic, and health care professionals ought not be coerced to provide treatment when such treatment affronts their sense of ethics.\textsuperscript{18} This point in the abstract has been described as a treatment that "merely preserves permanent unconsciousness or cannot end dependence on intensive medical care."\textsuperscript{19}

One obstacle that must be overcome is a determination of the type of action that should be taken once a physician determines that a treatment is futile. One suggestion has been to propose a policy that "would enable health care providers to make ethical but unilateral decisions regarding CPR [when CPR is deemed a futile treatment]."\textsuperscript{20} The argument is that, by acting unilaterally, "physicians would avoid causing unnecessary suffering for the patient, as well as an unfair burden of guilt for the family."\textsuperscript{21} Moreover, treatment decisions made by the family may be based on factors (e.g., fear of death or losing a loved one, or guilt over not visiting patients) that have little to do with what the patient desires or what is in the patient's best interest.\textsuperscript{22} The problem, however, with this argument is that it whittles away at patient autonomy, whether the decision is being made by a patient himself or through a surrogate decision-maker. It does this in favor of an exercise of strong paternalism on the part of the physician.\textsuperscript{23} The idea of unilateral futility decisions also places an emphasis on the broader social issue of proper allocation of our nation's resources.\textsuperscript{24} This idea implicitly assumes that society has an interest in limiting futile interventions in order to divert limited resources to more productive use within, or even outside, the health care system.\textsuperscript{25}

Futility has also been defined in terms of statistical probabilities such that "[a] given intervention could be judged futile if the chance of achiev-


\textsuperscript{17} George E. Taffet et al., \textit{In-hospital Cardiopulmonary Resuscitation}, 260 JAMA 2069, 2069-72 (1988) (cited in Nancy S. Jecker and Robert S. Pearlman, \textit{Medical Futility; Who Decides?}, 152 \textit{ARCHIVES INTERNAL MED.} 1140, 1144 n.15 (1992)).


\textsuperscript{20} Donald J. Murphy, \textit{Do-Not-Resuscitate Orders: Time For a Reappraisal of Long Term Care Institutions}, 260 JAMA 2098, 2098-2101 (1988).

\textsuperscript{21} \textit{See} Youngner, \textit{supra} note 14, at 2094.

\textsuperscript{22} \textit{Id}.

\textsuperscript{23} \textit{Id} at 2095.

\textsuperscript{24} \textit{Id}.

\textsuperscript{25} \textit{Id}.
ing one or more of the goals [determined by the physician and the pa-
tient] is not entirely absent, but is highly unlikely. But exactly how low
the probability of success must be is a question whose answer has not
been agreed upon. Statistics are often used as a way to define the outer
bounds of futility. Whether or not a one-percent chance of success or
even a five-percent chance of success is low enough to be characterized as
futile treatment is highly debatable. Certainly, considerations such as
the probability of recovery, quality of life, ameliorative effects of treat-
ment, and statistical probability of success are all taken into account, but
the question of how much weight each factor is given remains open. In
other words, "[w]hen is an outside chance a chance worth taking?"

Additionally, the definition of the desired goal effectively determines
the outcome: "[f]or one patient, a life with extreme disability and pain
might be quite tolerable; for another, it might be totally unacceptable." As
another example, if the goal of a medical treatment is to “accomplish
an immediate purpose,” then keeping a patient such as Baby K on a
ventilator meets the goal (i.e., the ventilator keeps the patient breathing).
On the other hand, if the goal is that the treatment must offer a reason-
able chance of survival, then the ventilator treatment is futile since
anencephaly entails no real prospect of successful treatment and no rea-
sonable chance of survival.

Still, there is one more important factor that reveals itself: the human
factor. Even when a course of treatment is deemed futile, living for five
more days might give some patients the opportunity to say good-byes, to
wait for a loved one to arrive from another city, or simply to come to
terms with the grief of losing a loved one. In this instance, otherwise
futile treatment may become a way to achieve reasonable and desirable
goals.

All in all, the completely unilateral plan of leaving the decision solely
in the hands of the physician is a regressive step. This is so because,
"under the guise of medical expertise and concern for proper resource
allocation, it encourages physicians to substitute their own value judg-
ments for those of their patients." In a sense, it urges physicians to cut
off communication with patients and families regarding the futility of
treatment. This intervention is complex, symbolistic, and unwelcome.

Despite the importance of patient autonomy, and the importance of
the right of patients and their surrogates to participate in the medical

26. Id.
27. Id.
28. Id.
29. Id.
30. Id.
31. See Belkin, supra note 13.
32. See Taffet, supra note 17.
33. Youngner, supra note 14, at 2095.
34. Id.
35. Id.
36. Id.
decision-making process, the question still remains as to how far this right of participation extends. The right of the patient directly conflicts with the ethical and medical obligations of the physician who feels that he is not obliged to provide medically inappropriate treatment. Ideally, a balance should be struck between the patient's interest in autonomy and the medical profession's interest in avoiding medically futile treatment.

B. ANOTHER WAY OF CONCEPTUALIZING FUTILITY

The issue is really whether the concept of futility should always be undervalued in favor of the idea of patient autonomy. The answer is: not necessarily. Perhaps this problem can partially be solved by developing a rigorous definition of futility, so as to encourage clarity of thinking with regard to the larger ethical problem of withholding or withdrawing medical treatment.

Moreover, the resistance to the notion of futility may be derived from the fear that futility will masquerade for less defensible motivations:

[W]ill its acceptance revive discarded abuses of medical paternalism? Will it reverse recent advances in patient autonomy and shared decision making? Will the power to declare treatment futile provide a convenient excuse for physicians to neglect patients they deem unworthy? Will it entice nervous health care providers to avoid patients with life-threatening contagious illnesses? Will futility serve as a devious rationale for reducing medical costs?

All of these concerns are valid, and perhaps a clearer understanding of the concept will properly serve to safeguard the true notion of futility from these potential corruptions.

37. Edmund D. Pellegrino, Ethics, 270 JAMA 202, 202 (1993). The basic right of participation was first asserted as a patients's right to refuse life-sustaining treatment. See In re Quinlan, 355 A.2d 647 (1976). This was extended to include the right of surrogates for incompetent patients to refuse life-support measures even if a physician deemed them medically necessary and ethically appropriate. The cases and scenarios considered here, In re Baby K, 16 F.3d 590 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994); Baby L (discussed in Paris et al., supra note 10); and In re Jane Doe, 418 S.E.2d 3 (Ga. 1992), are the mirror images of the first “right to die” cases. In such cases, the physician determines that medical treatment is medically inappropriate or futile, and the patient/surrogate insists on treatment. They differ from the “right to die” cases in which the physician determines medical treatment is appropriate and the patient/surrogate insists on non-treatment. Ironically, the awareness of the futility of a treatment might be used to support the rationality of a patient's autonomous refusal of treatment, with all the weight being given to the autonomy based on a rationalization of futility.

38. Schneiderman & Jecker, supra note 19, at 437-41. The authors suggest that the notion most often confused with futility is that of rationing. The former implies no apparent therapeutic benefit, while the latter acknowledges therapeutic benefit but raises questions about cost-worthiness. This confusion serves only to complicate and devalue the positive aspects of dealing with futility in a rational and reasonable method.

39. Id. at 437.

40. Id. An analogy can be drawn to the period of uncertainty inherent in the definition of brain death. After considerable debate and expert testimony within the medical, philosophical, and legal communities, the Uniform Brain Death Act was adopted in most states. See President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Defining Death (1981); Guidelines for the Determination of Death, 246 JAMA 2184, 2184-86 (1981) (Report of the
One approach to a better definition or clearer standard takes into account the historical and traditional goal of medical treatment, which is to achieve a benefit above a minimal quantitative or qualitative threshold.\(^{41}\) The quantitative threshold of futility focuses on the probability that a particular outcome can be achieved and involves a judgment that this probability falls below a threshold considered minimal.\(^{42}\) For example, if in the last 100 cases a certain treatment has been used and has failed, the requirement of falling below the quantitative threshold could be considered met.\(^{43}\) Authority to render a judgment about quantitative futility rests squarely with the physician.\(^{44}\) In order to determine the minimal threshold, "[a] decision about how to define futility should be made by a broad consensus among health professionals and others."\(^{45}\) Thus, once a community-based standard is in place, physicians can be responsible for determining whether their patients meet the pre-determined conditions.\(^{46}\) Such pre-determinations are not properly based on vague clinical impressions, but on statistical information regarding the outcomes of specific interventions for the different categories of patients.\(^{47}\) While these types of value judgments are never purely technical exercises because they are uncertain and open-ended, these judgments are inherent in medical choices and are integral to the role of the physician.

The second threshold of futility as determined by Schneiderman and Jecker is the qualitative threshold. Who decides whether the quality of life associated with a particular medical treatment is futile? This can be a balance of two perspectives. One view is that even where the potential quality of life is extremely poor, only patients or their appropriate surrogates should be able to authorize the withholding or withdrawal of medical treatment.\(^{48}\) The alternative viewpoint is that there is a position somewhere along the continuum at which the quality of life associated with such an intervention becomes so poor that the decision to withhold or withdraw treatment should no longer rest with the patient or surrogate.\(^{49}\) It becomes, instead, the physician's prerogative.\(^{50}\) A fair resolution of these two views may be achieved by negotiating a compromise that both physicians and patients can accept. Going through such a pro-

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Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research).

41. Schneiderman & Jecker, supra note 19, at 437.


44. Jecker & Pearlman, supra note 42, at 1140.

45. Id.

46. Id.

47. George E. Taffet et al., In-hospital Cardiopulmonary Resuscitation, 260 JAMA 2069, 2069-72 (1988).


50. Id.
cess in hopes of a resolution necessarily requires acknowledging community values and goals, as well as sharing a broad consensus of opinion that reflects these values. These rights should be determined by a process that takes into account our societal views of what is proper or necessary to protect a patient's best interests.

Therefore, an appropriate method of achieving this goal suggests that therapeutic futility be evolved within the present context of "standards of care." Just as empirical studies are always gathering data about treatments that provide significant clinical benefits, so too should attention be paid to treatments that demonstratively do not provide such benefits. Standards of care, therefore, can refer not only to the employment of useful treatments but also to the withholding of useless treatment. "Since such standards of care serve as guidelines to the court, physicians who decline to use futile treatments, even in the face of demands from patients and families, will be able to make those decisions with ethical and legal support."

III. FEDERAL STATUTORY LAW

An initial understanding of how medicine and law conceptualize futility is required for a discussion of the federal laws implicated when a conflict between parent and health care provider is brought before a court for resolution. The Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, the Child Abuse Amendments of 1984, and the Emergency Medical Treatment and Active Labor Act can all logically be implicated and discussed in the struggle for autonomy between a physician and parent.

A. THE REHABILITATION ACT OF 1973

The Rehabilitation Act of 1973 was the federal response to disputes between parents and the state for resolution of conflicts involving the appropriate medical treatment given to minor children. Section 504 of

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52. Id.
54. Schneiderman & Jecker, supra note 19, at 438.
55. Id.
60. 29 U.S.C §§ 701-797.
61. See Bill Lawton et al., Governmental Action Regarding the Treatment of Seriously Ill Newborns, 11 J.C. & U.L. 405 (1985). The Rehabilitation Act of 1973 was, however, ultimately unsuccessful in its attempt to limit a parent's right to withhold or withdraw necessary medical treatment, including nutrition, to severely handicapped infants through promulgation of the Baby Doe Regulations. In Bowen v. American Hosp. Ass'n, 476 U.S. 610 (1986), the Supreme Court invalidated the "Baby Doe" regulations largely because the regulations were beyond the scope of the statute. The Court held that "nothing in § 504 of
the Rehabilitation Act of 1973 prohibits discrimination against an "otherwise qualified" handicapped individual solely by reason of his or her handicap, under any program receiving federal financial assistance. The statute provides in pertinent part:

No otherwise qualified individual with handicaps . . . shall, solely by reason of his or her handicap, 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 . . . .

The courts have devised a four-part test for determining whether Section 504 has been violated:

[T]o state a claim under Section 504, a plaintiff must prove (1) that he is a 'handicapped individual' under the Act, (2) that he is 'otherwise qualified' for the [benefit] sought, (3) that he was [discriminated against] solely by reason of his handicap, and (4) that the program or activity receives federal financial assistance.

The issue is whether a hospital violates the Rehabilitation Act by refusing to provide an infant or child with the treatment requested by the parents. Looking to the plain wording of the statute, nothing suggests that Congress intended to interfere with a physician's ability to make medically appropriate decisions in individual cases. Rather, the Act only guarantees that the disabled will have "meaningful access" to employment, housing, health care, and other services.

Moreover, nothing in the legislative history of Section 504 suggests that Congress intended to authorize federal interference with a physician's medical judgment. To the contrary, the legislative history, as well as the statute's initial definition of "handicapped individual," indicates that Congress was truly concerned with discrimination against disabled individuals in the employment context. Although subsequent amendments clarified that Section 504 requires meaningful, non-discriminatory access for the disabled in other areas, including health care, nothing in the legislative history of its subsequent amendments indicates congressional in-

the Rehabilitation Act] authorizes [the Secretary of Health and Human Services] to commandeer state agencies to force compliance [with the "Baby Doe" regulations] by other recipients of federal funds (in this instance, hospitals)." Id. at 642. However, the opinion only ruled on the four Baby Doe Rules and failed to address the larger question of the role of the federal government in the treatment decisions of seriously ill infants and minors. See id. at 624. The four invalidated provisions required: (1) health care providers receiving federal funds to post notices advising that, under § 504, health care cannot legally be withheld from infants on the basis of mental or physical impairments; (2) state child protective services agencies to establish procedures to prevent unlawful medical neglect of handicapped infants; (3) immediate access to patient records; and (4) expedited compliance actions. 45 C.F.R. §§ 84.55(b)-(e) (1985).

63. Id. § 794(a).
64. Johnson v. Thompson, 971 F.2d 1487, 1499 (10th Cir. 1992) (internal quotation omitted), cert. denied, 113 S. Ct. 1255 (1993).
tention to override individual treatment decisions of physicians. Arguably, to the extent that Congress included health care within the ambit of Section 504, it did so only in the sense of requiring providers to make health services equally available to all persons who are able to meet a particular program's requirements in spite of their disability. This is a far different situation from the intrusion into individual medical decisions that would result if the statute were violated by a hospital's refusal to provide aggressive treatment requested by a parent that conflicts with the treatment determined by the hospital to be medically appropriate.

Moreover, several judicial decisions have addressed the issue of whether or not Section 504 applies to individual medical treatment decisions for handicapped minors. In American Academy of Pediatrics v. Heckler, the court noted that the "legislative history [of Section 504] focuses on discrimination against adults and older children, and denial of access to federal programs." The court also found that "no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of newborn infants or establish standards for preserving a particular quality of life." Similarly, two circuits that have addressed this issue have both held that infants with birth defects are not "otherwise qualified" within the meaning of Section 504, when the handicapping condition is related to the condition to be treated. In University Hospital, the court exhaustively analyzed the full legislative record of Section 504, including post-enactment Congressional hearings. It then concluded that Congress' "overriding concern" was with guaranteeing disabled individuals access to programs receiving federal assistance and that the legislative history contained no statements that suggested a broader application of the statute to individual medical decisions.

Additionally, the Second Circuit ruled that Section 504 of the Rehabilitation Act could not be meaningfully applied to medical treatment decisions involving newborn infants with birth defects. The court reasoned, in part, that the term "otherwise qualified" cannot be applied in the "fluid context" of medical treatment decisions without distorting the Rehabilitation Act's plain meaning. The court observed that where the handicapping condition is related to the condition to be treated, it will rarely, if ever, be possible to say that a particular medical decision is discriminatory. Moreover, the court determined that the legislative his-

68. Id. at 401.
69. Id. (emphasis added).
71. University Hosp., 729 F.2d at 157-60.
72. Id.
73. Id. at 156.
74. Id. at 157.
ory of the statute demonstrated that Congress “never contemplated that
Section 504 of the Rehabilitation Act would apply to treatment decisions
involving defective infants or young children when the statute was en-
acted in 1973, when it was amended in 1974, or at any subsequent time.”

More recently, the Tenth Circuit in Johnson observed that the “other-
wise qualified” language poses a formidable obstacle for anyone alleging
discrimination in violation of Section 504 based upon the failure to re-
ceive medical treatments for birth defects. In Johnson, the court was
asked to determine whether the district court had properly dismissed a
Section 504 complaint of discriminatory medical treatment relating to a
study of sixty-nine infants with varying degrees of spina bifida, a congeni-
tal defect that leaves “the spinal cord and membranes that envelop it
exposed.”

In affirming the dismissal of the Section 504 claim, the court adopted
the analysis of the Second Circuit in University Hospital. The court ob-
served that in the case of severely ill infants, if the infant were not so
physically handicapped, “he or she would not need the medical treatment
and thus would not ‘otherwise qualify’ for the treatment.” This line of
authority obviously must be utilized on a case-by-case basis, whether the
infant or child has severe birth defects, is irreversibly comatose, etc.

The counter-argument to this line of reasoning analogizes birth defects
and other severe illnesses to racial discrimination. This theory reasons
that, if the infant or child had some other medical condition along with,
for example, pulmonary distress, the patient would receive the ventilation
treatment. Thus, the sole reason for withholding the ventilator treat-
ment from the minor is the medical condition, demonstrating accordingly
that the minor is “otherwise qualified” for the ventilator treatment and
that the patient is being discriminated against on the basis of his or her
handicap.

The problem with this reasoning is that treatment decisions properly
relate to the condition being treated. In deciding how to respond to any
clinical situation, physicians correctly consider the risks, benefits, and
costs of treatment modalities. For example, in Glanz v. Vernick, the
plaintiff was refused ear surgery because he had AIDS. The plaintiff sur-
vived a summary judgment motion under Section 504 because the refusal
to treat might have been based on the handicapping condition (AIDS),
and accordingly might not have been a bona fide medical judgment.

75. Id. at 161.
76. Johnson, 971 F.2d at 1493.
77. University Hosp., 729 F.2d at 146.
78. Johnson, 971 F.2d at 1493.
79. Id.
80. See Judge Winter’s dissent in University Hosp., 729 F.2d at 162.
81. See, e.g., In re Baby K, 832 F.Supp. 1022 (E.D. Va. 1993) (finding that, but for Baby
K’s anencephaly, ventilator treatment would be available, and holding the hospital liable
under Section 504 of the Rehabilitation Act of 1973).
83. Id. at 638.
Similarly, a refusal to provide aggressive care to a severely ill child based upon race would not be a **bona fide** medical judgment. However, this analogy to race, when the treatment decision is closely related to the conditions being treated, as in the case of Baby K, is inapposite.

More specifically, if this interpretation of Section 504 were to prevail, no medical decision to withhold or terminate an available treatment would ever be permissible. Considerations of cost, relative benefit, or even futility—based on accumulated scientific and clinical knowledge about the patient's condition—could no longer be taken into account. It is hardly an exaggeration to say that, under this reading of Section 504, patients who are sick must be treated as if they were not sick, and patients who are dying must be treated as if they were not dying. Thus, the conclusion is that Section 504 does not in any way mandate a hospital to provide the medically futile treatment, even in the face of the parent's demands.

### B. The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) prohibits public accommodations from discriminating against individuals with disabilities. A “public accommodation” includes any “professional office of a health care provider, hospital, or other service establishment.” Thus, a hospital providing medical services to severely ill infants or children is a public accommodation for the purposes of the ADA.

Section 302(a) of the ADA sets forth a general rule of nondiscrimination against the disabled:

> No individual shall be discriminated against on the basis of a disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public ac-

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84. *See University Hosp.*, 729 F.2d. at 162 (Winter, J., dissenting) (“A judgment not to perform surgery . . . because a person is black is not a bona fide medical judgment.”).


86. Any decision to hold a hospital liable under the Rehabilitation Act when confronted with demands made by parents for what is believed to be medically futile treatment would ignore the guidelines published by the U.S. Department of Health and Human Services, written to assist the interpretation of Section 504 relating to health care for handicapped infants. For example, the guidelines clearly state that the withholding of medical treatment from an anencephalic infant does not violate Section 504: “Withholding of medical treatment for an infant born with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.” *45 C.F.R. pt. 84, app. C* (1994). Again, the presence or absence of parental consent does not enter into the analysis. In either case it is the action or inaction of the hospital and its doctors that may or may not implicate Section 504.


88. *Id.* § 301, 104 Stat. 353 (codified at 42 U.S.C. § 12181(7)).
commodation by any persons who owns, leases (or leases to), or operates a place of public accommodation. 89

Furthermore, section 302 of the ADA sets forth specific prohibitions against discrimination. 90 Of particular relevance here is that “[i]t shall be discriminatory to subject an individual or class of individuals on the basis of a disability . . . to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, . . . or accommodations of an entity.” 91 The argument in favor of liability is that the “plain language” of the ADA does not permit the discontinuance of services to an infant or minor when life-saving services would otherwise be provided or continued.

The flaw in this argument is concordant with the arguments in favor of liability under Section 504 of the Rehabilitation Act of 1973. Treatment decisions properly relate to the nature of the condition being treated. In deciding how to respond to a specific clinical situation, physicians consider the likely risks and benefits of different courses of action. A construction of the ADA that displaces bona fide medical decision-making altogether is at war with clinical medicine.

For a number of reasons the ADA is no more applicable than the Rehabilitation Act. First, the two statutes are similar in purpose—both are designed to prohibit certain entities from discriminating on the basis of a disability, most notably with respect to access to programs, services, and places. 92 Second, the definition of “disability” is identical in both laws. 93 Third, the two statutes cross-reference one another, including an express statement by the ADA that its standards shall be at least as strict as those applied under Title V of the Rehabilitation Act (the title containing Section 504). 94

Fourth, like the Rehabilitation Act, nothing in the language of the ADA or its legislative history suggests that the statute was intended to interfere with the reasonable medical judgments of treating physicians. To the contrary, the ADA prohibits the application of eligibility criteria that tend to screen out any class of individuals with disabilities “unless such criteria can be shown to be necessary for the provision of the goods, services, [and] facilities.” 95 When it is necessary to draw a distinction based on the disability because the distinction is critical to the service given, as in the case involving the provision of futile treatment, such distinctions are allowed.

89. Id. § 302 (codified at 42 U.S.C. § 12182(a)).
90. Id. (codified at 42 U.S.C. § 12182(b)(I)(A)).
91. Id. (codified at 42 U.S.C.A. § 12182(b)(I)(A)(i)).
92. See, e.g., Coleman v. Zatechka, 824 F. Supp. 1360 (D. Neb. 1993) (treating the ADA and the Rehabilitation Act essentially identically with respect to rights and remedies, but noting that the ADA is not limited to programs that receive financial assistance).
Moreover, the legislative history of the ADA clarifies that a patient’s disabilities may be considered when relevant to medical decision-making. A committee report of the House of Representatives states that “[n]othing in this legislation is intended to prohibit a physician from providing the most appropriate medical treatment in the physician’s judgment . . .”96 This statement could not be more clear. In cases involving treatment characterized as futile, the physician’s best judgment is that a particular treatment will have no therapeutic or palliative benefit. Therefore, the ADA should not be used to force such treatment.

The legislative history illustrates the main premise underlying the analysis. Congress noted that a physician who specializes in burn patients could not refuse to treat the burns of a deaf person because of the deafness.97 This is so because a person’s hearing status is unrelated to his or her burn conditions. On the other hand, Congress did not state that physicians are prohibited from providing different types of treatment where a patient’s disability is directly related to, or intertwined with, the medical condition being treated. As discussed above, judicial decisions have rejected a broad construction of the Rehabilitation Act and “the ADA expressly contemplates that the voluminous precedent arising out of Section 504 of the Rehabilitation Act may serve as guidance for determinations involving the ADA.”98 In short, a reasonable construction of the ADA is to permit physicians to make treatment decisions based on their best medical judgments, particularly when a consideration of the disability is necessary due to its proximity to the acute medical condition.

C. THE CHILD ABUSE AMENDMENTS OF 1984

Congress responded to the challenges to the Baby Doe regulations99 by enacting amendments to the Child Abuse and Treatment Act.100 These amendments specifically addressed the issue of withholding medically indicated treatment (including appropriate nutrition) from disabled infants and children with life-threatening conditions.101 In contrast to the Rehabilitation Act and the ADA, the Child Abuse Amendments do not create a federal cause of action, but rather employ a grant program to build on existing state mechanisms for dealing with child abuse and neglect.102


97. Id. at 160.


99. See supra note 61.


101. Id.

The amendments confirm the primary role of the states in the area of child protection. The continued qualification by states for certain federal grants is conditioned upon development and implementation of certain new procedures to respond to reports of medical neglect, including but not limited to the withholding of medically indicated treatments.\(^{103}\) To receive a grant for its child protection service ("CPS") system, a state must establish procedures for: (1) coordination and consultation with designated individuals; (2) prompt notification of cases of suspected medical neglect, including instances of withholding medically indicated treatment from disabled infants with life-threatening conditions; and (3) legal remedies, under state law, for the CPS agency to prevent the withholding of medically indicated treatment.\(^{104}\) The federal role is limited to (1) establishing a clearinghouse for information regarding developments in treatment and support services for disabled infants, and (2) promulgating regulations to ensure that states fulfill their obligations under the statute.\(^{105}\) Ostensibly, there is no authority for a court to interfere with the medical judgment of the hospital and its physicians under the Child Abuse Amendments. At most, the amendments authorize a state agency to examine the hospital's decision and file suit in state court on its own behalf.

Procedural and jurisdictional questions aside, the issue is whether or not the actions taken by a hospital and its physicians in refusing to offer medically futile treatment constitute "abuse" or "neglect" under the Child Abuse Amendments. The Amendments define "medical neglect" to include the "withholding of medically indicated treatment from disabled minors with life-threatening conditions."\(^{106}\) "Withholding medical treatment" is in turn defined to mean "the failure to respond to the [minor's] life-threatening conditions by providing treatment... which, in the treating physician's reasonable medical judgment, will most likely to be effective in ameliorating or correcting all such conditions..."\(^{107}\) When care is believed to be futile and ineffective in ameliorating or correcting the child's condition, then the behavior of the hospital and the physicians should not fall within the ambit of the statute's definition of "withholding treatment" or "medical neglect."

Moreover, the statute explicitly excludes from its definition of neglect the failure to provide treatment (other than appropriate nutrition, hydra-
tion, or medication) when, in the treating physician’s reasonable medical judgment:

(A) the child is chronically and irreversibly comatose;
(B) the provision of such treatment would (i) merely prolong dying; (ii) not be effective in ameliorating or correcting all of the child’s life-threatening conditions; or (iii) otherwise be futile in terms of survival of the infant; or
(C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.¹⁰⁸

The statute is clear that any one of the above elements will take the case out of the realm of medical neglect.

In sum, as was the case with the other federal statutes, the Child Abuse Amendments do not authorize the federal courts to intervene in individual medical decisions. Moreover, even if such intervention were authorized by the statute, failure to provide life-prolonging treatment in cases of futility would not constitute medical neglect under the definitions contained in the act.

The argument in favor of obtaining relief under the Amendments is that the physician’s judgment cannot displace the parent’s judgment. The Department of Health and Human Services (DHHS) has stated that the parents have authority under the Child Abuse Amendments to make treatment decisions for the child:

The decision to provide or withhold medically indicated treatment is, except in highly unusual circumstances, made by the parents or legal guardian . . . . This is the parents’ right and responsibility . . . . The parents’ role as decision maker must be respected and supported unless they choose a course of action inconsistent with applicable standards established by law.¹⁰⁹

A parent’s medical treatment decision would be inconsistent with the law only if it constituted child abuse or neglect, which was the harm sought to be prevented by this statute.

This assertion by DHHS is inconsistent with the fact that DHHS itself has recognized that deference to parental decisions applies only to decisions to “provide or withhold medically indicated treatment.”¹¹⁰ When there is no treatment that will cure, correct, or ameliorate the illness, as in cases where treatment is considered futile, then the only issue is whether or not the requested treatment is “medically indicated.” When the standard of care for treating various illnesses in the United States is to provide only supportive care, and not to provide aggressive care, including ventilation, then that should be the only treatment “medically indicated.”

¹⁰⁸. Id.
¹¹⁰. Id. (emphasis added).
D. THE EMERGENCY MEDICAL TREATMENT AND LABOR ACT

In enacting the Emergency Medical Treatment and Labor Act (EMTALA), Congress sought to address the growing problem of private hospitals inappropriately refusing to provide emergency care to indigent or uninsured patients. Consequently, EMTALA requires that all hospitals, as a condition to participating in Medicare, provide (1) "an appropriate medical screening examination" for patients at the emergency department to determine whether they have an "emergency medical condition;" and (2) "necessary stabilizing treatment" for individuals in such an emergency state. An "emergency medical condition" is defined in the statute as "[a]cute symptoms of sufficient severity . . . such that the absence of immediate medical attention could reasonably be expected to result in . . . serious impairment to bodily functions, or serious dysfunction of any bodily organ or part." A "stabilizing" medical treatment is defined as "such medical treatment of the condition . . . necessary to assure, within reasonable medical probability, that no material deterioration of the condition" will result.

In cases such as Baby K, where continued treatment is determined to be futile, the emergency situation involves mechanical ventilation. For example, a child or infant may be brought to the emergency room suffering from respiratory distress; perhaps, the hospital staff is asking for a Do-Not-Resuscitate Order. When such instances arise, the hospital must look at the situation presented to determine whether it falls within the plain language of the statute. Arguably, respiratory distress would constitute an "emergency medical condition" under the statute. In addition, EMTALA's legislative history includes a position paper by the American College of Emergency Physicians stating that "stabilization" should include "[e]stablishing and assuring an adequate airway and adequate ventilation."

The "plain language" argument is susceptible, however, to a variety of alternative constructions that are compatible with a proper understanding of the Congressional purpose and intent of protecting indigent patients in need of emergency care. A child's ongoing treatment may not trigger any EMTALA duties at all. The infant or child is a patient whose condition is well known to the hospital. Because the relationship with the hos-

113. 42 U.S.C. §§ 1395dd(a),(b).
114. Id. § 1395dd(e)(1)(A).
115. Id. § 1395dd(e)(3)(A).
116. See In re Baby K, 16 F.3d 590 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994), discussed at supra notes 5-10 and accompanying text.
117. See supra note 113 and accompanying text.
hospital is ongoing and the problems are previously anticipated, the child or infant cannot be said to be an individual who comes to the hospital for whom a determination of her condition must be made. When the minor’s treatment involves the continuing treatment of a patient already under the hospital’s care, EMTALA should not be implicated.

Moreover, while the plain language construction focuses on the duty to stabilize, the term “stabilize” is inherently ambiguous. EMTALA’s own definition of the term asks whether treatment and release is “reasonable under the circumstances.” To the extent that there is a duty under EMTALA to stabilize in cases where such treatment is characterized as futile and inappropriate, the nature and scope of that duty must be construed in light of what is reasonable under the circumstances. If what is reasonable is to provide only supportive care, and this reasonableness determination is consistent with the standard of care, then the hospital should not be under any additional duty according to EMTALA.

In contrast, one may argue that by denying these minors needed emergency medical care requested by the minor’s parents, a court would be carving out a futility exception in EMTALA that does not exist and was never contemplated by the framers of the legislation. The statute’s purpose is to “provide an adequate first response to a medical crisis for all patients and send a clear signal to the hospital... community that all Americans, regardless of wealth or status, should know that a hospital will provide what services it can when they are truly in physical distress.” Applied to the respiratory distress example, a child’s respiratory distress would constitute a medical crisis and ventilation would provide an adequate response.

Upon closer examination, however, the EMTALA has a limited legislative purpose—to avoid patient dumping and to prevent disparate care, which is defined as inconsistent applications of a hospital’s own standard of care. This reading necessitates that, in order to achieve the purposes of the Act, EMTALA accept the standard of care that is within the hospital’s capabilities and is applied generally by the hospital. Thus, both the standard of care within the hospital and within the profession must be recognized and applied in any determination of liability under EMTALA. Because EMTALA itself does not establish the standard of care, the standard of care is governed by what a reasonably prudent practitioner would do under similar circumstances.

120. See 42 U.S.C. § 1395dd(b)(1).
123. Baber v. Hospital Corp. of Am., 977 F.2d 872, 880 (4th Cir. 1992) (internal citation omitted).
124. Id. at 880-81; Brooks, 996 F.2d at 713.
125. Id.
126. Id.
A decision not to provide aggressive treatment could very well be deemed reasonable where no medical course of treatment, not even aggressive measures, would improve the infant's or child's condition, lead to any conscious brain activity, or significantly extend the infant's or child's life. Additionally, nowhere in the statutory language of EMTALA itself or in its legislative history is a physician required to provide medically inappropriate treatment to patients in a hospital emergency department in order to stabilize their condition. In fact, the legislative history specifically notes that EMTALA was not intended to interfere with a physician's medical judgment. Senator Hatch chaired the Senate Committee on Labor and Human Resources when Congress passed the EMTALA in 1985. Chairman Hatch conclusively noted in a description of the EMTALA in the Senate Committee's report to Congress that "[t]he bill . . . does not interfere with the practice of medicine." 128

IV. WHO DECIDES AND HOW?

A. PARENTS AS PRIMARY MEDICAL DECISION MAKERS

FOR CHILDREN

Seventy years ago, the Supreme Court established that parents have a constitutionally protected right to "bring up children." This right is derived from the Due Process Clause of the Fourteenth Amendment. Furthermore, parents have the "primary role" in the "upbringing of their children." The Supreme Court established that decisions for children can be based on the parents' free exercise of religion and are protected by the First Amendment. Thus, for example, the state cannot compel a parent to send her child to public school rather than parochial school. 133

127. Enforcement mechanisms such as criminal and financial penalties were discussed in the context of assuring medically reasonable care in the emergency room: The Judiciary Committee shares the concern of the Ways and Means Committee that appropriate emergency room care be provided to patients faced with medical emergencies . . . . The Committee . . . has recommended a provision . . . which would provide that a $25,000 fine may be imposed on a physician, as well as a hospital, who fails to properly respond to the genuine medical needs of individuals who come to emergency rooms. H.R. Rep. No. 241, 99th Cong., 1st Sess., pt. 3, 6, 7, reprinted in 1986 U.S.C.C.A.N. 579, 726 (emphasis added).

Because of the difficulty in defining appropriate medical practice at a given time, Congress deleted from the final text of EMTALA sanctions against physicians who fail to provide treatment to stabilize the patient, even if the failure represents a gross deviation from the local standards of medical practice, or provide for treatment in a manner that is so inappropriate as to represent a gross deviation from prevailing standards of local medical practice. Id.


132. Id.
133. Pierce, 268 U.S. at 534.
Similarly, the state cannot compel Amish parents, over their religious objections, to send their children to formal high school; this would be an unconstitutional violation of the parents' rights under both the First and Fourteenth Amendments.\textsuperscript{134}

Arguably, these constitutional principles extend to the right of parents to make medical treatment decisions for their minor children. The Supreme Court has established that, "absent a finding of neglect or abuse, . . . [parents] retain plenary authority to seek such care for their children."\textsuperscript{135} It is also recognized that "the traditional presumption [is] that parents act in the best interests of their child,"\textsuperscript{136} reasoning that this is due to the "natural bonds of affection [that the parents have for their children]."\textsuperscript{137} In nearly all cases parents can be trusted to seek out and decide on medical treatment for their children.

In every instance, the patient's interests are paramount; however, the presumption is that the family is the best source for determining and protecting the patient's best interests. In the case of the pediatric patient, the priorities for treatment should first be set by the parents and then by other surrogates. The interests of infants or children are necessarily embedded within the interest of the family. The unique interdependence between the child and the family justifies the family's participation in treatment related decisions. Within the family unit, there is a strong presumption in favor of the parents as primary decision-makers for their children.\textsuperscript{138}

B. Conflicting Views Deserve Consideration

Parents do not have an absolute right to make medical decisions for their children.\textsuperscript{139} In fact, a state may under some circumstances override parental judgment in order to protect the welfare of the child.\textsuperscript{140} This being the case, the parents are not the only adults authorized by law to express a view of an ill child's interests. Significantly, when a court appoints a guardian ad litem,\textsuperscript{141} the state recognizes the possibility that a parent, however well-intended, may not be the best source for determining and protecting the child's best interests.\textsuperscript{142}

\textsuperscript{134} Yoder, 406 U.S. at 234.
\textsuperscript{135} Parham v. J.R., 442 U.S 584, 604 (1979). The Court does note, however, that such authority is "subject to a physician's independent examination and medical judgment." \textit{Id.}
\textsuperscript{136} Id.
\textsuperscript{137} Id. at 602.
\textsuperscript{138} Task Force on Ethics of the Society of Critical Care in Medicine, \textit{Consensus Report on the Ethics of Forgoing Life-Sustaining Treatments in the Critically Ill}, 18 \textit{CRITICAL CARE MED.} 1435, 1438 (1990) [hereinafter \textit{Report}].
\textsuperscript{139} Parham, 442 U.S. at 584; Prince v. Commonwealth, 321 U.S. 158 (1944); \textit{In re Cicero}, 421 N.Y.S.2d 965 (Sup. Ct. 1979).
\textsuperscript{140} \textit{In re Minor}, 393 N.E.2d 836, 843 (Mass. 1979).
\textsuperscript{141} \textit{See In re Baby K}, 16 F.3d. 590 (4th Cir.), \textit{cert. denied}, 115 S. Ct. 91 (1994); Paris et al., \textit{supra} note 10 (appointing guardians ad litem).
\textsuperscript{142} \textit{Report}, \textit{supra} note 138, at 1438.
C. Multiple Roles in the Treatment of Severely Ill Children

When an infant or child is close to death, medical professionals should provide the following assistance: First, they should help to educate the family or other surrogates as decision-makers by explaining the infant's condition, prognosis, and treatment options. A major portion of the professional's usefulness to the family lies in her or his ability to place treatment options in the context of achievable goals for the infant or child. For example, the Society of Critical Care Medicine guidelines note that "[a]ny treatment derives its medical justification from the benefits that the informed patient [or parent] and the physician hope to achieve by employing it. When the treatment has achieved those benefits, or can no longer reasonably be expected to do so, the treatment loses its justification and may be withdrawn.”143 Where a severely ill child is dying (specifically, a child in a persistent vegetative state or an anencephalic infant), the health care team members should make every effort to assist the family of such a patient to appreciate the medical futility of continued intensive care unit treatment and to understand the rationale for transfer to another level of care.144

Second, medical professionals should address misunderstandings and disagreements about the patient's care—both among family members and other surrogates and between families and caregivers. This communication function between the health care provider and the family is most important, and there is certainly a need to explain the futility of certain treatment options. When a patient or surrogate requests a treatment the physician considers inappropriate, physicians are urged to help the surrogate reassess the goals of the therapy.145 If caregivers and family disagree, health providers are counseled to work with patients to arrive at a "mutually satisfactory course of therapy."146

Finally, medical professionals should treat the patient. Whatever treatment is selected, by whatever process, these professionals are intimately involved with the care of critically ill patients. Every effort should be made to determine the wishes of the patient, including patients who are children.147 When patients are not able to express their wishes, family

143. Id. at 1435.
144. Id. at 1437.
145. Id. at 1438.
146. Id. The Child Abuse Amendments require the Department of Health and Human Services to promulgate guidelines that encourage hospitals to establish infant care review committees (ICRCs) to address the withholding of medically indicated treatment from disabled infants and children with life-threatening conditions. See 42 U.S.C. §§ 5101-5115 (1988 & Supp. V 1993). These ICRCs serve in an advisory capacity to the health care provider by educating hospital personnel and families of disabled children with life-threatening conditions, by recommending institutional policies and guidelines concerning the withholding of medically indicated treatment from the infant or child, and by offering counseling and review of cases involving conflicts between the parents and health care providers. See 45 C.F.R. pt. 1340 (1985) for DHHS model guidelines and analysis.
members or other surrogates are to be consulted as to the wishes of the patients or the patients' presumed interests. Most ethical guidelines for health care providers exhibit a real concern for the needs of the family. In particular, "providers are obligated to provide comfort and support to the patient's family throughout the entire process of decision-making and thereafter." The heart of the controversy is not whether to treat the patient, but how. The decision to end, or not to begin, aggressive medical treatment should never be confused with abandoning the patient.

D. Ethical Issues Arising from Forced Treatment

As is evident from the preceding discussion, health care providers should first be counselors and do their utmost to bring parents and families to an understanding of the sick child's medical status and treatment possibilities. Second, they should cooperate as far as possible with patients' and families' preferences. Unfortunately, those goals cannot always be achieved. The regrettable eventuality is that the parent rejects the explanations of medical providers as to the child's condition and advisable mode of treatment, while at the same time the medical and ethical conclusions of the providers prohibit them from acceding to the parent's wishes.

Medical decision-making is a collaborative process in which the physician explains reasonable alternatives to the patients and often expresses a preference among them. The patient decides whether to select that therapy, another therapy named by the physician, or no therapy at all. The patient may seek another physician but may not, within the boundaries of medicine as it is normally practiced, force a physician to undertake treatment that the physician does not think would benefit the patient.

The general principles noted above are relevant whether the patient is an infant or an adult. Parents believe that they speak for the child, and the law recognizes and validates that belief in almost all instances. Still, nothing can completely obviate the necessity for the physician to exercise independent judgment if parents demand intervention that is clearly unwarranted. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research addressed this difficult issue and concluded in relevant part: "Therapies expected to be futile for a seriously ill newborn need not be provided;

148. Id.
149. Id. at 1439.
150. Id. at 1437.
151. Moreover, if a physician or hospital concludes that a parent's decision to withhold treatment is unjustified, the provider may (or, in some cases, must) seek judicial intervention. See, e.g., the Child Abuse Amendments of 1984, 42 U.S.C. § 5106a(b)(10) (1988 & Supp. V 1993) (requiring states to have procedures to take action where indicated medical care is withheld).
152. See supra notes 129-138 and accompanying text.
parents, health care professionals and institutions, and reimbursement sources, however, should ensure the infant's comfort.153

An article recently published in a leading medical journal reiterates these principles:

If after the physician has listened to the concern of the family members and explored the possibilities with them—including the transfer of the patient to a willing physician—the family persists in its demands for continued life-prolonging treatment that the physician believes to be beyond well established medical criteria, the physician ought not feel obliged to provide it . . . . This is done not because the patient no longer has any values or because the physician lacks respect for the family's wishes. It is done because the obligation of physicians, as articulated in the Hippocratic Oath, is to act for the benefit of the patient according to their ability and judgment.154

This passage serves to emphasize the ethical and moral dilemma that faces doctors when making futility decisions. The dilemma goes to the very heart of his profession.

The legal and political communities have also embraced the notion that physicians cannot be forced to act against the best interests of their patients. Thus, for example, a Massachusetts court held that a hospital and its staff "should not be compelled . . . to withhold food and water contrary to [their] moral and ethical principles, when such principles are recognized and accepted within a significant segment of the medical profession and the hospital community."155 Moreover, the President's Commission Report stated that while "health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment . . . in doing so they may not abandon a patient."156

V. CONCLUSION

As for Baby K, the end result leads us only to contemplate the future conflicts in this area, and anxiously to anticipate a response from society through state legislatures and Congress. In Baby K, the district court found for the mother, and held that the Rehabilitation Act of 1973, the ADA, and the EMTALA prohibited the hospital from denying treatment to Baby K.157 Furthermore, the court held that the presumption under both common law and constitutional law is that Ms. H was the appropriate decision-maker for Baby K.158 Therefore, the court concluded that

156. Paris et al., supra note 154, at 356.
158. Id. at 1030.
absent a finding of neglect or abuse, parents retain plenary authority to seek medical care for their children.\textsuperscript{159} The court's sweeping ruling mandated the hospital to continue to provide treatment to Baby K.

The issues arose again on appeal to the Fourth Circuit, which was asked to decide whether the district court had drastically misinterpreted Congress' intent under the federal statutes. However, the appellate court offered little help, since it held for the mother based solely on the EMTALA and declined even to discuss the other statutes.\textsuperscript{160} While the EMTALA is certainly the most difficult argument to make in favor of the doctors and hospital, the holding of the court leaves us with an answer for only a very narrow situation. It does not answer the broader question of whether physicians can be forced, in situations that do not implicate the EMTALA, to administer treatment that is deemed medically inappropriate and futile. It also sheds no light on how these types of decisions concerning futility will be dealt with in the future and where the physician's autonomy fits in with the right of parents to make decisions regarding the health care of their children.

Such is the case whereby prevailing standards of medical ethics accord patients the right to accept or reject the treatment recommended by their physicians. In the case of children, this right generally may be exercised by their parents, whom the law rightly presumes to be acting in the child's best interests. This presumption, however, must be balanced with the interest of the doctors and hospital administering the care. Medical ethics do not permit patients to require a physician to render treatment that, in the physician's judgment, would be futile or otherwise medically inappropriate. It is ethical for a physician to refuse to accede to such a demand—be it from a patient on his own behalf or from a parent on behalf of a child. This may even be true if the parent would derive psychological comfort from the futile treatment, where the treatment is determined to be futile according to the prevailing standard of care within the medical profession. In other words, the treatment is not simply one doctor's subjective opinion, but a consensus of medical opinions and diagnoses throughout the profession. Accordingly, where a patient insists on treatment that the physician or hospital considers medically inappropriate and futile, an impasse is created. The patient can of course go elsewhere to seek such treatment. If this is not an option, then the process of redefining the goals of continued care by the parents needs to be started, and a real effort by both the parents and the physicians and hospital should be made.\textsuperscript{161} If it is necessary to continue the treatment while this period of reevaluation is occurring, then that is a necessary cost. In the long run, however, a parent acting on behalf of the child cannot force a physician to act against his or her own medical judgment.

\textsuperscript{159} Id.
\textsuperscript{160} Baby K, 16 F.3d at 590.
A variety of federal statutes are seemingly implicated by these struggles between physician and parent, although none of them were ever intended to interfere with a physician's medical judgment or ethical responsibilities. Rather, these statutes principally guarantee the disabled access to an array of social benefits, including medical care. Nothing in the statutes, nor in their legislative history, suggests that Congress intended to suspend any physician's ability—and obligation—to form independent medical judgments and to act on them. Thus, medical decision-making should be primarily left to the states and adjudged according to the prevailing standard of care. In the alternative, a federal statute that directly addresses the issue of futility and the implications thereof should be promulgated or amendments made to the federal statutes so that courts will have a clearer directive in this very difficult area of decision-making.