

Articles

BABY DOE CASES: COMPROMISE AND MORAL DILEMMA

by
Phoebe A. Haddon*

The birth of a child is usually a joyful occasion, culminating months of anxious waiting and preparation for the anticipated arrival. The happiness of the long awaited event stems not only from the birth itself, but also from the initial reassurance that the baby delivered is healthy, responsive, lovable and loving.

For some parents, however, that relief of begetting a "normal" child is not forthcoming. Some infants are born with significant mental or physical problems that make "normal" development impossible and leave it questionable whether more than bare survival can be expected.¹ For many of them, immediate medical intervention is required for even short term or bare survival; they may require frequent intervention to sustain life. "Normal" life may be precluded because of physical or mental disorders related to the

* Associate Professor of Law, Temple Law School. B.A., Smith College, 1972; J.D., Duquesne Law School, 1977; LL.M., Yale Law School, 1985.

¹ This article is concerned with severely disabled newborns, *i.e.*, infants who are not likely to survive without medical intervention and whose prognosis, even assuming medical intervention, may be "poor in terms of cognitive life and minimal functioning." Ellis, *Letting Defective Babies Die: Who Decides?*, AM.J.L. & MED. 393, 393-94 (1982). The Department of Health and Human Services (HHS) has reported that 2½% of all births in the United States involve a "significant" physical defect of some kind. See 50 Fed. Reg. 14,886 (1985)(final rule). In 1974 it was estimated that 30,000 "severely disabled" babies were born each year in the United States. *Medical Ethics: The Right to Survival, 1974: Hearings on the Examination of the Moral and Ethical Problems Faced with the Agonizing Decision of Life and Death Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare*, 93d Cong., 2d Sess. 26 (1974) [hereinafter cited as *1974 Hearings*]. See also Note, *Withholding Treatment from Defective Infants: "Infant Doe" Postmortem*, 59 NOTRE DAME L. REV. 224, 225 & nn. 9-11 (1983)(statistics relating to spina bifida and Down's syndrome). More precise and updated numbers relating to children who may typify "Baby Doe" candidates, *i.e.*, infants with severe physical defects, or newborns with profound mental handicaps and surgically correctable physical disabilities, are controversial and not classified or reported by the Public Health Center.

initial problem or other independent disabilities that are predictably recurrent as a result of the initial disabilities. The child's present life-threatening condition and gloomy prognosis render treatment decisions that need to be made immediately at birth or soon thereafter understandably difficult: withholding life sustaining treatment is an alternative that looms in the midst of discovery that there is little reasonable expectation of normal development despite medical intervention or parental care.

Whether the alternative of withholding treatment is ever appropriate has become a matter of public controversy and that controversy has drawn into issue who is the appropriate decision maker. Parents, doctors and society each can assert some stake in decision making both in terms of the ability to address the interests of the child and in terms of their own interests in the outcome of the decision.

On October 9, 1984, after several well publicized cases involving care extended to handicapped infants,² and following several controversial, federal administrative attempts to address the issues,³ Congress enacted legislation which expressly allocates decision making responsibility between parent and state. Under the statute, the parent is told that medical care may only be withheld if certain circumstances exist, and the authority to determine whether these circumstances exist is given to the physician.

This article explores the issue of withholding treatment of infants in light of the conflicting interests among available decision makers and the existing legal and political frameworks for resolving the conflict. I will argue that parents rather than other potential decision makers should appropriately assume the principal decision making responsibility. I reach this conclusion not on the strength of often troublesome privacy or autonomy notions which have evolved in the legal responses to other similar controversies involving medical treatment and child rearing, but because parents more than others must face the moral dilemma of a choice of withholding treatment for the profoundly infirm infants when the ben-

² See *infra* notes 86-124 and accompanying text.

³ See *infra* notes 89-121 & 132-138 and accompanying text.

efits of treatment are uncertain. Congress' compromise response to the "Baby Doe" cases, focusing on medical decision making to delineate the kind of life worth saving, represents a hostile reaction to autonomy and privacy rationale for leaving decision making in the hands of the parents, but inappropriately masks the uncertainty and moral dilemma that are present in such decision making. There are, however, procedural mechanisms available which can better ensure that the decision making is reflective, deliberate, and exercised truly with the interest of the child and the perspective of the family in mind.

There are clearly grave personal consequences to family life that can accompany the treatment and health care regime that must be followed for the survival of the profoundly disabled infant. The emotional toll and economic costs of maintenance can be sources of family upheaval and can lead to family disintegration.⁴ There may be little in the way of comfort offered to parents if the response of the child to their loving care and sacrifice is little that is humanly cognizable beyond pain and suffering. The parents' concern for the child's welfare and the limited life he or she will lead may be inextricably bound to their own disappointment and fears about their future and the future of other family members in connection with the care of the infant. Thus the appropriateness of parental decision making may turn on whether and to what extent interests other than the infant's may be considered in treatment decision, and whether it is appropriate or possible to effectively exclude them.

Great strides in medical technology, therapy, and treatment make it possible to treat and maintain newborns who, until re-

⁴ See Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 N. ENG. J. MED. 890, 891 (1973); Strong, *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, 1 BIOETHICS REP. 1182 (1983). Parents have published moving, personal accounts of the emotionally traumatizing events related to their discovery that their newborn is seriously disabled: caring for him in the midst of the imposing technological and professional support systems which maintain his existence; experiencing the upheaval in their personal and professional lives; and suffering over the child's uncertain health condition. See, e.g., Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, 11 HASTINGS CENTER REP., Dec. 1981, at 6, 17-19; Stinson & Stinson, *On the Death of a Baby*, 7 J. MED. ETHICS 5 (1981); see also *The Baby Doe Quandary*, THE ATLANTIC, April 1985, at 6 (letter to the editor in response to January 1985 article by Nat Hentoff).

cently, would not have had a chance of survival. In particular, specialization in critical care and neonatal management has made possible amazing changes in preservation of life capabilities. Sophisticated medical instrumentation has permitted the subsistence of infants not imagined twenty years ago.⁵ Rapid improvements in care and management have made at-birth survival prognostications which were acceptable a decade ago now appear to be archaic. These advances, and the resulting increased technical nature of treatment decisions, cast doctors and other health care professionals in even more prominent roles than in the past in appropriate treatment decision making. A preference for professional medical decision making over that of the emotionally wrenched parents is questionable, however, in light of other consequences that may arise from the technological advances made in medicine and which extend beyond the benefit of infant survival. Notably, escalating economic costs of new life saving techniques and technology should not be ignored by medical personnel, particularly in this age of shrinking resources for health care allocated by the government.⁶ In addition, there may be a psychological toll from the depersonalized treatment of infants resulting from increased specialization and dependence on technology which may affect professionals (as well as family participants) who are involved in the maintenance and treatment of the infant.⁷ In some circumstances, the quest for more radical and successful life saving measures can render the patient a mere human pawn, a subject useful merely to the venture of scientific exploration. In short, treatment decisions by doctors, like parents, may be made with interests other than the child's well-being in mind.

The state's role in determining the fate of the seriously impaired newborns has only recently become a matter of attention, spurred by reports of instances of withholding treatment for newborns, sometimes with the effective sanction of courts, which shroud the

⁵ See, e.g., Todres, *Problems of Uncertainty: Medical Criteria in Neonatal Treatment Decisions*, in *DILEMMAS OF DYING* 83 (1981).

⁶ See, e.g., Roe, *Treatment Decisions and Triage: The Physician's Burden*, in *DILEMMAS OF DYING* 89 (1981).

⁷ See, e.g., *id.*; Bridge & Bridge, *supra* note 4; see also *Doctors Ask, Who Lives? When to Die?*, N.Y. Times, Jan. 16, 1985, at B1, col. 1.

decision in privacy. Newspaper accounts and reports of judicial response have provoked public controversy concerning whether parents or doctors, alone or in consultation, should be able to decide in some circumstances to reject life sustaining measures for an infant born with profound physical and/or mental disorders. Some answers to that question entail a more active role of the state than was heretofore assumed and a reevaluation of notions of autonomy as they relate to medical decision making and parental authority. As in the case of parents and doctors, the interests of the state in the decision making need not be limited to the protection of the child's interest per se but may extend to the accommodation of other values important to society. A decision implicating an increased role of the state in a decision bearing on the sustaining of life, moreover, necessarily draws into question matters concerning the allocation of responsibility for the sustenance and nurturing of the infirm infant whose life is being maintained, with fiscal and other political implications extending beyond the peculiar concerns for the child.

In focusing on the appropriateness of state intrusion, this article first considers the autonomy issues present in related areas. It next assesses the judicial and political responses that have been made to the question of withholding treatment from infants in light of that analysis. It then considers the persuasiveness of grounds justifying intervention in the decision to withhold treatment to newborns despite the insulation of medical decision making and parental authority in other circumstances. Finally, this article attempts to develop an appropriate framework for limited state intervention in view of the competing values at stake.

I. DEVELOPING NOTIONS OF AUTONOMY IN THE CASE LAW

The issue of whether the state should intrude in matters relating to the treatment of newborns can be considered in the context of developing notions of autonomy. The concept of autonomy has become a catchall term often used to describe personal liberty, individual private choice and the limits of governmental control over

the individual in a liberal society.⁸ It has had a powerful influence on legal issues relating to doctor-patient relations, parental control of minors, and state intrusion in family matters. Competing with autonomy, however, are other values important to the social order. Thus, even in areas of life where idiosyncrasies are most tolerated, some interference with private choice is justified when other important values are threatened. Establishing when and how the state should intrude therefore involves considering whether "autonomy" has meaning or significance as it relates to withholding treatment of infants, who themselves lack decision making capacity; as well as considering whether competing values are unduly affected if decision making is isolated from state control.

A principal ingredient of rights theory, the moral concept of autonomy is that human beings have authority to control their lives and to take self critical responsibility for the ends they choose toward attaining their conception of the good life.⁹ Autonomy expresses the fundamental idea of rational self direction that stems from the classical Kantian ideal of persons as "free and rational

⁸ Autonomy is generally used to express the idea of respect for liberty and freedom of action that is owed each individual and which supports a right of self determination—a right to make decisions without the interference of others. The concept of autonomy also encompasses a notion of equality relating to the respect owed each person as a moral agent, a notion which is distinguishable from the "admiration and similar attitudes which are commanded unequally by men in proportion to their unequal possession of different kinds of natural excellence." Williams, *The Idea of Equality*, in *PHILOSOPHY, POLITICS AND SOCIETY* (Second Series 1962) 110, 115; see, e.g., Callahan, *Autonomy: A Moral Good, Not A Moral Obsession*, 14 *HASTINGS CENTER REP.* 40, Oct. 1984, at 40, 40-42; Richards, *Rights and Autonomy*, 92 *ETHICS* 3 (1981); see also Berlin, *Two Concepts of Liberty*, in *FOUR ESSAYS ON LIBERTY* 118 (1969). Gerald Dworkin distinguishes the concept of autonomy and related ideas of privacy, freedom, liberty, and power, emphasizing choice and the exercise of will. Those other values, however, may be "necessary conditions" for autonomous individuals to develop their aims and interests, and to make their values effective in the living of their lives. Dworkin, *Autonomy and Informed Consent*, 1 *BIOETHICS REP.* 309, 316 (1983).

The meaning of autonomy characterized by Kant as the "ultimate respect for the choice of ends," Richards, *supra*, at 9 (citing I. KANT, *FOUNDATIONS OF THE METAPHYSICS OF MORALS* 53) (L. W. Beck trans. 1959), is instrumental in democratic liberal theory which conceives independent moral agents who consent to be bound together and governed by the political order of the state but who nonetheless retain for themselves the liberty to determine and pursue their own private ends free from state intervention, within reserved enclaves of privacy.

⁹ Dworkin, *supra* note 8, at 310-12; Richards, *supra* note 8, at 9.

sovereigns in the kingdom of ends.”¹⁰ The modern conception of autonomy in human rights theory emphasizes that a person’s own choices, plans, and conception of self should generally dominate over what others believe to be in his best interest and that coercion, manipulation, and undue influence violate his moral personality. Mutual respect and fostering of autonomy guarantees on equal terms to each individual the opportunity to adopt, evaluate, and revise a point of view on how to live his life.¹¹ Under the ideal conception, “liberty coincides with law: autonomy with authority.”¹² In the real world, that coincidence is not forthcoming; constraint and coercion are often more aptly paired with law and authority. Reciprocity in respect of others’ values may not always be perceived as appropriate, and a conflict in values may lead to a resolution which subordinates one person’s choice for another in the interest of paternalism¹³ or for the protection of overriding values of society.¹⁴ Society’s promotion of the development and exercise of autonomy, moreover, may be limited by other values important to its sense of social justice.¹⁵

¹⁰ Richards, *supra* note 8, at 9 (citing I. KANT, FOUNDATIONS OF THE METAPHYSICS OF MORALS 51-56) (L.W. Beck trans. 1959)).

¹¹ *Id.* Autonomy can be said to form the basis for “moral enfranchisement, establishing standing as an equal in the community and liberty to pursue [one’s] own ends.” Callahan, *supra* note 6, at 40.

¹² Berlin, *supra* note 8, at 149.

¹³ Paternalism has been described as “one of self-determination’s contrary siblings.” J. KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 110 (1984). In contrast with autonomy’s association with self determination, paternalism is concerned with the personal good linked to self fulfillment. Paternalism thus may reflect a good of helping others to avoid bad choices, but the assistance rendered violates free choice. Though choice can be valued because it is “liberating and leads to progress,” it can be disfavored because of the good that might be achieved from protecting others from bad choices. G. CALABRESI & P. BOBBITT, TRAGIC CHOICES 48 (1978). In liberal political theory, the interference with individual liberty can be thought of as an objectionable evil. See H.L.A. HART, LAW, LIBERTY AND MORALITY 47-48 (1963). Moreover, in addition to negating egalitarian and libertarian notions of autonomy, paternalism is often suspect and may be objectionable because of the danger that the decision maker who decides and acts on the other’s behalf does so by imposing his own values of good which may be inconsistent with those for whom the decision is made. See G. CALABRESI & P. BOBBITT, *supra*; see also Dworkin, *Autonomy and Behavior Control*, 6 HASTINGS CENTER REP., Feb. 1976, at 23.

¹⁴ It can be argued, for example, that the principal value of autonomy is that it merely provides a means to other, more desirable community values. See Callahan, *supra* note 8. Cf., e.g., Dworkin, *supra* note 8, at 73 (autonomy has both intrinsic and instrumental value).

¹⁵ See, e.g., R. DWORKIN, TAKING RIGHTS SERIOUSLY 266, 266-78; Macklin, *Moral Con-*

Thus, while autonomy notions provide a theoretically appealing framework for evaluating issues related to competing claims of decision making authority, in actual application autonomy concepts—particularly when raised in response to morally troublesome issues such as withholding life sustaining treatment in the case of infirm infants—do not satisfactorily resolve conflicts in values.

The problem of accommodating the concept of autonomy with other values can be appreciated in two related, contemporary legal developments generally supporting individual choice and private decision making: (1) the doctrine of informed consent and the movement toward recognizing a right to refuse life sustaining treatment; and (2) parental autonomy in the care of children. Reflective of the contemporary autonomy related values emphasizing personal liberty and choice, it is the case in both of these areas that the individual decision maker has been given broad leeway. There are nonetheless problems that arise in delineating the limits of decision making freedom present even in those areas, which bear significantly on the issue of treatment of newborns.

A. *Informed Consent*

The right of a "free citizen" to personal inviolability, requiring a physician to seek consent for medical treatment was first recognized at the turn of the century.¹⁶ Until the late 1950's, however, the view that patients should play a prominent role in medical decisions was unheard of, much less seriously considered.¹⁷ Instead, patients were treated as objects of decision making—victims, whose ignorance and infirmity precluded active participation in the treatment process or any response helpful to the learned doctor administering treatment or therapy.¹⁸ Several cases challenged the

cerns and Appeals to Rights and Duties, 6 HASTINGS CENTER REP., Oct. 1976, at 31.

¹⁶ *Pratt v. Davis*, 118 Ill. App. 161 (1905), *aff'd*, 224 Ill. 300, 79 N.E. 562 (1906).

¹⁷ See *Salgo v. Leland Stanford, Jr. Univ. Bd. of Trustees*, 154 Cal. App. 2d 560, 317 P.2d 170 (1957) (holding in favor of informed consent as part of doctor's duty); Meisel, *The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability by Way of Informed Consent*, 56 NEB. L. REV. 51, 77-86 (1977).

¹⁸ See J. KATZ, *supra* note 13, at 1-48 & App. A (Code of Ethics of A.M.A., 1847). Dr.

assumption of nonparticipation of the patient, evoking an intense debate in law, medicine, and ethics concerning the roles of doctor and patient in medical decision making.¹⁹

Early cases founded the right to be free of invasion of bodily integrity on notions of consent and liberty.²⁰ In *Canterbury v. Spence*,²¹ the court reasoned that: "The patient's right of self-decision shapes the boundaries of the duty to reveal And to safeguard the patient's interest in achieving his own determination on treatment, the law must itself set the standard for adequate disclosure." The implication of patient autonomy found in that statement, however, has never fully been realized. By the 1970's, competent patients were legally entitled to information upon which to make decisions about treatment; without that information, treatment by the doctor is unjustified even if consented to by the patient.²² But the limits of the patient's entitlement to critical information and the allocation of responsibility for deciding what treatment is appropriate in light of information that is available

Katz traces the lack of patient participation through history to the Greeks, who believed that the obedience and trust of the patient led to the cure. *Id.* at 5-7.

Indeed, reflective of the view that humans do not have the capacity to order their lives and to pursue them as independent persons, Plato envisioned the ruler in *The Republic* as:

a benevolent physician who alone understands the health of the balanced organism, [and who] has unlimited power to realize the desirable health which humans cannot realize on their own. Such a benevolent physician may quite completely control the life of the disabled patient, as in chattel slavery and the institutionalized subjection of woman, both of which Aristotle justifies, for such intrusive control is the indispensable means to the health desired.

Richards, *supra* note 8, at 8-9.

¹⁹ See, e.g., J. KATZ, *supra* note 13, at 59-84; Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decision-making*, 1979 WISC. L. REV. 413, 413-18 (1979); 75 HARV. L. REV. 1445 (1962) (critical of physician's duty to warn of possible adverse results of proposed treatment as dependent upon general practice followed by medical profession in the community); see also Dworkin, *supra* note 8, at 130-11 (exploring varied justifications for informed consent).

²⁰ E.g., *Mohr v. Williams*, 95 Minn. 261, 263, 104 N.W. 12, 13 (1905).

²¹ 464 F. 2d 772, 786-87 (D.C. Cir. 1972). As Judge Cardozo had recognized earlier: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

²² See, e.g., *Scaria v. St. Paul's Fire & Marine Ins. Co.*, 68 Wis. 2d 1, 227 N.W. 2d 647, 652 (1975); *Cobbs v. Grant*, 8 Cal. 3d 229, 244, 502 P.2d 1, 11, 104 Cal. Rptr. 505, 515 (1972); Meisel, *supra* note 19, at 413-23.

has never been clearly marked in the case law.²³ In ordinary practice, moreover, the physician recommends treatment and the patient accepts it, with little questioning or effective control over the course of treatment.

Theoretically, "patient autonomy" requires that autonomous individuals—those who have the capacity to consent to treatment—should be informed of the risk and treatment alternatives before any treatment is made and, absent an emergency, should consent to a treatment alternative before it is taken.²⁴ Without informed consent the intrusion on bodily integrity by treatment is unwarranted. Even among supporters of patient choice, however, there remains disagreement about how to implement it. In part this is because there is not agreement about how to resolve the tension between recognizing the benefits of medical judgment based on knowledge and experience that is useful in making a treatment decision, and according a "right of self determination" out of respect for the individual.²⁵ Patient autonomy in treatment decisions promotes the view that—at least in circumstances where others are not directly harmed—human dignity requires deference for even idiosyncratic choice in matters affecting an individual's medical life, even if the decision reached is contrary to the patient's best interest from another's perspective, even one more rational or enlightened.²⁶ Decision making by the doctor based on what the *doctor* believes to be in the patient's best interest in his medical judgment is paternalistic, and violates the patient's auton-

²³ See generally, J. Katz, *supra* note 13, at 48-84; Meisel, *supra* note 19, at 462-65.

²⁴ See Meisel, *supra*, note 19, at 418-22.

²⁵ As Robert Veatch has observed:

At the individual level the Hippocratist pulls us paternalistically to benefit patients even at the expense of violating their autonomy while our Judeo-Christian heritage and its secular successors tell us to benefit but only within the constraints of respect for autonomy.

Veatch, *Autonomy's Temporary Triumph*, 14 HASTINGS CENTER REP., Oct. 1984, at 38, 40; see Meisel, *supra* note 19, at 418 (battle being waged under the banner of informed consent reflects ambivalence about how authority is to be allocated between doctor and patient in determining how patient is treated).

²⁶ See *Canterbury v. Spence*, 464 F.2d 772, 790 (D.C. Cir. 1972); *In re President & Directors of Georgetown College, Inc.*, 331 F.2d 1000, 1008 (D.C. Cir. 1964); see also Gadow, *Advocacy: An Ethical Model for Assisting Patients with Treatment Decisions*, in DILEMMAS OF DYING 135 (1981), J. Katz, *supra* note 13, at 104-29; Veatch, *supra* note 25, at 38-39.

omy, whether or not the outcome of decision making will prolong life, enhance it, or otherwise be beneficial to the patient's health.²⁷ There is the danger, moreover, that what passes as "medical judgment" may be in effect what the doctor thinks best, utilizing his own values for decision making.

The tension that arises between medical judgment and patient autonomy is increased when the doctrine of informed consent is extended to support a right to refuse life saving treatment. Though the patient's "right" to refuse treatment is one arguably rooted in the ideas of liberty, consent and self determination which form the basis of autonomy notions, it conflicts with the traditional value of promoting health, a societal interest²⁸ and a value that the medical profession has sworn to uphold. Emphasizing the value of autonomy, the argument is that patients should have the right to determine not only what treatment should be accorded them but also whether any treatment should be administered—a right to "bodily self-determination."²⁹ Human dignity requires that one affected by illness should play a prominent role in treatment decisions, and choice should extend to rejecting life saving medical intervention, opting for no treatment, or choosing an alternative that may be life threatening, as compared with others.³⁰ Stating this argument in its extreme, "free" choice permits the patient to refuse life saving treatment—or even to request life ending action—for any reason. But such a conception of patient autonomy, embracing a right to die, baldly contradicts the sanctity-of-life ethic which is the accepted focus of medical decision making,³¹ and a value protected

²⁷ See, e.g., Clarke, Sorenson & Hare, *The Limits of Paternalism In Emergency Care*, 10 HASTINGS CENTER REP., Dec. 1981, at 20, 20-21; Dworkin, *supra* note 8.

²⁸ See Meisel, *supra* note 19, at 423-28; Note, *Compulsory Medical Treatment: The State's Interest Re-evaluated*, 51 MINN. L. REV. 293, 298-301 (1966); see also Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1977)(discussed *infra* notes 41-56 and accompanying text).

²⁹ Steinbock, *The Intentional Termination of Life*, in KILLING AND LETTING DIE 69, 71 (1980); see Saikewicz, 373 Mass. at 742, 370 N.E.2d at 426.

³⁰ Steinbock, *supra* note 29.

³¹ A statement adopted by the House of Delegates of the American Medical Association on December 4, 1973 provided:

The intentional termination of the life of one human being by another—mercy killing—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association.

by the state for the sake of the community.³² Even a more modest conception of autonomy, one that precludes the choice of euthanasia³³ but permits patient choice among alternatives that are not directly aimed at death, is controversial.³⁴ The problem lies in es-

The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family.

See Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78, 78-80 (1975).

Interpretation of the AMA position has been subject to controversy and has led some to argue that the AMA has made a distinction between active and passive euthanasia, supporting the latter as appropriate treatment. See, e.g., Rachels, *supra*, at 63; Tooley, *An Irrelevant Consideration: Killing Versus Letting Die*, in KILLING AND LETTING DIE 56 (1980). But the apparent intention of the statement is to condemn the intentional termination of life, yet permit the cessation of life-prolonging treatment and thus it is not addressed to the proposition that the medical professional association condones euthanasia, or the right to take one's life. See Steinbock, *supra* note 29, at 70; see also Eichner *ex rel. Fox v. Dillon*, 73 A.D.2d 431, 462-64, 426 N.Y.S.2d 517, 541-42 (1980)(the dying may be in need of comfort rather than treatment); *infra* note 33.

In mid-March, 1986, the AMA's judicial council unanimously decided that it would be ethically appropriate to withhold "all means of life prolonging medical treatment," including food and water, from patients in irreversible comas. Under the new policy, the patient need not be terminally ill for the halting of treatment to be acceptable. See New York Times March 17, 1986 B-7; New York Times March 23, 1986 E-24 col. 3.

³² See, e.g., Glantz, *Legal Limits to Refuse Treatment*, in DILEMMAS OF DYING 53 (1981).

³³ Euthanasia, which is literally translated to "well dying," means choosing death as an end. Steinbock and others argue that the recognized right to refuse treatment is distinguishable from a right to voluntary euthanasia. Although both can be derived from the right to bodily self-determination, the right to refuse treatment is not equivalent to a right to die. Rather, it enables the individual to be protected from unwarranted interference of others and to discontinue treatment which has little chance of improving the patient's condition and/or which brings greater discomfort than relief, even if death follows. When the point or justification of withholding or withdrawing treatment is not for the intentional *purpose* of bringing about death but for one of those aforementioned purposes, it is not euthanasia, active or passive. A doctor who follows the directions of one who exercises the right to refuse treatment is not considered to be intentionally terminating life even though the withholding of treatment is with the foreseeable consequence of death. This is because the termination of life can be justified if done in the context of the patient's right to refuse treatment, and because the right restricts the doctor's freedom to continue treatment. B. Steinbock, *supra* note 29, at 71-75. Refusal of treatment in this sense is not suicide and the doctor's honoring of the patient's wishes to withdraw or withhold treatment is not the practice of euthanasia. *Id.*

³⁴ Compare, e.g., *id. with P. RAMSEY, ETHICS AT THE EDGES OF LIFE* 160-71 (1978)(rejecting a patient's right to refuse treatment) and Annas, *Learning to Live with Judges*, in DILEMMAS OF DYING 151, 152 (1981)(patient has the right to refuse treatment for any

establishing the preferable balance between radical individualism without any recognition of an individual's social interdependence with others, and limited individual choice which is so respectful of community that it fails to maintain individual integrity. Identifying the appropriate balance in the context of life threatening medical decision making is complex because of the importance of the competing value of life at stake and the involvement of the professional who is traditionally committed to life preservation. Thus not only is the question raised of how to accommodate competing societal values like life preservation in a way that leaves tolerable leeway for individual choice, but also who is best able to make the appropriate accommodation—the individual, the state, or the professional.

Even doctors who are inclined to accept some notion of patient autonomy as reflected in the doctrine of informed consent may be unwilling to accept a patient's choice of withdrawing treatment or preferring nontreatment to life prolonging treatment. Some doctors may simply refuse to abide by a patient's decision, leaving the patient to seek another professional who will respect that choice. Other doctors may go further, however, and seek to dictate that a more acceptable life preserving course be taken on the basis that autonomy extends only to "competent" decision making, and a decision favoring death over life is irrational, one that a competent patient could not make.

In some cases, courts have been persuaded to intervene to support the doctor's overriding of a nontreatment or life threatening treatment alternative, on the basis of the irrationality of the patient's decision,³⁵ or on the grounds that private choice is precluded by more important values protected by the state such as: (1) the value of life; (2) wrongfulness of suicide; and (3) maintaining the integrity of the medical profession.³⁶ The judicial trend,

reason).

³⁵ See, e.g., R. BURT, *TAKING CARE OF STRANGERS* 1-21 (1979).

³⁶ E.g., Glantz, *supra* note 32, at 53-61; Byrn, *Compulsory Lifesaving Treatment for the Competent Adult*, 44 *FORDHAM L. REV.* 1, 16-24 (1975); *Euthanasia: Criminal Torts, Constitutional and Legislative Considerations*, 48 *NOTRE DAME LAW.* 1202, 1203-04 (1973)(survey).

however, has been to consider the choice of treatment as a private matter, absent extenuating circumstances such as harm to another caused by the treatment decision.³⁷

In none of these alternatives is there a wholly satisfactory accommodation of individual choice and community values. Though private resolution of conflicts among values may seem preferable to state imposed, coercive choice, there may be a legitimate social concern about whether the competing values should be accommodated without at least some societal participation, even if limited to the opportunity for supervision or review. It can be argued that, at a minimum, there needs to be some societal assurance that the decision making that takes place is deliberate, reflective of values embraced by the individual, and its ramifications understood.³⁸

³⁷ When the patient has children, the court may view the state's interest in life preservation for the protection of the children more strongly than a right to refuse treatment, on the basis that the children may become wards of the state and that the children need the emotional support of the parent. Compare *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537 (1964)(transfusion required to save fetus) and *Georgetown College*, 331 F.2d at 1000 (patient had a young child) with *In re Osborne*, 294 A.2d 372 (D.C. 1972)(patient had older children). Statutes authorizing "living wills" allow competent patients to assert in advance that they do not want medical intervention which will prolong life under certain circumstances. See, e.g., CAL. HEALTH & SAFETY CODE §§ 7185-95 (West Supp. 1982).

³⁸ See, e.g., Miller, *Autonomy and the Refusal of Lifesaving Treatment*, 11 HASTINGS CENTER REP., Dec. 1980, at 20, 20-21; Callahan, *supra* note 8, at 42. If the concern is that the individual's choice is truly reflected in the action taken, then crafting a concept of autonomy that better ensures reflection may be preferable, particularly in the patient's decision to forego life-saving treatment. For example, Miller argues that the concept of autonomy can be parsed to include several components:

(1) *freedom of action*—that the decision is not the result of external considerations which make the decision a result of duress, coercion or undue influence of others;

(2) *authenticity*—that the submission to or refusal of treatment appears to be consistent with the personal attitudes, values, and life plans of the patient;

(3) *effective deliberation*—that the patient is aware of the alternatives and consequences of his decision; and

(4) *moral reflection*—that there is acceptance of the moral values that the patient purports to act on.

Thus, a doctor or other professional would evaluate the patient's decision in light of the foregoing considerations and would honor the decision if the patient appears to be exercising choice consistent with them. Miller, *supra*, at 24-25. This approach assumes that the patient and doctor engage in dialogue which permits the doctor (or other counselor) to make such an evaluation and requires that the patient give some explanation for his decision. See J. KATZ, *supra* note 13, at 136-63. Compare, e.g., Veatch, *supra* note 25, at 38 (respecting the patient's autonomy always takes precedence over benefitting the patient against the

The issue of withholding or withdrawing treatment for incompetents is even more conceptually troublesome. The autonomy notions which can support a right of private choice for competent patients do not apply in those cases where the capacity to choose does not exist due to mental or physical disability. Nonetheless, there are concerns that should not be ignored merely because the individual is incompetent, for to do so negates the incompetent's personality and violates his or her human dignity.

In non-life-threatening situations, treatment decisions are often made privately by physicians and family or guardians. If the decision is for the withdrawal or withholding of treatment under life threatening circumstances, there is greater concern that the conclusion reached is made with the patient's interest in mind. Where the patient has once been competent, the problem may be eased, though not necessarily solved, by attempting to ascertain what the patient would have desired, based on what is known to those familiar with him or her and choices he or she made as a competent person, rather than paternalistically attempting to decide what is in the patient's best interest.³⁹ If the incompetent has never been competent, there is no information to draw upon in simulating choice and defining the best interest of the patient. The danger is that the decision maker—whoever that may be—will inject his own life views and idiosyncrasies, totally submerging the “will” of the patient for that of the decision maker, in violation of the incompetent's individuality. The question of withholding or withdrawing life sustaining treatment to a seriously disabled incompetent thus draws into issue whether there is any meaningful way of extending to an incompetent some protection respectful of his or her moral personality.⁴⁰

patient's autonomous will) *with* Dworkin, *supra* note 13, at 27-28 (presents guidelines for controlling behavior in a manner which reflect notions of independence and authenticity supporting autonomy). *See also infra* notes 174-83 and accompanying text.

³⁹ *See, e.g.,* Gutheil & Appelbaum, *Substituted Judgment: Best Interest in Disguise*, 13 HASTINGS CENTER REP., June 1983, at 8.

⁴⁰ Essentially two decision making approaches have been taken: proxy and substituted judgment. The first, generally characterized as the “best interest” approach, is made by a decision maker who vicariously determines what course of action would be in the best interest of the incompetent. What is “best,” however, entails a value judgment that is nearly impossible to be guided by meaningful standards. Moreover, even if the decision maker may

In two well known decisions, *Superintendent of Belchertown State School v. Saikewicz*⁴¹ and *In re Quinlan*,⁴² each court recognized that treatment could be withheld or withdrawn from incompetents, though disagreeing on the appropriate decision making procedures.⁴³ Each case indicates that under limited circumstances, a decision favoring the withdrawal or withholding of life sustaining treatment may be permissible for the sake of the incom-

know something about the patient and his life experiences, there is the danger that the response will be the product of the decision maker's own values.

The substituted judgment approach requires the decision maker to decide what the incompetent would have decided if he or she were capable of making a decision. But if the incompetent never was competent, that approach is unrealistic and inevitably leads to a conclusion about the best interests of the patient as perceived by the decision maker. Even if the incompetent has been competent at another time, there is no way to ascertain what he or she now, if lucid, would consider best. *See, e.g., Annas, supra* note 34, at 151, 155-58; Gutheil & Appelbaum, *supra* note 39.

A possible third approach is to leave the decision to the medical professional, who begins with the assumption that most patients would ask that all available medical help be given if it would lead to some tolerable level of existence at worst and recovery at best, and that the patient would not want "heroic" measures to be undertaken which would prolong pain without some measure of quality of existence. This approach, however, involves three troublesome evaluative questions that are not clearly "medical" in nature:

- (1) What is the definition of a "tolerable level" of existence?
- (2) What is recovery of health in the case of the patient?
- (3) What are "heroic" or "extraordinary" as contrasted with ordinary measures for maintaining life?

See Robitscher, The Right to Die, 2 HASTINGS CENTER REP., Sept. 1972, at 11; *see also P. RAMSEY, supra* note 34, at 178-88 (Medical Indications Policy for incompetents).

⁴¹ 373 Mass. 728, 370 N.E.2d 417 (1977).

⁴² 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied*, 429 U.S. 922 (1976).

⁴³ Unlike Quinlan, a teenager who suddenly fell unconscious at a friend's party and became comatose, Saikewicz was institutionalized for most of his life and was considered profoundly retarded. After he became ill with leukemia, in a state-initiated lawsuit, a guardian ad litem recommended against chemotherapy treatment for the 67-year-old incompetent. The Commonwealth of Massachusetts took a contrary position. Thus, in effect, the state represented interests on both sides of the Saikewicz case. Liacos, *Keynote Address: The Saikewicz Decision*, in DILEMMAS OF DYING 13 (1981). The Massachusetts Supreme Judicial Court concluded that the trial judge must determine whether chemotherapy treatment for Saikewicz was warranted "viewed from the unique perspective of the [incompetent person] . . ." 373 Mass. at 747, 370 N.E. 2d at 428.

The Supreme Court of New York agreed with the procedural approach followed in Saikewicz. *Eichner v. Dillon*, 73 A.D.2d 431, 474-75, 426 N.Y.S.2d 517, 500 (1980). In contrast, in response to an appeal from the trial court decision, the New Jersey Supreme Court in Quinlan ruled that Quinlan's father could be appointed her guardian "with full power to make decisions with regard to the identity of her treating physicians." 70 N.J. at 55, 355 A.2d at 671.

petent's human dignity.⁴⁴ But the decisions differ as to how to ensure the preservation of the incompetent's human dignity. Both decisions have been roundly criticized and have engendered further legal, medical, and ethical debate concerning the proper approach to protecting incompetents.⁴⁵ It is clear that no simple solu-

⁴⁴ In the *Saikewicz* case the Attorney General initiated the action under its *parens patriae* duty to protect an incompetent's right to have life prolonging medical treatment and asserted the state's interest in life preservation. The Civil Rights Division of the Attorney General's Office, on the other hand, represented Saikewicz's interest in asserting the incompetent's right to refuse the administration of chemotherapy. Massachusetts' highest court suggested that court involvement was required to supervise the decision to withdraw or withhold treatment in the case of the incompetent. 373 Mass. at 759, 370 N.E.2d at 434. The trial judge in *Saikewicz* has observed that, after the *Saikewicz* decision rendered by the Supreme Judicial Court of Massachusetts, the protection of the individual's right to accept or reject life prolonging treatment may be considered a separate and independent state interest, at odds with other asserted interests of the state which circumscribe the individual's freedom of choice. Judicial involvement in decision making which involves a confined incompetent may be necessary to ensure that the state's action is consistent with its limitation on power as well as respective of the individual's rights. See Liacos, *Keynote Address: The Saikewicz Decision*, in *DILEMMAS OF DYING* 15-17 (1981). Compare *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978)(specifying circumstances when no "code" or "do not resuscitate" order can be made without prior judicial approval) with *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980)(court makes the decision).

In the *Quinlan* case, however, the supreme court did not suggest that judicial involvement was warranted in every case. Rather, the New Jersey court stated that if the responsible doctor, with the concurrence of the guardian and family of the patient, concludes that the patient has "no reasonable possibility of . . . ever emerging from her present comatose condition" and that conclusion is agreed with by a hospital ethics committee or similar body, then treatment can be withdrawn without exposure to liability on the part of any participant. 70 N.J. at 39-42, 55, 355 A.2d at 663-64, 671-72. The court thus recommended the organization of hospital ethics committees to evaluate the moral, ethical and social considerations that are presented in a decision to withhold treatment. Often viewed as in the forefront in its decision making concerning the right to refuse treatment, the New Jersey Supreme Court has recently further emphasized that courts need not be involved in every decision relating to the withholding of treatment for incompetents. See *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978) (state's interest in preserving life declines with degree of bodily interference of treatment); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) (net burdens test); see also *Minnesota Cases Set a Life-Support Precedent*, N.Y. Times, Dec. 2, 1984, at A30, col. 3 (committee reports of two independent medical ethics committees relied on by state supreme court); *infra* note 170.

⁴⁵ Compare R. BURT, *supra* note 35, at 144-73 with P. RAMSEY, *supra* note 34, at 170-71 (decisions should rest upon a medical indications policy) and Annas, *In re Quinlan Decision: Disconnection: The Clinician's View*, 6 HASTINGS CENTER REP., Feb. 1976, at 11. See generally *In re Quinlan: A Symposium*, 30 RUTGERS L. REV. 243-328 (1977)(implications of medico-legal issues—privacy and the right to die); Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, 4 AM. J.L. & MED. 367 (1979); Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*,

tion is possible since the spectre of conflict in interest is ever present when someone other than the patient makes the treatment decision, whether the judgment of the agent is "substituted" for the incompetent patient or the decision is made in the patient's "best interest."⁴⁶ This spectre, moreover, arises and has significance whether the decision ultimately reached is to prolong or to terminate life sustaining treatment.

The incompetent patient cannot assert a right as an autonomous agent to be spared the paternalistic intervention of others because the incompetent lacks the capacity to make choices on his or her own behalf. The incompetent can, however, have a *claim* that the decision making reflect his or her own interest and not others, in respect of the incompetent's own individuality—his or her existence as a separate entity, distinct from others. Respect for this separate identity and interest not only promotes human dignity, it reflects equality. The problems arise in determining how best to ensure that these interests are reflected in a decision about withholding or withdrawing treatment.

Both the *Saikewicz* and *Quinlan* conclusions suggest that the quality of life experienced by the patient could affect the treatment decision. Each court considered physical condition, prognosis, and mental functioning in determining whether life sustaining treatment was justified.⁴⁷ Theoretically, the introduction of quality of life considerations can promote human dignity in a determination of whether treatment is warranted. Yet there is the risk of injecting considerations that are contrary to the interest of the pa-

46 Mo. L. Rev. 337 (1981); Relman, *The Saikewicz Decision: Judges as Physicians*, 298 NEW ENG. J. MED. 508 (1978).

⁴⁶ See, e.g., Annas, *supra* note 34, at 151.

⁴⁷ See, e.g., Glantz, *supra* note 32, at 53; Swazey, *Treatment and Nontreatment Decisions: In Whose Best Interests?*, in DILEMMAS OF DYING 95 (1981) see also *infra* notes 182 & 183 and accompanying text. Compare *In re Quinlan*, 70 N. J. 10, 38-42, 355 A.2d 647, 662-64 (1976)(no possibility of returning to cognitive, sapient life state) with *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 753, 370 N.E.2d 417, 431 (1977)(though the court rejected consideration of quality of life factors, in determining whether chemotherapy was warranted, it considered pain and suffering related to the life preserving treatment). But see *Maine Medical Center v. House*, Civ. Action No. 74-145 (Me. Sup. Ct. 1975)(fact that child had been born blind and deaf did not warrant withholding treatment).

tient where quality of life factors have not been clearly identified or considered in all their ramifications, but have nonetheless been applied in an effort to determine whether life is worth living. An investigation of the kind of quality of life that can be experienced by the patient ultimately raises the question whether there is present a moral personality to whom human dignity should be accorded.⁴⁸

The *Saikewicz* court sought to avoid the danger of decision making being made against the incompetent's interest by requiring court involvement in decisions relating to withholding or withdrawing treatment of incompetents.⁴⁹ Judicial intervention in each case, however, affects privacy that usually shrouds the treatment process. Judicial intervention, moreover, intrudes into the medical decision making process and is potentially disruptive and upsetting to the relationship of physician and family or guardian. Indeed, other courts have been persuaded that the *Saikewicz* requirement of judicial involvement in each case was unduly obtrusive and unnecessary.⁵⁰

Beyond the privacy implications, the intervention of courts in decision making affecting incompetents is troublesome since it is questionable whether the court's intervention fares any better than private efforts in assuring that decisions respect the personal inviolability of incompetents, especially in view of the lack of a satisfactory judicial standard for decision making.⁵¹ The *Saikewicz* court proposed to determine what is appropriate treatment by taking the perspective of the incompetent. Yet it is doubtful whether a normal person can assume the role proposed without the incompetent's experience; the decision making may reflect the inherent biases of normality.⁵² Finally, the intrusion of the court can be

⁴⁸ See *infra* note 169.

⁴⁹ See *supra* notes 43-44.

⁵⁰ See *supra* note 44. It can be argued that privacy is essential to human dignity in tragic situations and thus a *requirement* like court intervention, which necessitates that we bare ourselves, violates dignity. G. CALBRESI & P. BOBBIT, *supra* note 13, at 55.

⁵¹ See, e.g., Annas, *supra* note 34, at 157-59; see also *supra* note 38.

⁵² See R. BURT, *supra* note 35, at 144-73; Fiedler, *The Tyranny of the Normal*, 14 HASTINGS CENTER REP., Apr. 1984, at 40 (deep ambivalence toward fellow creatures who are perceived as "disturbingly deviant").

viewed as itself offensive to human dignity.

Eschewing the substituted judgment approach of *Saikewicz*, other courts, like *Quinlan*, have preferred the best interest of the patient standard for decision making.⁵³ Yet that standard is indeterminate and really no standard at all in that it lacks any tenable guideline which can be transferable in a determination of what is best where each incompetent is concerned.⁵⁴ It allows the court to evaluate the treatment decisions with unbridled discretion and is therefore no check on value laden, private judgments which seem offensive to the personality of the incompetent.

Paternalism is a poor substitute for autonomy; it presents troublesome problems in ensuring for incompetents some measure of protection afforded other patients in medical treatment decisions utilizing autonomy notions. But an individual's human dignity should not be lost merely because individual choice is precluded by incapacity. As the courts in *Quinlan* and *Saikewicz* suggest, human dignity supports withholding or withdrawing of treatment for incompetents in limited circumstances. Some aspects of principles theoretically underlying autonomy—such as equality and respect of the separate personality—can serve the interest of the incompetent in those circumstances despite the fact that the incompetent must rely on others to make the decisions on his or her behalf.⁵⁵ There may be a need for some assurance that the incompetent's interests are being served by the treatment decision, but it is questionable whether state intervention through case by case judicial participation accomplishes that objective, at least in a

⁵³ See *supra* note 44.

⁵⁴ See, e.g., Annas, *supra* note 34, at 154-57; see also Mnookin, *Child Custody Adjudication: Judicial Functions in the Face of Indeterminacy*, 39 LAW & CONTEMP. PROB. 227, 230 (1975); *infra* notes 71-74 and accompanying text.

⁵⁵ See Swazey, *supra* note 47, at 96 (whoever the decision maker is, and whatever the standard, the decision making role is moral, and the obligation is that of a steward, to act as nonpaternalistically as possible, with the value assumptions underlying the decision making fully explicated to distinguish the interests actually being served). But see, e.g., Capron, *Ironies and Tensions in Feeding the Dying*, 14 HASTINGS CENTER REP., Oct. 1984, at 33 (symbolic character of caring can predominate and often distorts or minimizes the patient's needs). 98 N.J. 321 (net burdens test applied in the absence of evidence of patient's preference; ombudsman required for decision to withhold or withdraw life sustaining treatment of nursing home patient).

way that does not offend human dignity. Though the patient may no longer be able to make decisions independently, the human experience requires that some degree of respect be accorded the patient. The trend again, therefore, has been to leave the decision in the private domain, permitting the choice to be made by the doctor and a relative or next friend.⁵⁶

B. Parental Autonomy

If autonomy concepts raise disturbing issues concerning withholding treatment for other incompetents, reference to autonomy notions for infants is even more inadequate conceptually, since newborns have no life experiences, however minimal in quality, which connote personality. As in the case of other incompetents, a critical factor for consideration is the appropriateness of state intrusion in respect of human dignity. In the case of infants, however, resolution of the issues is further complicated by contemporary understandings about parental or family autonomy in matters affecting children. It is thus important to consider the existing justifications for parental authority and their relationship to evolving autonomy concepts discussed in the preceding sections in order to assess the ultimate question of withholding medical treatment for newborns.

Traditionally, parental decision making authority stemmed from the view of children as property, without rights or separate interests from parents.⁵⁷ Reflective of that view, early case law assumed

⁵⁶ *E.g.*, *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) (net burdens test applied in the absence of evidence of patient's preference; ombudsman required for decision to withhold or withdraw life sustaining treatment of nursing home patient); *In re Dinnerstein*, 6 Mass. App. Ct. 466, 470, 380 N.E.2d 134, 137 (1978) (validity of a physician's order of resuscitation not depending on prior judicial approval); see *supra* notes 35 & 42. The psychological motive for casting a decision in privacy has also been raised by commentators. Professor Burt, for example, has argued that there is reflected in the move to privatize such decisions a "retreat toward greater impotence and denial of any transactional participation"—a reluctance to be drawn into the conflict because of an unwillingness to enter into sustained interaction with the dying or diseased person. R. BURT, *supra* note 35, at 153; Capron, *supra* note 55; see also *supra* note 49.

⁵⁷ See, e.g., *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); Burt, *Developing Constitutional Rights of, in and for Children*, 39 LAW & CONTEMP. PROBS. 118, 123 (Summer 1975); Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV.

the mutuality of interest of parent and child and limited state interference in child care matters.⁵⁸ Though that image of children has changed, parental autonomy has prevailed, protecting decision making rights of parents in most circumstances.

Contemporary cases, like *Griswold v. Connecticut*,⁵⁹ suggest a concept of family autonomy, with emphasis on the importance of family integrity. Since *Griswold*, family autonomy has sometimes been characterized as a fundamental, constitutionally protected right. Drawn from language in that case as well as earlier cases, it is a personal right to be free from state interference—for parents and children, separately and mutually—which arises from the intimate family relationship.⁶⁰

From cases like *Griswold*, *Eisenstadt v. Baird*⁶¹ and *Poe v. Ullman*,⁶² it can be inferred that family intimacy projects an enclave of privacy which includes child rearing decisions of parents.⁶³ The enclave is said to foster the sense of family security necessary for the child's maturation process to continue. This family privacy interest, which has constitutional dimensions, insulates the family from undue state intrusion into family affairs.⁶⁴

The insulation from state interference, however, has never been considered absolute under any view. In fact, many of the Supreme Court cases recognizing the parents' (and child's) right to be free of state intrusion limit parental authority in the context of the

1383 (1974). See generally M. GLENDON, *THE NEW FAMILY AND THE NEW PROPERTY* 17-20 (1981).

⁵⁸ See, e.g., *Prince v. Massachusetts*, 321 U.S. 158, 165-166 (1944); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

⁵⁹ 381 U.S. 479 (1965).

⁶⁰ See also *Meyer v. Nebraska*, 262 U.S. 390 (1923); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Prince v. Massachusetts*, 321 U.S. 158 (1944); *Cleveland Bd. of Educ. v. La Fleur*, 414 U.S. 632 (1974). Cf. *Parham v. J.R.*, 442 U.S. 584 (1979) (parents could validly consent to child's commitment to state mental institution). But see Dworkin, *supra* note 8, at 66-67 (distinguishing autonomy from privacy concept and criticizing confusion of two concepts in *Griswold*).

⁶¹ 405 U.S. 438 (1972).

⁶² 367 U.S. 497 (1961).

⁶³ See also *Roe v. Wade*, 410 U.S. 113 (1973).

⁶⁴ See *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972).

facts of the case.⁶⁵ Despite the strong emphasis on parental authority, the state has in particular cases overridden parents in child rearing decisions on two separate bases: (1) when the parents' decision is contrary to the child's interests and (2) when state interests requiring the subordination of parental liberty are at stake.

The doctrine of *parens patriae* permits the state to step in to protect the interest of any of its citizens.⁶⁶ For competent individuals, state intervention even in the interest of the citizen is acceptable only in limited circumstances because it precludes valued decision making freedom and privacy. But someone always has to make decisions for young children and other incompetents. For children no less than other individuals, however, state intervention is intrusive and disrupts private relationships that can foster communication. For children the interference may be more harmful than it would be for others because it suspends the family bonding and thus the good that generally comes from the family relationship. Nevertheless, if it is determined that, despite the natural bond of parent and child, the child-rearing decision of the parent conflicts with the child's interests, the state may by prescribed procedures terminate or suspend parental rights and act in *loco parentis*.⁶⁷ Accordingly, state child protection statutes define acts of abuse and neglect which negate the assumption of mutuality of interest of child and parent and provide for the appointment of a guardian ad litem to act in the interest of the child. State child abuse agencies and other social service agencies are authorized by statute to supervise child-rearing practices of parents and to enlist the court's assistance in appointing a guardian or ordering other

⁶⁵ See, e.g., *id.* at 231-32; *Prince v. Massachusetts*, 321 U.S. 158 (1944); *Meyer v. Nebraska*, 262 U.S. 390 (1923); see also *Bellotti v. Baird*, 443 U.S. 622 (1979) (invalidating statute conferring absolute veto over minor's decision to have abortion).

⁶⁶ See, e.g., *Prince v. Massachusetts*, 321 U.S. 158, 166 (1943) (suggesting that state has broad power in case of children); *In re Clark*, 21 Ohio App. 2d 86, 90, 185 N.E.2d 128, 132 (1962) (duty to protect child's right to live and grow up); *McCord v. Ochiltree*, 8 Blackf. 15, 19-20 (Ind. 1846) (state's duty to look after welfare of those who, tender in age or of unsound mind, are incapable of caring for themselves).

⁶⁷ See Brant, *supra* note 45, at 362-63. See generally Note, *supra* note 57; Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 28 STAN. L. REV. 623 (1976).

action for the protection of the children.⁶⁸

Though the doctrine of *parens patriae* authorizes state intervention for the child's protection, its invocation has been tempered by the long standing preference for decentralized decision making in matters concerning the family. Supreme Court decisions, even before any well formed notion of constitutionally protected privacy had been articulated, consistently reflected an ideological preference for protecting family decision making.⁶⁹ As has been mentioned earlier, this policy preference reflects the view that children profit from the continuous intimate relationship with parents and that, generally, the parent rather than any other decision maker—much less a judge or other government official—is in the best position to make decisions in the interest of the child. Thus under this view, state intervention is appropriate only where parental decision making is clearly contrary to the interest of the child.⁷⁰

However, when also at stake are societal values that have been clearly recognized as serving the state's interest, parental autonomy has not always prevailed. Indeed, in several areas relating to child rearing, the authority of the parent has been overridden because of an important competing state interest: education,⁷¹ vaccination inoculation,⁷² and abortion decisions⁷³ are examples of areas where the courts have been willing to overcome parental autonomy in support of other values deemed important by the state. But the number of these instances is small because a policy of minimal interference serves the state's own interest. The nurtured family is a source of productive citizens.⁷⁴ Tolerance of individual choice mak-

⁶⁸ *E.g.*, *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971)(chemotherapy treatment ordered); *see Brant, supra* note 45, at 361-68.

⁶⁹ *See* J. GOLDSTEIN, A. FREUD & A. SOLNIT, *BEFORE THE BEST INTEREST OF THE CHILD* (1979); Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645, 654-57 (1977).

⁷⁰ *Id.*

⁷¹ *See, e.g.*, *Wisconsin v. Yoder*, 406 U.S. 205 (1972)(limiting acknowledged power of state).

⁷² *E.g.*, *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

⁷³ *E.g.*, *Bellotti v. Baird*, 443 U.S. 622 (1979).

⁷⁴ *See* *Moore v. City of East Cleveland*, 431 U.S. 494 (1977); *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *Abrams, Problems in Defining Child Abuse and Abuse and Neglect in*

ing in parenting, moreover, can contribute to the diversity of society, in itself considered to be a desirable social good.⁷⁶ As in the case of medical treatment decisions for incompetents, the troublesome problem is the lack of a satisfactory standard for making that determination. The "best interest of the child" standard, which is generally applied in abuse and neglect cases, has been criticized as "inherently indeterminate,"⁷⁶ allowing overly broad discretion by a judge who may inappropriately give expression to his own value preferences or supposed societal preferences in *derogation* of the child's interest. Even if parental discretion should be limited under some circumstances in pursuit of other societal interests, those interests ought at least to be clearly defined and identified as reflective of strong societal consensus before parental authority is constrained. There is substantial risk that a decision made under the guise of a best interest standard will neither protect the child's interest nor truly reflect values widely shared by society.⁷⁷

The effects of abridging the decision making power of the parent, moreover, may have profound effects on the child's well being. There is the risk that the family ties will be broken.⁷⁸ It is ques-

HAVING CHILDREN (1979); Goldstein, *supra* note 69.

⁷⁶ Beyond undercutting the richness of diversity, state intervention thereby limiting parental discretion in family decision making presupposes that there are identifiable community norms which ought to govern child-rearing practices. A general policy favoring parental autonomy, on the other hand, recognizes the general lack of community consensus about what is best for the child and encourages experimentation when it is not clearly contrary to the interests of the child. In short, the state is served by the promotion of a way of life which is family-oriented, relieving the state from supervision of child development. Thus in questionable circumstances it may be preferable that the state not intrude for the sake of preserving its policy favoring the family structure. Abrams, *supra* note 74; Blustein, *Child Rearing and Family Interest*, in HAVING CHILDREN 115 (1979); Goldstein, *supra* note 69, at 657; see *Wisconsin v. Yoder*, 406 U.S. 205, 231-33 (1972).

⁷⁶ See Note, *supra* note 57, at 1391; Mnookin, *supra* note 54, at 256, 264; Katz, *Foster Parents vs. Agencies: A Case Study in the Judicial Application of "The Best Interests of the Child" Doctrine*, 65 MICH. L. REV. 145, 153 (1966).

⁷⁷ Abrams, *supra* note 74; Goldstein, *supra* note 69, at 654-55. It can be argued that the family serves as a buffer between the child and state, and that thus judicial and other state intervention should be restricted. *But see Wisconsin v. Yoder*, 406 U.S. at 243 (Douglas, J., dissenting). See Goldstein, *supra* note 69, at 654; Schoeman, *Rights of Children, Rights of Parents and the Moral Basis of the Family*, 91 ETHICS 6 (1980) (defining parent-child relationship in terms of societal intrusion); Tribe, *Childhood, Suspect Classifications and Conclusive Presumptions: Three Linked Riddles*, 39 LAW & CONTEMP. PROBS. 8, 36 n.85 (1975).

⁷⁸ *E.g.*, GOLDSTEIN, A. FREUD & A. SOLNIT, *supra* note 69, at 16. Goldstein argues that in

tionable, moreover, whether the state has the capacity or resources to ensure that an adequate substitute for the family environment can be developed, or that the previous parent-child relationship can be restored.⁷⁹

Where medical treatment is at issue, doctors are introduced into the conflict of who decides for the child. In light of the importance of family integrity and parental authority in the interest of the young child's development, the right of parental decision making generally prevailed in the past—even over medical judgment—in most circumstances where non-life threatening decisions were being made.⁸⁰ In life threatening circumstances, however, the question of who should decide becomes more complex, particularly in the case of a newborn.

Until recently, there had been little refinement of the moral, medical, and legal issues raised by disagreement among the potential decision makers. The controversy about who decides has

cases where there are allegations of child abuse, including allegations of withholding life-preserving medical treatment, the state must overcome a strong presumption that the decision making was made in the child's best interest. The standard of inquiry he proposes to apply in the case of medical treatment is whether no reasonable person would agree that the withholding of treatment under the circumstances would be preferable. Goldstein, *supra* note 69, at 652. A state which has challenged the parent's decision making in such a case would have the duty to provide the child with appropriate emotional, medical, and other necessary support in loco parentis, through adoption or institutionalization, to replace the bond that has been broken and naturally assumed by the parent. *Id.* at 657. In the case of a child with ongoing medical problems, since he or she is in need of attention as well as the day to day other needs of a child, it is questionable whether the state can in fact live up to these responsibilities. See J. GOLDSTEIN, A. FREUD & A. SOLNIT, *supra* note 69; Roe, *supra* note 6, at 89; Longino, *Withholding Treatment from Defective Newborns: Who Decides, and on What Criteria?*, 31 KAN. L. REV. 377, 397 (1983); see also Schrag, *Children, Their Rights and Needs*, in WHOSE CHILD? 243-44 (1980).

⁷⁹ See *supra* note 74.

⁸⁰ See, e.g., *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955)(harelip and cleft palate); *In re Frank*, 41 Wash. 2d 294, 248 P.2d 553 (1952)(speech impediment); *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972)(spinal fusion operation); see also *Deciding to Forego Life-Sustaining Treatment: President's Commission for the Study of Ethical Problems in Medicine & Biomedical and Behavioral Research* (March 1983), reprinted in III BIOETHICS REP. 571-79 (1983) [hereinafter cited as *Deciding to Forego Life Sustaining Treatment*. But see, e.g., *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S. 2d 641 (N.Y. Fam. Ct. 1970), *aff'd*, 37 A.D.2d 668, 323 N.Y.S.2d 253 (1971), *aff'd*, 29 N.Y.2d 900, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972)(severe facial deformity); *Custody of a Minor*, 378 Mass. 732, 393 N.E.2d 836 (1979)(cancer treatment nutritionally suspect).

heightened now for several reasons: First, the preeminent role of the doctor as the decision maker has been questioned in the informed consent cases and the developing case law concerning the treatment of other incompetents. This development may have led both to greater awareness of conflict in decision making authority among parents and doctors, as well as increased sensitivity to the potential legal effects of undue deference or allocation of decision making responsibility on the part of hospitals.⁸¹ Second, the increasing recognition of the individual rights of children has led to heightened concern for the protection of the interests of children who cannot themselves make decisions, tempering the recognition of parental or family autonomy.⁸² Third, the right to life movement relating to the highly controversial abortion decisions has spawned both an interest in societal protection of the interests of the child as well as general interests of the society in preserving the ethos of the sanctity of life. Finally it appears that issues related to the family have recently become more politicized than in the past, perhaps in reaction to the privacy notions that supported the abortion cases, and in response to heightened awareness of child abuse.⁸³

Debate focused on the question of withholding or withdrawing treatment for infants surfaced in medical, ethical and legal literature scarcely a decade ago.⁸⁴ Recently, these issues have provoked political controversy and hostility toward the tendency to "priva-

⁸¹ See *Darling v. Charleston Community Memorial Hosp.*, 33 Ill. 2d 326, 211 N.E.2d 253 (1965), *cert. denied*, 383 U.S. 946 (1966).

⁸² See, e.g., Kett, *The Search for a Science of Infancy*, 14 HASTINGS CENTER REP., Apr. 1984, at 34; Macklin, *supra* note 15. See generally M. GLENDON, *supra* note 57.

⁸³ See, e.g., Baron, *Medicine and Human Rights: Emerging Substantive Standards and Procedural Protections for Medical Decision Making within the American Family*, 17 FAM. L.Q. 1 (1983); Silverman, *Mismatched Attitudes About Neonatal Deaths*, 11 HASTINGS CENTER REP., Dec. 1981, at 12.

⁸⁴ Some of the most provocative and sensitive of the early literature include: Duff & Campbell, *supra* note 4; Englehardt, *Euthanasia and Children: The Injury of Continued Existence*, 83 J. EDUC. 170 (1973); Freeman, *The Shortsighted Treatment of Myelomeningocele: A Long-Term Case Report*, 53 PEDIATRICS 311 (1974); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975); Shaw, *Dilemmas of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 886 (1973); Smith, *On Letting Some Babies Die*, 2 HASTINGS CENTER REP., Dec. 1974, at 37; Tooley, *Abortion and Infanticide*, 2 PHIL. & PUB. AFF. 37 (1972).

tize" treatment decisions relating to infirm infants, as had been done with decisions concerning other incompetents.

II. POLITICAL RESPONSE TO WITHHOLDING TREATMENT FOR INFANTS

It was doctors—not parents, right to life supporters, or other group members—who brought to the forefront the question whether withholding of treatment for newborns could, in some cases, be justified. In the midst of controversy concerning the limits of informed consent in medical decision making, and at the time of the first responses anticipating the decision in *Roe v. Wade*,⁸⁵ two physicians familiar with the practices of neonatal care units extended those debates by publicly acknowledging an "open secret"⁸⁶—namely, that some doctors in critical care nurseries made decisions to withhold medical treatment, often without the knowledge or consent of the parents of the affected newborns. In a professional journal, the doctors provided statistical evidence of such decision making in the Yale-New Haven Hospital and suggested that similar conduct took place in other units in hospitals throughout the country.⁸⁷ They urged that steps be taken to legitimize those actions taken by doctors.⁸⁸

The journal article provoked Congressional hearings⁸⁹ but no legislative action. It did spur commentary from doctors and other medical professionals, from lawyers, and from ethicists and other philosophers.⁹⁰ Most of this discussion centered on whether all human life should be protected or whether quality of life distinc-

⁸⁵ See, e.g., Tooley, *supra* note 84. See also Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, 2 HASTINGS CENTER REP., Nov. 1972, at 1.

⁸⁶ Duff & Campbell, *supra* note 4, at 894.

⁸⁷ *Id.* at 890. The doctors reported 299 deaths of disabled infants over a period of thirty months in the neonatal care unit. Eighty-six percent of those deaths were related to pathologic conditions that developed despite aggressive treatment. The remaining 43 deaths were associated with severe impairment from congenital disorders for which there were decisions not to treat.

⁸⁸ *Id.* at 894.

⁸⁹ See 1974 Hearings, *supra* note 1.

⁹⁰ See *supra* note 78. The controversial article continues to provoke harsh response, leading at least one of the commentators to question its service. Conversation with Dr. Raymond S. Duff, Yale-New Haven Hospital, Mar. 22, 1984.

tions could support the withholding of a "right" to life at some stage of infant development—often as an extension of arguments favoring or precluding the right to abortion.⁹¹ Some arguments focused on the role of the medical profession in making life and death decisions, an authority which had been questioned by the doctrine of informed consent.⁹²

The shift from theoretical discussion to political debate was subsequently provoked by publicity concerning the decision of two Bloomington, Indiana parents to reject life saving measures as treatment for a newborn with Down's Syndrome.⁹³ The Indiana courts affirmed the authority of the parents to make the decision.⁹⁴ The baby died as lawyers were seeking further alternatives for legal intervention.⁹⁵

Notably, in this Baby Doe case, the life threatening infirmities that warranted medical intervention were separable from the permanent mental retardation that would limit, but not negate, the infant's potential for physical and mental development. Thus, the

⁹¹ See Fletcher, *Four Indicators of Humanhood—The Enquiry Matures*, 4 HASTINGS CENTER REP., Dec. 1974, at 4. In addition some commentators have emphasized that there is an historically manifested societal ambivalence about the preservation of infants. See, e.g., Silverman, *supra* note 83; Kett, *supra* note 82.

⁹² See Veatch, *The Technical Criteria Fallacy*, 7 HASTINGS CENTER REP., Aug. 1977, at 15; Robertson & Fost, *Passive Euthanasia of Defective Newborns: Legal Considerations*, 88 J. PEDIATRICS 833 (1976); *Focus: Current Issues in Medical Ethics*, 7 J. MED. ETHICS 117 (1981).

⁹³ See *Baby Dies Before Court Could Be Asked to Save It*, Boston Globe, Apr. 16, 1982, at 7, col. 1; Tift, *Debate on the Boundary of Life*, TIME, Apr. 11, 1983, at 68, col.1. Several other cases have received similar news publicity and public attention: Freeman, *The God Committee*, N.Y. Times, May 21, 1972, § 6 (Magazine), at 84; Fletcher, *supra* note 85; N.Y. Times, Jan. 30, 1972, at 44 (Down's syndrome newborn denied low risk operation); Robertson, *Dilemma in Danville*, 11 HASTINGS CENTER REP., Oct. 1981, at 5 (siamese twins); *The Moral Dilemma of Siamese Twins*, NEWSWEEK, June 22, 1981, at 40, col. 1 (siamese twins); see also Ellis, *supra* note 1, at 398-401 (discussing cases).

⁹⁴ *In re Infant Doe*, No. 608 204-004A (Monroe County Cir., Apr. 1982)(declaratory judgment), writ of mandamus dismissed *sub nom.* State *ex rel.* Infant Doe v. Bloomington Hosp., cert. denied, 464 U.S. 961 (1983).

⁹⁵ See *Baby Dies Before Court Could Be Asked to Save It*, *supra* note 93. Monroe County prosecutors did not file criminal charges against either the parents or doctor who had advised them. *Charges Weighed for Parents Who Let Baby Die Untreated*, N.Y. Times, Apr. 17, 1982, at 6, col. 1. There have been several attempts to prosecute parents and doctors who made nontreatment decisions but none have been successful, See Note, *supra* note 1, at 233, 234-35.

controversy concerning infants afflicted with permanent life threatening conditions requiring medical treatment for mere sustenance was not present in that case. Moreover, many doctors would agree that a Down's Syndrome child like Baby Doe would not present a case where the withholding of treatment could easily be justified since the congenital anomaly that threatened life was amenable to surgical correction.⁹⁶ Nor did the Baby Doe case clearly involve the more ethically and medically troublesome question of whether life sustaining measures to preserve the infant's life would have any moral significance insofar as the mental or physical defects were so great as to seriously impair the expected quality of life and chances for independent existence.⁹⁷ Finally, the doctor, with the parents' approval, had ordered withdrawal of food and water, hastening the death of Baby Doe. The Baby Doe case to some presented an instance of an extraordinary free-wheeling exercise of decision making, backed by the court.⁹⁸ Cast in this extreme, a simple judicial affirmation of private decision making belied the complexity of the issues engendered by the typical case. It prompted heated response from advocates of the handicapped and right to life groups—and spurred political action.⁹⁹

Two weeks after Baby Doe died, President Reagan sent a memorandum to the Attorney General and the Secretary of the Department of Health and Human Services (HHS), citing the "Baby

⁹⁶ See *Infant Doe*, at 1. The concern in this case expressed by doctors and parents was that due to his mental retardation the infant would not have a minimally adequate quality of life. *Id.* at 2, 3. Surveys of pediatricians and pediatric surgeons have indicated that physicians favor passive and active euthanasia in a broad range of cases and a sizable percentage include cases of Down's Syndrome with no lethal complications. Post, *Putting Hospitals on Notice*, 12 HASTINGS CENTER REP., Aug. 1982, at 5; Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A Nationwide Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588-99 (1977)(cited in Robertson, *supra* note 93, at 6 n.9).

⁹⁷ See *Deciding to Forego Life Sustaining Treatment*, *supra* note 80, at 587-90; McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 1 BIOETHICS REP. 1197 (1983).

⁹⁸ Compare, e.g., 130 Cong. Rec. S 8953 (Nat Hentoff article) with, e.g., J. LYON, *PLAYING GOD IN THE NURSERY* 21-39 (W.W. Norton ed. 1985).

⁹⁹ As a result of reports of another case during the same month the Spina Bifida Association called for an investigation by HHS. *Sounding Board: The Government and Selective Nontreatment of Handicapped Infants*, 1 BIOETHICS REP. 1209 (1983) [hereinafter cited as *Sounding Board*].

Doe” case and noting that federal law prohibits discrimination against the handicapped.¹⁰⁰ In response, the Secretary, on May 18, 1982, issued a “notice” to health care providers “to remind affected parties of the applicability of Section 504 of the Rehabilitation Act of 1973.”¹⁰¹ The notice stated that Section 504 made it unlawful for hospitals receiving federal financial assistance to withhold nutrition or medical or surgical treatment from “handicapped infants” if required to correct a life threatening condition, and suggested that the withholding of parental consent for treatment should not be “aided” by allowing the infant to remain in the receiving institution.¹⁰² The notice further stated that failure to comply with Section 504 subjected institutions which were financial aid recipients “to possible termination of Federal assistance.”¹⁰³

Invoking the authority of Section 504, the Secretary subsequently promulgated an “interim final rule,” requiring hospitals and other medical institutions receiving financial assistance to permanently post “in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward and each nursery, including each intensive care nursery”¹⁰⁴ a notice, *inter alia*, stating:

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: Handicapped Infant Hotline . . . or your State Child Protective Agency . . . Identity of callers will be held confidential.¹⁰⁵

Federal investigators—nicknamed Baby Doe squads—had twenty-

¹⁰⁰ *Id.* Section 504 of the Rehabilitation Act of 1973 provides:

No otherwise qualified handicapped individual . . . shall, solely by reason of his 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.

29 U.S.C. § 794; *see infra* note 121.

¹⁰¹ Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers, 47 Fed. Reg. 26,027 (1982)(Office for Civil Rights, HHS).

¹⁰² *Id.*

¹⁰³ *Id.*

¹⁰⁴ Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9,630 (1983)(modifying 45 C.F.R. 84.61)(Office of the Secretary, HHS).

¹⁰⁵ *Id.* at 9,631-32.

four hour access to hospital records and facilities during any investigation and could subject physicians, families and hospital staff to immediate questioning on the scene.

The American Academy of Pediatrics and other medical associations challenged the regulation in the district court.¹⁰⁶ Terming the regulation "novel and far-reaching,"¹⁰⁷ the court concluded that the rule offended the requirements of the Administrative Procedure Act¹⁰⁸ since the agency had failed adequately to consider factors central to the application of Section 504 to medical care of newborn infants before promulgating the rule. In particular, the court determined that HHS had made no weighing of the "disruptive effects of the twenty-four hour or toll free 'hotline,'" nor considered the effects of the "sudden descent of 'Baby Doe' squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment."¹⁰⁹

Although the court declared the regulation invalid on the basis that it was arbitrary and capricious, and in violation of the procedural requirements of the APA, it also noted its concern that the regulation exceeded authority extended by Congress under Section 504 concerning civil rights protection of the handicapped.¹¹⁰ Moreover, though it hedged on the consideration whether the regulation infringed on constitutional privacy interests expressed by the Supreme Court, the court did state that "the regulation is intended, among other things, to change the course of medical decision mak-

¹⁰⁶ American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983). The Academy had issued an official position concerning the HHS action:

The effort of the executive branch to solve this complex problem through strict interpretation and enforcement of the letter of section 504 may have the unintended effect of requiring treatment that is *not* in the best interest of handicapped children Withholding a medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients.

Official Statement of the American Academy of Pediatrics, June 21, 1982; *see infra* notes 121-22.

¹⁰⁷ 561 F. Supp. at 397.

¹⁰⁸ *Id.* at 398-401.

¹⁰⁹ *Id.* at 399-400.

¹¹⁰ *Id.* at 401-02. Even the advocate groups, which supported the government in briefs filed *amicus curiae*, conceded that the rule was poorly drawn and could be improved. *See American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 at 11 & n.4; *infra* note 121.

ing in these cases by eliminating the *parents' right to refuse to consent to life-sustaining treatment of their defective newborn.*"¹¹¹ The court—as well as the parties—assumed there was a parental right to refuse treatment, though the source of that right, when it arose, and how it could be delimited, were not defined.¹¹²

Soon after the pediatricians' challenge, New York appellate courts let stand parental refusal to consent to treatment for "Baby Jane Doe" who was suffering from multiple birth defects, including myelomeningocele (spina bifida, as it is more commonly known), despite a contrary ruling of the trial court and an attempt by an unrelated attorney to represent the child and consent to treatment.¹¹³ The Baby Jane Doe controversy continued, however, when HHS, acting on an anonymous discrimination complaint it had re-

¹¹¹ 561 F. Supp. at 401 & n.6.

¹¹² In addition to ruling on the basis of the other procedural infirmities of the regulations, the court found that the record disclosed no weighing by the Agency of "sensitive considerations touching so intimately on the quality of the infant's expected life." *Id.* at 400. The rulemaking was silent concerning "legal and constitutional considerations," and the Agency apparently had failed to review alternatives available for regulatory action, including those suggested by the soon-to-be-published report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Id.* The Commission itself criticized the HHS notice and interim rule as adding uncertainty. *Deciding to Forego Life Sustaining Treatment, supra* note 80, at 595-97. The Commission rejected such governmental intrusion into the decisionmaking process and proposed that a review process be established within hospitals, including committees utilized for review of the difficult cases. *Id.*

¹¹³ See *United States v. University Hosp., State Univ. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984), *aff'g on other grounds*, 375 F. Supp. 607 (E.D.N.Y. 1983). The state court action was initiated by A. Lawrence Washburn, a Vermont attorney who had learned that Baby Jane Doe's parents, in consultation with her doctor, had decided to forego surgical "shunt" procedures. Washburn sued to represent the child as guardian ad litem to seek an order to commence the surgical treatment. 729 F.2d at 146. Though the parents and doctors agreed that the procedures were not in the child's best interest, the trial court was persuaded to the contrary and ruled that a guardian should be appointed. Both appellate state courts which heard the matter on review disagreed with the trial court decision, but ruled on different bases: the Appellate Division of the Supreme Court ruled that the conservative course of treatment chosen by the parents was in the best interest of the infant and, therefore, there was no basis for judicial intervention. *Id.* at 147. The New York Court of Appeals affirmed the result, but on the basis that Washburn had failed to utilize the appropriate child neglect procedures available for challenging parental decision making, and, since the trial court also had failed to seek the state's abuse and neglect agency's investigative assistance, that court had abused its discretion by permitting the proceeding to go forward. *Id.*

ceived during the state court proceedings, brought a federal suit against the hospital. The agency alleged that the hospital had violated the revised regulation and Section 504 by refusing to allow HHS access to Baby Jane Doe's records.¹¹⁴ Baby Jane Doe's parents intervened as defendants.

The district court ruled in favor of the hospital and parents and was affirmed on appeal.¹¹⁵ The court concluded that the hospital "failed to perform the surgical procedures in question, not because Baby Jane Doe is handicapped, but because her parents have refused to consent to such procedures."¹¹⁶ Moreover, the court concluded that the parents' decision "was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interest of the child."¹¹⁷

On appeal, the court concluded that Congress never contemplated that Section 504 would apply to medical treatment decisions involving defective newborns—particularly as was required by the regulatory action of HHS.¹¹⁸ The court added, "congress, rather than an executive agency . . . must weigh the competing

¹¹⁴ Notably, HHS had referred the complaint to the state agency responsible for investigating suspected incidents of child abuse, mistreatment and neglect. But that agency subsequently concluded that there was no cause for state intervention. Before that conclusion was reached, however, HHS pursued the federal action when the hospital refused to make available those records concerning Baby Jane Doe which had not been made public as a result of the state litigation. 729 F.2d at 147. The case was the first in which a suit against a federally assisted hospital was lodged by HHS pursuant to the revised ruling, 45 C.F.R. § 80.6(c) (as incorporated by 45 C.F.R. § 84.61), for refusal to make available records for inspection in an investigation relating to a disabled infant. See Kerr, *Reporting the Case of Baby Doe*, 14 HASTINGS CENTER REP., Aug. 1984, at 7.

The HHS revised regulations continue the use of the "hotline" and the posting of notices but "merely" require the posting in a "conspicuous" place near the neonatal care area. The revised rule emphasized that section 504 comes into effect only "when non-medical considerations such as subjective judgments that an unrelated handicap makes a person's life not worth living, are injected in the decision-making process." The rule exempts terminally ill infants and others for whom treatment would be futile from the regulation. In addition, the regulation requires state protection agencies to work with HHS. See 48 Fed. Reg. 30, 846 (1983). But despite those changes, the regulation still retains an intrusive, threatening nature; *infra* note 121.

¹¹⁵ 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

¹¹⁶ 575 F. Supp. at 614.

¹¹⁷ *Id.* at 615

¹¹⁸ 729 F.2d at 154, 160-61.

interests at stake."¹¹⁹

Although the lawsuits that challenged the HHS regulations differed in approach,¹²⁰ neither court forthrightly challenged Congress' capacity to provide that the withholding of treatment from profoundly infirm newborns because of disabilities violated their civil rights. Rather, each court concluded that HHS's inclusion of the medical treatment decisions under existing civil rights laws for the protection of the handicapped was beyond the contemplation of the lawmakers at the time the laws were passed.¹²¹ The courts thus challenged Congress to respond.

Congress responded to the courts' actions in a delicately bal-

¹¹⁹ *Id.* at 161.

¹²⁰ Compare 561 F. Supp. at 401-02 with 729 F.2d at 151-63.

¹²¹ Part of the reason for this conclusion was that the arguments raised by HHS to substantiate its authority for the regulatory action were strained. Moreover, before initiating the action, HHS had failed to permit public comments on the proposed rulemaking. Quite clearly, the federal courts were persuaded that the agency had paid inadequate attention to defining and detailing what was unlawful, discriminatory conduct, constituting a violation of the civil rights of the handicapped. The regulatory provision simply did not adequately distinguish cases where a handicap disqualified the infant from treatment from other cases where the handicap was not the basis for decision making relating to the infirm infant. See *supra* note 114. The court thus rejected agency reasoning that the problem of withholding medical treatment from infants was merely an extension of existing civil rights protection for the handicapped. By the courts' language, however, there is the suggestion that they were troubled by the absolute position taken by HHS that no decision could be made taking into account the profound disability of the infant. Given the complexity of that issue, the courts were understandably troubled by the grossly intrusive investigative procedures established by HHS and the lack of evidence that HHS had conscientiously sought information on or reflected upon the relevant medical, social and ethical concerns or considered alternatives that accommodated the competing interests at stake. HHS, however, has taken the position that the regulations promulgated pursuant to the compromise legislation do not preclude its utilization of the challenged revised rule pursuant to section 504 if the HHS appeal which is awaiting decision by the Supreme Court is successful. See 50 Fed. Reg. 14,884-85 (1985); see also *Bowen v. American Hosp. Ass'n*, 54 U.S.L.W. 3507, Feb. 4, 1986. In the spirit of their compromise coalition, a part of which included professional groups and others strongly opposed to the intrusive nature of the section 504 regulation, the Senate sponsors have consistently disclaimed any position connected with HHS's interest in utilizing section 504. The sponsors invoked a policy of neutrality. See 130 CONG. REC. S12,392 (daily ed. Sept. 28, 1984)(letter to Sen. Weicker); see also *id.* at 59,307 (daily ed. Jul. 26, 1984)(remarks of Sen. Kassebaum concerning intrusion). On January 15, 1986, the Supreme Court heard argument on the issue whether section 504 prohibits a hospital receiving financial assistance from withholding medically indicated treatment "or otherwise discriminating against" a disabled child. *Bowen v. American Hosp. Ass'n*, 54 U.S.L.W. 3507, Feb. 4, 1986.

anced compromise effort supported by right to life groups and advocates for the rights of the handicapped, who had favored extending civil rights protection to the withholding of treatment of infants, and some doctors and members of related professional organizations who had decried the gross federal interference in medical decision making effected by the HHS regulation.¹²² In contrast with the controversial civil rights focus of the regulations, the compromise measure was tied to child protection under the Child Abuse Prevention and Treatment Act and the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978.¹²³ Thus the compromisers linked the highly charged issue of withholding medical treatment to the general problem of preventing and treating child abuse—a matter about which there has been increasing public awareness and alarm and general support for further regulatory action.¹²⁴

This compromise legislation was enacted on October 9, 1984 with little public attention.¹²⁵ The approach taken by the legislation

¹²² For a listing of organizations which supported the compromise legislation, see 130 CONG. REC. S9324 (daily ed. Jul. 26, 1984)(remarks of Sen. Nickles). The AMA did not join the other medical professional organizations in endorsing the legislation, apparently in the belief that there ought to have been some direct consideration of quality of life factors which bear on a decision to withhold treatment and that decision making related to the withholding of treatment should be a private matter. *See* Kerr, *supra* note 114, at 9. On the other hand, the American Academy of Pediatrics, which had led the challenge against the HHS regulations under section 504, did support the compromise effort. *See id.* That organization had been roundly criticized by the Administration and other pro life groups for guidelines which the Academy had proposed because they were process-oriented and failed to clearly and unequivocally adopt the "best-interest-of-the-child" standard as a substantive criterion for decision making. The guidelines had provided for mandatory committee review in all cases in which foregoing life sustaining treatment is proposed and discretionary review in other cases. *See* American Academy of Pediatrics, Principles of Treatment of Disabled Infants (Nov. 29, 1983).

¹²³ Pub. L. No. 98-457, 98 Stat. 1749 (1984)(to be codified at 42 U.S.C. §§ 5101-5104).

¹²⁴ *See* 130 CONG. REC. H10,327 (daily ed. Sept. 26, 1984)(remarks of Rep. Murphy).

¹²⁵ Writer Nat Hentoff has observed that silence rather than political fanfare ushered in the legislation because two rival, competing Administration camps could not agree. The pro-life, anti-abortionists wanted the Administration to take a strong vitalist position; the budget conscious, anti-federalist faction feared further assistance which would entail federal budgetary support. Neither group was clearly vindicated in the resulting compromise. Thus, in contrast with the political election year response which was reflected in the earlier HHS regulatory response to Infant Doe (*see supra* notes 92-97 and accompanying text), the silence at the passage of the legislation was deafening. Address by Nat Hentoff, Yale Right to

and implementing regulations, however, may have some significance other than to those who may find themselves confronted directly with a decision as to whether treatment should be withheld from their child. This is because of the legislation's focus on medical determinations concerning the benefits of sustaining life in situations of uncertainty and the use of committees and child abuse agencies to monitor treatment decisions, according to the regulations' standards.

The reliance on professional judgment concerning medically indicated treatment as a principal focus suggests a shift in the allocation of responsibility for decision making away from the parent. This reliance, however, is not a satisfactory way to deal with the complex moral issues at stake. Even if that shift avoids a federal intrusion in the decision making process, it reinforces the image of the doctor as the monolithic decision maker, an image that has been challenged over the last two decades in other medical decision making contexts.

The legislation has several distinctive features. First, it defines the problem as the "withholding of medically indicated treatment," considered to be medical neglect, except under certain limited circumstances where treatment is not considered "medically indicated." They include where: (1) the infant is "chronically and irreversibly comatose;" (2) the treatment will merely "prolong dying"; or will not correct or ameliorate all of the life threatening conditions; or the treatment is "futile in terms of the survival of the infant"; and (3) the treatment would be "virtually futile in terms of the survival" of the infant and "inhumane" in light of the condition of the infant.¹²⁶ It relies on "reasonable medical judgment" as the determinative factor and standard of decision making.¹²⁷

Second, the legislation requires state recipients of federal abuse program funds to maintain procedures which respond to reports of the withholding of medically indicated treatment, thus placing

Life Group (November 1984).

¹²⁶ 98 Stat. 1752 (amending 42 U.S.C. § 5102).

¹²⁷ *Id.*

responsibility on existing state child protection service systems rather than the federal government to respond to and investigate allegations of medical neglect.¹²⁸ Third, it authorizes grants for and requires that there be identification and provision of educational and other child care support services for affected families. The state agencies, in cooperation with the health care facilities, are to set up programs of assistance for affected families in identifying support services.¹²⁹ Health care facilities are encouraged to establish committees to educate hospital personnel and families of disabled infants, to recommend institutional policies and guidelines about withholding treatment, and to offer counsel and review. For this purpose, the Secretary of HHS was authorized to propose and promulgate regulations concerning hospital review committees¹³⁰

¹²⁸ *Id.* (amending 42 U.S.C. § 5103 (b)(2)).

¹²⁹ 98 Stat. 1753 (amending 42 U.S.C. § 5103).

¹³⁰ Pub. L. No. 98-457, 98 Stat. 1754 (amending 42 U.S.C. § 55103); see HHS Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893 (1985) (Office of Health and Human Services). These guidelines which are "purely advisory," recommend that health care facilities, especially facilities with tertiary level neonatal care units, establish Infant Care Review Committees (ICRC's) with educative, counseling and reviewing functions. It is recommended that those committees also recommend institutional policies "consistent with the statute and regulations." See *infra* notes 131, 146, 151 (concerning withholding of medically indicated treatment). The Secretary recommended that the ICRC's have a "multidisciplinary approach" and be composed at least of core members including a practicing physician, a practicing nurse, a hospital administrator, a social worker, a representative of a disability group, a lay community member, and a member of the facility's organized medical staff; law and clergy representatives are suggested as optional members. A primary aim of the guidelines is to establish a centralized agency for gathering up to date and complete information concerning medical treatment procedures and resources in the hospital with which the committee is affiliated and in others with which the hospital has referral agreements, and concerning support programs and services available for disabled infants and their families. In addition, it is proposed that ICRCs offer counsel and review prospectively and retrospectively in cases in which treatment decisions are presently being or will in the future be made. The regulations recommended that one member of the ICRC be appointed a "special advocate" for the infant, to ensure that "all considerations in favor of the provision of additional treatment are fully evaluated and considered." 50 Fed. Reg. at 14,896.

HHS has recommended that after hearing from affected parties, the ICRC have authority to render a recommendation about whether to undertake treatment when there is disagreement between doctors and families about appropriate treatment or when doctors and families agree to withhold treatment that is contrary to the federal regulation. See *id.* A decision about withholding treatment is to be made "in accordance with the policies, principles and procedures" which include "interpretive definitions" established by HHS, "clarifying" and "defining" terms relating to the withholding of medically indicated treatment. See *infra*

and decision making procedures in health care facilities, in addition to other regulations to implement the legislation,¹³¹ and is to report to Congress in 1987 on the effects of the regulatory effort.

The legislative provisions have been called a "classic compromise."¹³² As an alternative to the earlier HHS regulations, this regulatory approach is certainly preferable. Both the interim final rules and the subsequent modified version of the HHS regulations promulgated pursuant to Section 504 were hastily drawn, counter-productive, grossly intrusive actions,¹³³ and were clearly immediate

note 151; 50 Fed. Reg. 14,896. If there is disagreement between doctors and the family concerning the withholding and the ICRC concludes that treatment is warranted under the legislation and "basic policy" reflected in the guidelines, as well as interpretive definitions presented by HHS, see 50 Fed. Reg. 14,895; *infra* note 151, the ICRC will recommend referral to an appropriate court or child protective service agency and will recommend that the status quo be preserved (or efforts be made to prevent the infant's condition from worsening) until a decision is made or action taken.

Finally, the ICRC is proposed to have retrospective review of records involving withholding or terminating treatment to determine whether institutional policies have been followed. Institutional policies are to follow the "basic policy" set forth in the Act, as well as HHS interpretive definitions.

¹³¹ 98 Stat. 1754. HHS promulgated final rules and responded to over 116,000 comments submitted in reaction to its proposed rulemaking, 49 Fed. Reg. 48,160 (1984). Principal sponsors of the legislation had asked that HHS consider whether parts of the proposed regulations, particularly the binding clarifying definitions, had gone beyond the intent of Congress. In addition, HHS received a bipartisan plea from the Senate to reconsider the proposed regulatory action. In response, HHS did move some questioned phrases included in the proposed rules to an appendix described as "interpretive guidelines" for doctors and hospitals. See *infra* note 151. These "guidelines," however, are recommended to govern the policy setting and implementing function that is to be performed by the ICRCs discussed *supra*, and are to guide medical personnel. Thus it appears that, despite the critical reaction to its proposed rules' definitions, the HHS has maintained them as substantive directions for the principal decision makers. It can be expected that the effect of retaining the life preserving focus in the definitions termed "interpretive guidelines" will be to upset the delicate balance of the legislative action and provoke misguided action on the part of overly cautious doctors, or zealous scrutiny by committees and state abuse agencies. Such action may be contrary to the interest of the child.

¹³² 130 CONG. REC. S9,321 (daily ed. Jul. 26, 1984)(remarks of Sen. Hatch).

¹³³ See e.g., Annas, *Disconnecting the Baby Doe Hotline*, 13 HASTINGS CENTER REP., June 1983, at 14. The posted notices and hotline seemed designed to evoke fear rather than reflection about moral choices to be made. See *supra* notes 100-21 and accompanying text. They also encouraged duplicity and an atmosphere of distrust. There is evidence that the heavy handed approach was uncalled for. From March 17 to April 14, 1984, for example, there were over 600 "hotline" calls; only sixteen included specific allegations warranting further action. *Id.* Moreover, HHS had provided no opportunity for public comment before promulgating the rule. See 561 F.Supp. at 399-400. As was observed in *American Academy*

political responses to an issue that demanded further reflection and deliberation. In contrast, there is a more conciliatory thrust to the legislation. It focuses on offering child abuse grants to states as incentives to regulate the withholding of treatment rather than utilizing the coercive sanction of depriving health care facilities of funds for federal civil rights violations.¹³⁴ In addition to reasserting primary responsibility for investigating improper treatment complaints to state agencies already involved in child abuse concerns, the legislation provides for information gathering and education concerning the condition of severely handicapped infants, as well as support services available to families. The legislation provides for the coordination of investigatory and information gathering activities between the state child protection agencies and the hospital or other health care facilities, which could result in more informal communication aimed at resolution of conflicts.

The role of the proposed review committees, which are to be established by the health care facilities, was undefined by Congress, which left it for consideration of the Secretary of HHS through rulemaking.¹³⁵ The Secretary has responded with advisory guidelines recommending the establishment of Infant Care Review Committees (ICRCs), especially for hospitals that provide tertiary level neonatal care. The committees could be helpful in establishing treatment guidelines and making accessible throughout the country prognostic information concerning the fate of infants considered to be at risk.

There are clear political advantages to the legislative measure over the earlier regulatory efforts. Supporters in Congress, span-

of Pediatrics:

It is clear that a primary purpose of the regulation is to require physicians treating newborns to take into account only wholly medical risk-benefit considerations and to prevent parents from having any influence upon decisions as to whether further medical treatment is desirable. The Secretary did not appear to give the slightest consideration to the advantages and disadvantages of relying on the wishes of the parents, who, knowing the setting in which the child may be raised, in many ways are in the best position to evaluate the infant's best interests.

Id. at 400; see also *Sounding Board*, *supra* note 99.

¹³⁴ See Pub. L. No. 98-457, 98 Stat. 1752-1753 (amending 42 U.S.C. § 5103(b)(2)).

¹³⁵ See *supra* note 130.

ning the political spectrum of views,¹³⁶ brought together interest groups, including those who had urged the government to take a strong vitalism position, advocates of the handicapped, who feared that quality of life exceptions would have a prejudicial impact on infants with mental and physical disabilities, and others, like physicians, who were concerned about governmental intrusion in medical decision making.¹³⁷ Indeed the compromise that was eventually worked out was described by one Congressional supporter as designed "to balance a faith in medical technology against the realities of painful and often uncertain prognoses."¹³⁸

The sparse commentary that accompanied the legislation suggests that lawmakers were concerned about "protecting" parents who were often distraught and incapable of rational, infant focused judgments during their time of grief for their disabled child.¹³⁹ Such a paternalistic motive for relying on medical judgment, however, is not merely contradictory to theoretical concepts of patient autonomy and to the underlying values of parental or family autonomy; most importantly, the legislative deference to medical judgment, without more than passing reference to the critical decision making responsibility of parents, ignores the strong interests of parent and child for maintaining focus on the parent, *particularly* in cases where uncertainty in medical prognostication renders the benefits of treatment questionable.

The introduction of legislative exceptions to the requirement of "medically indicated treatment," aimed at compromise by qualifying an absolute pro life stand,¹⁴⁰ makes sole reliance on medical judgment even more troublesome. As HHS has recognized, the ex-

¹³⁶ See e.g., 130 CONG. REC. S8,956 (daily ed. June 29, 1984)(remarks of Sen. Nickles). Congressional supporters included: Senators Hatch, Denton, Dodd, Cranston, Nickles, and Kassebaum; House members Murphy, Erlenborn, Miller, Barlett, and Hawkins.

¹³⁷ See *id.* at S12,383 (daily ed. Sept. 28, 1984)(remarks of Sen. Denton); *id.* at S12,392 (letter from Senate supporters to Sen. Weicker dated Aug. 20, 1984).

¹³⁸ *Id.* at S9,324 (daily ed. July 26, 1984)(remarks of Sen. Nickles).

¹³⁹ *Id.* at H10,327 (daily ed. Sept. 26, 1984)(remarks of Rep. Murphy); *id.* at S12,383 (daily ed. Sept. 28, 1984)(remarks of Sen. Hatch); see *id.* at H9,805 (daily ed. Sept. 19, 1984)(Conference Report); *id.* at H9,816 (Appendix: Joint Explanatory Statement by Principal Sponsors of Compromise Amendment Regarding Services and Treatment for Disabled Infants.)

¹⁴⁰ See *id.* at S12,389 (daily ed. Sept. 28, 1984)(remarks of Sen. Cranston).

ceptions language can be construed in different ways, giving broad latitude to the medical decision maker.¹⁴¹ What are “virtually futile” efforts? The controversial rules initially *proposed* by HHS explained that this characterization is limited to permitting non-treatment in cases where death is “imminent.”¹⁴² In effect this may relate only to a child “born dying.”¹⁴³ This explanation was criticized as distorting the intent of the legislative compromise and was subsequently modified.¹⁴⁴ But as the public response to the HHS proposed rules attempting to “clarify” the “ambiguities” left by the exceptions suggest,¹⁴⁵ it is clear that doctors—and others—do not agree on the answers to questions relating to the statutory exceptions. Must “heroic” measures be taken despite great risk of imminent death when alternative treatment is not undertaken? What are “heroic” as compared with “ordinary” measures? What risk is high risk for a profoundly infirm infant? How does uncertainty in prognosis affect this decision making matrix? What is the effect of uncertainty about the capacity to manage infirmities resulting from the original disability or anticipated other problems that are expected to manifest themselves later in the infant’s life? How does that answer affect whether a disability can be “corrected”? How does uncertainty about related anticipated problems affect the “futility” consideration? What treatment is “inhuman”? Should that determination be divorced from an assessment of the availability of technical resources or capacity for family support presently or in the future?

¹⁴¹ See 49 Fed. Reg. 48,163-64 (1984)(clarifying ambiguities).

¹⁴² *Id.* at 48,164 (clarifying paragraph). Because of opposition by principal sponsors of the legislation to the use of the word “imminent” to describe death which can be anticipated and to restrain medical discretion, that word was dropped from the final rule even in the clarifying “nonbinding” definitions that were attached as interpretive guidelines in an appendix to the rule. See *supra* note 146; *infra* note 151.

¹⁴³ See P. RAMSEY, *supra* note 34, at 191-201. Ramsey, while eschewing a quality of life approach, attempts to distinguish the child born dying from those for whom benign neglect causes death. Others are skeptical of that clear distinction. See also *The Baby Doe Quandary*, *supra* note 4; Veatch, *supra* note 92. HHS emphasizes that, despite the removal of the term “imminent” to describe death for which no preventative treatment need be required, treatment may not be withheld solely due to a “distant prognosis” of death. 50 Fed. Reg. 14,880 (1985)(HHS’s response to comments on notice of proposed rulemaking).

¹⁴⁴ See 50 Fed. Reg. 14,890-91 (1985).

¹⁴⁵ See *id.* at 14,880-81, 14,890-92.

While the sole statutory reference to medical judgment suggests that these considerations are rationally ascertainable matters peculiarly within the competence of doctors, each necessarily is affected by nonmedical considerations. Thus, to the extent that the legislation and promulgated rules leave the answers to these questions to the judgment of doctors, they allow troublesome evaluative decision making that is not necessarily actually "medical" in focus. By not confronting the fact that the values affect decisions about treatment, the legislative provisions invite discretion by doctors, permitting them to make value judgments in a cast of medical rationality and objectivity.¹⁴⁶ The exceptions, moreover, imply that there is certainty in medical judgment that in fact is lacking. Doctors admit that technological developments in the care of newborns have not clearly advanced prognostic certainty, and results of therapy or nontherapy are often uncertain.¹⁴⁷ In some cases information about survival of newborns allows no more than presumptions about the future to be made.¹⁴⁸ Medical decision making concerning the expectations of more than immediate survival of some infants involves the interpretation of data which is necessarily dependent on the physician's assessment of the quality of survival. As one doctor has pointed out:

When physicians look at statistics relating to treatment, they need to consider not only mortality but also morbidity—that is the quality of survival. In the newborn, when we debate

¹⁴⁶ It is not unusual to hide what are true moral conflicts behind a mask of rational certainty to avoid confronting troublesome choices. Critical of the rise of scientism which he saw as indicative of the "rationalization of life in a modern capitalist society," Max Weber in *Science as Vocation*, observed that:

Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside, or assumes for its purposes, whether we should and do wish to master life technically, and whether it ultimately makes sense to do so.

M. Weber, *Science as Vocation*, in FROM MAX WEBER 144-45 (1946); see also Cassell, *Life as a Work of Art*, 14 HASTINGS CENTER REP., Oct. 1984, at 35; Annas, *The Supreme Court and Abortion and the Irrelevancy of Medical Judgment*, 10 HASTINGS CENTER REP., Oct. 1984, at 23, 24; Annas, *Parents, Children and the Supreme Court*, 9 HASTINGS CENTER REP., Oct. 1979, at 21; Veatch, *supra* note 92. See generally G. CALABRESI & P. BOBBITT, *supra* note 13; Stent, *The Poverty of Scientism and the Promise of Structuralist Ethics*, 5 HASTINGS CENTER REP., Dec. 1976, at 32.

¹⁴⁷ See Todres, *supra* note 5, at 83.

¹⁴⁸ *Id.* at 86.

this quality of survival, it is usually because of the likelihood of a mental or physical handicap or both. At the outset, we must recognize that quality of life is a value judgment that is relative to the person making the judgment.¹⁴⁹

Uncertainty about the future condition of a profoundly disabled infant requires human evaluation of how uncertainty affects life considerations. The reliance on "medical judgment" in the legislative provision does not eliminate discretion that is value laden. It merely places faith in "reasonable" professional judgment about life saving efforts to be made. But it should be recalled that it was reports of doctors who were making judgments about withholding treatment that originally inflamed the Baby Doe controversy.¹⁵⁰

The rules which have been issued by HHS render the legislation even more problematic. The proposed rules purported to remove the "ambiguities" that were present in the definitions presented in the legislation, but they did so in a manner that swallowed up the exceptions and distorted the language which had made possible the compromise.¹⁵¹ By constricting the meaning of the exceptions and

¹⁴⁹ *Id.* at 83.

¹⁵⁰ See *supra* notes 79-99 and accompanying text; see also Darling, *Parents, Physicians, and Spina Bifida*, 7 HASTINGS CENTER REP., Aug. 1977, at 10, 11-12 (negative reactions of physicians toward severely handicapped children conforms with medical judgments to withhold necessary treatment; parents often do not share views); Kelsey, *Which Infants Should Live? Who Should Decide?* 5 HASTINGS CENTER REP., Apr. 1975, at 5 (interview with Dr. Duff concerning the decision making process that families go through in resolving the problems they must face when a severely handicapped baby is born); Moore, *This is Medical Ethics?* 4 HASTINGS CENTER REP., Nov. 1974, at 1 (discussing medical ethics and the point that the physician is ultimately the one who makes decisions in most cases). The President's Commission found that most physicians had not worked out their philosophical positions relating to the question of withholding treatment. *Deciding to Forego Life Sustaining Treatment*, *supra* note 80, at 580.

¹⁵¹ HHS's attempt to eliminate ambiguity in the definition of medically indicated treatment, in effect, removed "medical" discretion and is an indication of the problem of relying on medical or technical criteria as certain and objective. Although in responding to comments, HHS pays lip service to the principal decision making responsibility of parents, its regulatory focus is doctor-centered and based on "reasonable medical judgment." See Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14,878, 14,879-80, 14,890. As modified pursuant to public comments, HHS's clarifying definitions, however, broaden the circumstances where "medically indicated" treatment may be required under the "basic policy" of the legislation. See *id.* at 14,882 (appendix of clarifying guidelines should be referred to by interested parties). It can be said that HHS has fostered the *image*

definitions relating to medical judgment and requiring treatment in situations where certainty is not possible, they in effect attempt

of rationally determinable medical certainty by removing the opportunity to exercise the judgment which led some supporters to join the compromise. It is not at all clear, however, that the Agency position is taken in the child's best interest.

Some "clarifications" made in response to commentators' criticisms of the "clarifying" definitions included in the notice of proposed rulemaking inject further uncertainty concerning the kind of evaluation doctors are required to make. In defining what is a "life-threatening condition," *id.* at 14,889, and necessary "treatment" in the context of multiple treatments, *id.* at 14,890, for example, HHS attempts to defend its overbroad interpretation that treatment is *required*, while emphasizing that the result of any treatment decision must be according to reasonable medical judgment. Responding to the criticism that its definition of the term "not be effective in ameliorating or correcting all of the infant's life threatening conditions," HHS, in effect, abolishes one of the exceptions in the legislative compromise, since HHS says that the withholding of treatment because one of the infant's disabilities is a future life threatening condition is not permitted. *Id.* at 14,891. It then vaguely defines "future life-threatening condition" as one which "although not life-threatening in the near future, will become life-threatening in the more distant future." *Id.* The clarifying definitions also purport to eliminate the ambiguity in terms like "futile" and "merely prolong dying." *Id.* at 14,890, 14,891. By interpreting those terms to apply only when the treatment is "highly unlikely" to prevent imminent death," HHS virtually eliminates judgment about when treatment is not justified because, though bare survival or sustenance is possible, no treatment will enhance the opportunity of life. See Child Abuse and Neglect Prevention and Treatment Program 49 Fed. Reg. 48,160, 48,164 (1984). This interpretation seems to eliminate another legislative exception concerned with treatment which would not eliminate a condition, and to press physicians to use experimental techniques. After eliminating "imminent" as a limitation on the kind of death excepted from the treatment requirements, the Agency has retained its guideline, again arguing that "reasonable medical judgment" adequately provides a standard for decision making and eliminates any ambiguity.

Although the final rule purports to cast these "clarifications" as "interpretative" guidelines, both the ICRCs that have been recommended to be established, as well as other "interested parties," are referred to the guidelines in the regulatory appendix. See 50 Fed. Reg. 14,880, 14,882, 14,895, 14,899. Thus the opportunity for disagreement between the meaning in the legislation and interpretive guidelines is significant and there is increased potential for intrusion into the decision making process caused by contradictory positions taken by HHS. Even if the parent (or doctor, who may be civilly or criminally prosecuted) prevails, the potential disruption is troublesome. Moreover, a child at risk may be harmed by the action regardless of the outcome as he or she awaits the outcome of the action. In addition, to the extent that it can be said that the HHS rule broadens the scope of coverage of the legislation, then the problem of scarce resources for support of disabled children may become even more critical. Although the Act provides a network of support, counseling and other resources related to assisting a life preserving decision, it is questionable whether resources allocated by the 1984 Act are actually adequate for the cases contemplated by Congress, much less for those additional cases that may be included by virtue of the HHS regulatory action. See *supra* notes 78-79 and accompanying text. Finally, the fear of intrusion and the potential determination of the yet undefined "medical neglect" may lead well intentioned, anguished parents to consent to treatment even in cases where it can be said that, morally, a decision to forego treatment is in the *child's* interest.

to impose a hardened pro life stand which is reminiscent of the earlier administrative regulatory efforts challenged in the courts.¹⁵² In addition, the proposed rules further emphasize the statutory suggestion that there is a bright, objectively determinable line between cases which indicate that medical treatment is required and others where treatment is not warranted.

Some compromisers who supported the legislation and medical professionals who favored the compromise because of the discretion left in their hands expressed dissatisfaction with the proposed administrative interpretation. As a result, the final rules which HHS has substituted do not retain the most controversial interpretive definitions as "binding" rules. However, many rules have been retained as "guidelines" for decision making by doctors and by the ICRCs that are recommended to be established in tertiary neonatal care facilities. Because the legislation and regulations require the referral of cases which raise questions about appropriate treatment to child protection agencies for review, the effect of having the guidelines may be to lead to increased governmental intrusions despite the compromise legislation's attempt to avoid undue interference,¹⁵³ or lead to a return to secretive action taken by the professional, with or without the advice of the parents.¹⁵⁴ Thus the new regulations may in effect upset the "delicate balance" envisioned by the compromise both in terms of those cases that are considered to be outside the legislation's coverage as well as the kind of "reasonable medical judgment" that can be exercised by the medical professionals under the legislation.¹⁵⁵ In either case, it is questionable whether the child—or parent—stands to benefit from the administrative rulemaking. Neither the legislation nor the rules encourage the parents to play a prominent role in the decision making process.¹⁵⁶ Moreover, both blur the truly troublesome quality of life issues raised by the provocative commentary con-

¹⁵² See *supra* note 133.

¹⁵³ See 50 Fed. Reg. 14,878, 14,879 (1985)(response of Congressional supporters).

¹⁵⁴ This, ironically, is the prediction of Dr. Duff, who first exposed the "open secret" of selective nontreatment. Conversation with Dr. Duff at Yale-New Haven Hospital (March 22, 1985).

¹⁵⁵ See 50 Fed. Reg. at 14,881 (Apr. 15, 1985)(response of medical groups).

¹⁵⁶ See *supra* note 151; *infra* notes 159-173 and accompanying text.

cerning withholding medical treatment of infants.

Political compromise blunted the serious moral dilemma of whether withholding treatment is ever appropriate by purporting to remove nonmedical considerations and leaving the principle decision making to medical experts. This approach is disingenuous. It is questionable whether the statutory involvement of state abuse agencies or the recommended Infant Care Review Committees will avoid the danger of value laden decision making since the definition of medically indicated treatment reinforces the illusion that medical certainty can be achieved and relied upon.

III. ANALYSIS OF THE DECISION MAKING ISSUES

The willingness of disparate groups to quickly come together in political compromise reflects strong social reaction favoring change in the handling of Baby Doe cases. It could have been argued that because of family interests at stake, and in the interest of privacy in medical decision making, further legislative response was unnecessary. In most states, child protection statutes as well as general criminal sanctions were already available to reach extreme cases where decisions to withhold treatment were clearly contrary to the interest of the infant and thus amounted to unauthorized killings.¹⁵⁷ The existing approach *theoretically* would allow some tolerance for diversity of individual views about life saving treatment, while it captured other acts which were clearly inconsistent with well established social norms about the value of life. It would permit the slow evolution of a life saving norm relating to the withholding of treatment of infants through case by case adjudication, ultimately removing from parental control those medical treatment cases that run contrary to the evolving social norm. It would allow refinement of the life saving norm, focusing on the individual persons and families in a particular case, by reference to a gamut of infant treatment decisions. It also would allow a deliberative assessment of the kinds of considerations that ought to come into play in a treatment decision. This approach was consistent both

¹⁵⁷ See Ellis, *supra* note 1; Robertson, *supra* note 84; Note, *supra* note 1, at 224, 231-37, 246-50.

with medical treatment cases, in which a concept of patient autonomy had emerged and is still evolving, as well as with the traditional considerations of most matters related to family. Despite the risks of arbitrary and capricious judgments in the individual case, the approach allowed some flexibility in meeting morally uncertain predicaments by affording the evolution of a norm to take its course through case by case adjudication.

The reluctance of state prosecutors and courts to respond with available sanctions even in the arguably extreme case, however, reflects the reality that norms concerning which lives are worth saving are in a state of flux. Rather than considering whether society or children have interests that warrant protection by the state, courts which had been confronted with infant Doe cases had summarily concluded that the treatment decisions are private ones, leaving doctors and parents free to proceed without fear of legal challenge or liability, but also without guidance about how to order competing values of life and liberty at stake in the decision making. The political response can be characterized as a rejection of a position favoring extreme individuality because of the perception that, left unregulated, treatment choice in Baby Doe cases in effect appears to authorize killing.¹⁵⁸

The legislative compromise attempts to provide a more certain, scientific standard for individual decision making. Yet, as I have argued earlier, the certainty is illusory and there is only the appearance of limiting medical discretion. More importantly, the political response suggests that decision making responsibility between parent and state is being reallocated, increasing the power of paternalism in the interest of the child (and, it can be argued, in the interest of parents).¹⁵⁹ Under the compromise, that power is, in effect, delegated to the doctor. The preference for the doctor, who is "anchored in medical reality"¹⁶⁰ avoids having parents directly confront the moral dilemma of individual choice in treatment by referring the problem at the first instance to a purportedly neutral

¹⁵⁸ See Burt, *Authorizing Death for Anomalous Newborns—Ten Years Later* (unpublished paper).

¹⁵⁹ See Mnookin, *supra* note 54, at 266-68.

¹⁶⁰ P. RAMSEY, *supra* note 34, at 163.

and objective expert.¹⁶¹ But although the medical professional is more comfortable with a paternalistic assumption of decision making in treatment, preference for the doctor's decision making in this context is questionable. The doctor may have interests that transcend the immediate circumstances involving the life or death of the individual infant. The doctor may be affected by his or her own values about withholding treatment, or may be persuaded that the "objective" interests of science ought to prevail,¹⁶² even though those interests are at odds with those of the individual life at stake. It is questionable, moreover, whether the doctor can adequately represent the interests of society and its concerns that reach beyond the protection of the child from potential harm.¹⁶³ This is not to suggest that the doctor's involvement in the decision making process is inconsequential; nor that an implicit authorizing of death in a decision not to treat would not affect the life preserving ethos of the profession, justifying the doctor's participation in decision making. A proper response, however, to the problem of withholding or withdrawing treatment should emphasize, rather than downplay, the parents' ultimate responsibility.

The peculiar status of the infant arguably justifies a *subjective*

¹⁶¹ See *supra* note 146. It has been observed that:

Medicine has nudged aside the more traditional institutions [religion and law] concerned with social control. . . . [I]t is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts.

Silverman, *supra* note 83, at 16; See also Capron, *Shifting the Burden of Decision Making*, 6 HASTINGS CENTER REP., Feb. 1976, at 17 (physicians raised to status of unquestioned priests as their decisions control the care of their dying patients); cf. P. RAMSEY, *supra* note 34, at 168 (favors a "medical indicative" policy because, although it may be value-injected, it is not as subjective as other standards because it is "anchored in medical reality").

¹⁶² See *Doctors Ask, Who Lives? When to Die?*, *supra* note 7; Bridge & Bridge, *supra* note 4; see also *supra* note 150. The danger of the infant becoming a pawn in scientific experimentation may actually be increased by HHS's attempt to clarify the situations where treatment is required. See 50 Fed. Reg. at 14,892.

¹⁶³ Besides not having an intimate connection with the child, which may tend to "objectify" the individual infant's case in his or her eyes, the doctor may be concerned with avoiding his or her own personal liability in decision making, see *infra* note 172; cf. Capron, *supra* note 161, may be interested in pursuing scientific data, or may simply have consciously or unconsciously formed personal views about the desirability of treating infirm newborns which will affect prognostic evaluations. See *supra* note 96. Thus to the extent that society's interest is in preserving life, at all cost, it is questionable whether the physician is the best "guardian" of that interest in the case of disabled infants.

consideration of the appropriate steps to be taken in his or her interest, with moral reflection on the consequences of the action. It is parents who, though emotionally torn, have a moral stake which can guide decision making where uncertainty about the benefits of treatment to the child is strongest. It is they who must live in a profoundly personal way with the consequences of a decision which ultimately preserves or ends the life of the child.¹⁶⁴ Thus the parents' role in the decision making should be a prominent one—not because of abstract issues of autonomy in decision making but because their relationship with the infant makes them most clearly morally accountable.

Both the prior judicial responses and legislative reaction to those rulings underscore the shortcomings of a legalistic concept of autonomy as a means of resolving actual conflicts in the cases of profoundly infirm infants. Autonomy-linked arguments favoring parental decision making for the family as well as those favoring state paternalism for the protection of the infant or the society do not adequately resolve the problems of decision making. They fail to satisfactorily confront the moral implications which arise from the status of the infant and the infant relationship with the family.

Three factors generally have been considered in addressing the problem of withholding treatment for infants: (1) family autonomy; (2) the state's interest in preserving life and other values; and (3) the role of the medical profession. A central figure in the controversy—the infant—has been left out of separate consideration. Unlike other incompetents who have already had life experiences (however minimal in quality), the personality of the child can only be framed in terms of a future potentiality. Moreover, although there is a general unwillingness to forthrightly and deliberately confront the fact that individual quality of life decisions are being made in all cases involving the withholding or withdrawing of treatment of profoundly infirm persons, the search for a standard and an appropriate decision maker in these cases are exacerbated

¹⁶⁴ See *supra* note 3. Dr. Duff describes as profoundly personal the experience of parents who generally agonize over the impending decision about whether to withhold treatment from a newborn and grieve the loss. Conversation with Dr. R. Duff, at Yale-New Haven Hospital (March 22, 1985).

by the silent presence of the nascent individual.

The concept of family autonomy emphasizes that infants are not self directing or self defining beings, but exist in terms of and for their families; they are in the present persons only in a social sense, but have the potential to develop through the nourishing and care extended by parents and family members¹⁶⁵ or their substitutes. Under this conception, parents hold in trust the rights and duties for the person yet to develop. Thus the family autonomy concept suggests that respect for the newborn's freedom or privacy in medical treatment decision making can best be accorded by honoring the wishes of the parents made on behalf of the infant. The role of the physician, respectful of autonomy, is to present prognostic and treatment information to aid the parents in decision making. The blurred identity of the infant leaves open the possibility that parents can make choices which "autonomous" individuals have the capacity to make on their own behalf.

The conception of family autonomy theoretically provides the rationale for permitting parents to decide against life sustaining treatment when it is unlikely the infant will develop into a "meaningful" personality. But the fact that there is not established a shared understanding of quality of life factors which render a life "meaningful" raises problems with this characterization of family autonomy and parental authority in decision making. It has been argued, for example, that since the infant is a person only in the social sense at birth, having meaning only in relation to the family, the decision whether or not to treat the infant can be objectively based on consideration of the needs of the child and family. The probability of the infant becoming a person and the costs of achieving personhood in light of that probability, including financial burden as well as the toll of anxiety and suffering of the family which can affect the capacity of the family to care and nourish the infant are factors which this approach would consider essential.¹⁶⁶ The possibility that life can have no moral consequence for the

¹⁶⁵ See Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD?* 142-43 (1980).

¹⁶⁶ See Engelhardt, *Ethical Issues in Aiding the Death of Young Children*, in *KILLING AND LETTING DIE* 81-85 (1980).

infant in the future—that the infant can anticipate no distinctively human benefit from living, such as the ability to think, to communicate, to give and receive love—is relevant in determining his or her future status as a separate moral personality. On the other hand, since the infant has no moral standing apart from the family at present, the cost to the family may be considered as well, since the present satisfaction or burden of caring for the child are matters indistinguishable from the child's interest at infancy and affect the future development of a separate personality.

Under an extreme conception of autonomy, the life that an infant can expect in the future and the present burden of family care form the calculus for determining whether treatment is required.¹⁶⁷ State intervention for the protection of the infant is justified under this conception of family autonomy, but only when parents violate the trust by refusing to care or consent to treatment despite the fact that there is the likelihood of a qualitatively “good life” with costs to the family which are not unduly burdensome.

There are obvious problems with framing the decision to withhold medical treatment with such a conception of family autonomy as the focus. Stated in this extreme, it is clear that by minimizing the presence of the child as an individual, separate and apart from the family entity or parental relationship, and negating the child's connection with others, the concept invites the use of a utilitarian calculus which contradicts established understandings about personhood.¹⁶⁸ Because of the difficulty in qualitatively evaluating the present and future life of the infant, there is always the risk that the child will be sacrificed for the sake of the parents' interest in being free of costs and care. Yet, despite the controversy of the

¹⁶⁷ *Id.*; see also Tooley, *supra* note 84, at 60 (moral symmetry principle).

¹⁶⁸ Philosophers have proposed less offensive principles for capturing the appropriate limits of parental autonomy over the developing child. See, e.g., Crocker, *Meddling with the Sexual Orientation of Children*, in *WHOSE CHILD?* 145 (1980) (whether child would agree in the future—imagine rational, informed infant); Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD?* 142-43 (1980) (right to open future sets limits on ways parents can raise children and imposes duty on state to exercise role as *parens patriae*); Ruddick, *Parents and Life Prospects*, in *HAVING CHILDREN* 124 (1979) (prospect provision principle). None seems satisfactory, practically, for evaluating claims of the infant that immediately arise at birth.

abortion cases about when a fetus is to be recognized as a separate entity, those cases unquestionably confirm the view that an infant is a cognizable being with separate interests even before birth. Although the infant, like other incompetents, may not be able to make decisions and choices, respect for the emerging personality and human dignity demands some recognition and consideration of his or her separable interest. Because the infant, unlike other incompetents, has never had the opportunity to experience life, the fact that there may be some uncertainty about his or her future potential suggests that there be more, not less, concern about the untoward effects of competing interests in the decision making process. The argument that an infant who is born with life threatening infirmities lacks any identity as a cognizable being is objectionable particularly in the absence of any clear and articulate standards as to what physical and mental qualities make possible a life worth living under a family autonomy analysis.¹⁶⁹

Family autonomy and resulting conclusions about parental authority to withhold treatment, moreover, tend to view the decision making in a social isolation. Yet, the separateness of even theoretically autonomous beings is illusory; no person is disengaged from the community setting, and each is affected by the choices of others. Though the ideal conception of autonomy envisions rationality in decision making, and thus impels liberty to pursue choice, in actuality, even autonomous human beings are not spared the state's intervention out of paternalistic concern for a poor or irrational judgment or when individual choice directly impinges on others. In the case law that has emerged relating to the doctrine of informed consent and leading to the withholding of treatment in other contexts, autonomy and related notions of human dignity and equality have been tempered, mindful of the interdependence of the community. Similarly, the reality is that choices concerning treatment decision making for infants have ramifications for others

¹⁶⁹ In a different light, Tooley, for example, makes the point that true reflection about the practical difficulty in demarcating the boundaries on one side of which a "serious right to life" arises may lead to even more trouble, since "one may find himself driven to conclude that our everyday treatment of animals is morally indefensible, and that we are in fact murdering innocent persons." Tooley, *supra* note 84, at 63-65; see also Macklin, *supra* note 15, at 31.

in society and for society itself. But the distinction between restraining choice for the good of the infant, others, or society may be blurred as a result of the nascent status of the infant. Because concrete information about the future life of the infant is not available, the infant may be identified with an abstract conception of life's potential. Thus clarifying and resolving conflict about what is in the infant's interest, the interest of others, or society is more problematic than in other cases involving the issue of withholding treatment.

A search for appropriate decision making responsibility and the limits of judgment in cases involving the withholding of treatment for infants should not ignore that there is moral conflict in such life and death decision making. Identifying the decision maker by reference to abstract notions of autonomy or a preference for paternalism does not avoid the essential problem of moral dilemma of choice when benefits of treatment are uncertain; moreover, it appears to suggest that there is a decision maker capable of making the "right" decision on the infant's behalf. Yet the fact that uncertainty exists about the ultimate question of the benefits of sustaining life for the profoundly infirm infant evokes no unitary vision of right. Recognition of the infant personality—both in relationship to his family and others in the community—cannot lead to the infant's protection from the wrong decision. It can, however, assist in deriving an alternative to autonomy formulations in determining how the community may act responsibly in a morally troublesome situation where value conflict seems inescapable.¹⁷⁰

Autonomy issues aside, there are clearly two principal concerns of the community which justify constraint on choice in the infant Doe cases. First, the need for protection of values important to society, and second, the uncertainty about how to fully account for the interests of the emerging infant personality. An accommoda-

¹⁷⁰ It can be argued that the political response to the Baby Doe controversy represents a continued reaction to a "personalized" radical individualism that fostered the development of a right to refuse treatment in the seventies. Some have argued that the trend of viewing individuals as "atomized moral agents disengaged from a cultural setting" distorts ethical theory and should be stopped. See Callahan, *supra* note 8, at 41; Cassell, *Life as a Work of Art*, 14 HASTINGS CENTER REP., Oct. 1984, at 35; Morison, *The Biological Limits on Autonomy*, 14 HASTINGS CENTER REP., Oct. 1984, at 43.

tion of these concerns, however, does not lead to a conclusion that parents should not be the principal members of the community making decisions about the treatment of profoundly infirm newborns.

Restrictions on decision making involving the withholding of treatment can be justified when choices directly interfere with the socially desirable value of life preservation. Enshrined in the Constitution, the right to life is unquestionably a value to be protected by the state. But the meaning of "life" has been affected by technological advances as well as other decisions outside the context of withholding treatment for infants. These developments cannot simply be ignored in considering decision making about withholding treatment for infants.

The potential danger to other institutions and socially important values is of concern to the state as well. Unrestrained choice in withholding treatment for infants may, for example, affect societal views about the status of children, the handicapped, and incompetents, each of whom may be dependent on the decision making of others. The caring and nourishing ethos of the family as well as the life preserving ethos of the medical profession may be affected by unbridled choice in treatment decision making for the infant. But the fact that there are legitimate concerns of the state does not resolve the question of what limits the state should place on decision making. Any action taken by the state should be tailored to the dangers present, with a deliberate consideration of alternatives other than those which constrain decision making.

The state, of course, has an interest in intervening to preclude the opportunity for individual decision making if the practice is considered immoral and therefore destructive of social order, quite apart from the question of protecting against potential harm to the infant *per se*.¹⁷¹ Thus if withholding treatment for infants as a general matter is, by consensus of the community, considered immoral, state action designed to prohibit such decisions, at least when benefits of treatment cannot be established with certainty, may be appropriate.

¹⁷¹ See H.L.A. HART, *supra* note 13, at 47.

Enforcement of a public conception of morality in the case of treating infants, however, is troublesome. Because of the close connection between parent and child, it is arguably objectionable that a majority conception of right should prevail over that of individual parents without clear justification for that ordering. The fear that in some cases decision making will result in highly controversial outcomes does not lead to the conclusion that parents are not generally in the best position to confront the moral dilemma of withholding treatment, particularly where there is uncertainty about the prognosis of the child's development.

There are additional reasons why parents should be featured in decision making as well as given broad latitude in choice where the benefits of treatment are questionable. The familial relationship characteristically embodies the connection between "self" and "other" which supports rather than negates a communal sense of decision making responsibility. To extend communal responsibility in decision making in this and other situations while ignoring or downplaying the most clear example of human connection thus seems inappropriate. It is the parents who are most closely drawn to whatever can be understood about the life in being of the baby. Parents, who naturally anguish over life and death decisions relating to newborns, cannot simply be cast as motivated by self interest or a life negating impulse. If informed, parents may be uniquely able to appreciate questions of uncertainty about life limitations of the infant because the newborn is a reflection of themselves, their understandings of life, and hope for the future.

Recognition of these factors which favor featuring parents in the decision making process, however, does not preclude an active role and responsibility in decision making by other community participants. Rather it suggests that, in the final analysis, no one is better able than parents to confront the moral dilemma which arises when there is uncertainty about the benefits of treatment.

IV. FRAMEWORK FOR DECISION MAKING

The decision to withhold or withdraw treatment for profoundly infirm infants is clearly a morally perplexing, problematic one, particularly in light of the doctrinal, institutional and human limita-

tions discussed above. It could be argued that precisely because the issues are so highly charged and subject to moral disagreement, the government's only role should be to ensure that an enclave of privacy is maintained, permitting parents, with the assistance of the doctor, insulated from public view and reprobation, to work out their own resolution.

The privatization of moral dilemma is an approach often suggested and, in fact, was used to address this problem earlier in this society and in others. However, here, perhaps more than in other situations where there are competing claims of right, it can be countered that because of the presence of a defenseless, morally cognizable, newly emerging being, a simple resolution based on privacy is disturbing. It is my view, however, that ignoring the dilemma of choice in some circumstances does not solve it and that the uncertainty in decision making ought to be accounted for. The danger of masking uncertainty and ignoring choice is that it is made nonetheless, privately, and without standards from or participation by society.

The following are recommendations which address some of the problems and address some of my dissatisfaction with the legislative compromise approach. In summary, they are aimed at (1) constricting the area of concern by developing, normatively, an understanding of the cases where uncertainty is greatest; (2) returning the prominent decision making responsibility to the parents in those areas; (3) ensuring that, in those cases, the parents' decision is reflective and deliberate, to the extent possible, and with minimal coercion of others; and (4) withdrawing decision making responsibility from parents who clearly act in a manner contrary to the interests of a disabled newborn.

A. Reconstruction of the Federal Regulatory Structure

Because the existing federal framework reflected in the compromise legislation and implementing regulations unduly downplays the role of parental decision making and creates an aura of medical certainty in some circumstances where certainty cannot be scientifically supported, I urge that efforts be undertaken to challenge the present regulatory structure. I believe that this challenge is one

which each of the interest groups who supported and questioned the compromise legislation has a stake in effectuating, since, as I have argued, the result has been unsatisfactory in clarifying the state's role in protecting the newborn infant.¹⁷² In particular, Section 3 of the 1984 Act and regulations defining and clarifying what is "medically indicated treatment"¹⁷³ should be withdrawn to allow for further reflection and understanding of the kinds of cases that clearly should be considered medical neglect. Because the presently existing state child care protection schemes and other legislation have the capacity to reach clearly offensive conduct, such a step need not leave the extreme cases involving "Baby Does" unprotected; it may in fact force state action that will allow for the refinement of a normative conception of appropriate decision making because of increased public sensitivity to this issue. In my view, the federal definitions that now regulate action not only principally focus on the wrong decision maker, they, in effect, construct substantive standards that are confusing and contradictory. The appropriate present aim of federal legislation should be to foster the future development of appropriate uniform standards for decision making which emphasize the role of parents in a working relationship with doctors and encourage the participation of others who have some expertise in problems related to medical uncertainty and quality of life decisions involving disabled infants. Although it can be argued that the legislative compromise had just that aim in mind, when read together, the legislation and regulations do not successfully meet that objective. Moreover, beyond the concern for unduly emphasizing medical rationality discussed above, the legis-

¹⁷² See *supra* notes 146-164 and accompanying text. Doctors who may have been pleased by the compromise reference to reasonable medical judgment in decisionmaking should be particularly concerned about the effect of the HHS regulations and "clarifying guidelines" on the exercise of that judgment. Moreover, assuming that the legislation and regulations vest discretion in the exercise of reasonable medical judgment relating to the statutory exceptions for requiring treatment, that discretion should not easily be embraced. With the heightened awareness of Baby Does, the doctor-focused regulation may expose a doctor to increased risks of criminal liability for withholding treatment (for example, when favored by parents) and malpractice liability if he or she fails to prevent death or "creates" a life of only minimal sustenance. Cf. Capron, *supra* note 161, at 17-18 (malpractice increases when decision making resides in the physician).

¹⁷³ Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 102, 98 Stat. 1752 (1984) (to be codified at 42 U.S.C. § 5102).

lation and rules confuse counseling, information gathering and regulatory responsibilities of other participants in decision making. In part, this is because of the lack of normatively developed information about cases in which the child's interest is drawn in question; in part, it is because of the politically motivated interest in establishing a life supporting emphasis that is not necessarily focused on the individual life at stake in a particular case.

Until there is accumulated sufficient data and time has elapsed to allow reflection on the problems of effectuating informed decision making on the part of parents, a federal attempt to establish specific substantive standards with the purpose of uniformly resolving ambiguities related to prognostic uncertainty and quality of life considerations in the treatment of infants should be postponed. In the interim, federal activity should be concentrated in areas such as the increased gathering and dissemination of information related to prognostic capabilities and resources available beyond the local areas, counseling related to parental decision making in the hospital setting, and identifying and supporting resource groups which specialize in the maintenance of disabled children for whom a life sustaining decision has been made.¹⁷⁴

B. Identifying the Troublesome Cases

Rather than taking a global, condemnatory stand on the question of withholding or withdrawing treatment from infants, it is preferable that society focus on defining and delineating the contours of the *real* moral dilemma—*i.e.*, identifying areas where

¹⁷⁴ The compromise legislation includes an evaluation mandate which may serve the purpose of implementing this recommendation: section 126 of the Act requires the Secretary of HHS to make a detailed report to the appropriate committees of Congress on the efficacy of the regulatory effort no later than October 1, 1987. Pub. L. No. 98-457, § 126, 98 Stat. 1754 (to be codified at 42 U.S.C. § 5103).

Acknowledging that it is the tendency of administrative agencies to seek the preservation of their regulatory power, I would not anticipate that a recommendation by HHS consistent with the proposal suggested herein would be forthcoming; this is particularly so in light of the agency's insistence on maintaining its position that regulations promulgated pursuant to Section 504 of the Rehabilitation Act should be effective despite contradictions of Congress and the courts. *See supra* note 121; *see also* G. CALABRESI, A COMMON LAW FOR THE AGE OF STATUTES 46-58 & n. 19 (1982)(examining why administrative agencies fail to update laws).

choice and uncertainty is greatest. Thus, instead of state legislation aimed at developing one prohibitory "bright line," based on a pro life, utilitarian, medical rationality—or other valuative position concerning medical treatment of infants—it should be recognized that there is a "gray zone," in which presently there can be no categorical answer about whether life should be maintained by medical technology, but in which, in the individual case, legal issues about the appropriateness of decision making can be raised.¹⁷⁵ Conceptually, the gray zone would include cases which can be considered "medically undeterminable" situations. As has been suggested earlier, doctors have argued that in some cases there is uncertainty about prognosis, and assessment about the future condition of an infant may be blurred by other conditions, increasing the likelihood of a poor prognosis. There are also human condi-

¹⁷⁵ The President's Commission described three kinds of cases which raise concerns about the question of withholding treatment,

- (1) those in which available treatment will clearly benefit the infant;
- (2) those in which treatment is expected to be futile; and
- (3) those in which the benefits to the infant from choices available are quite uncertain.

Deciding to Forego Life Sustaining Treatment, *supra* note 80, at 587-93. It can be argued that the compromise legislation was aimed at clearly mandating treatment in cases included under (1), leaving to doctors the determination whether, in a particular case under (2), non-treatment should be the appropriate course; and purporting to eliminate category (3) or leaving those cases to "reasonable medical judgment" as to whether they should be considered under (1) or (2). The HHS regulations, on the other hand, more clearly assert that in cases which fall under category (3), treatment is mandated, though in response to criticism, HHS has paid lip service to the use of reasonable medical judgment as the basis of decision making in those cases.

It is my position that cases which fall within category (3) are precisely those which should be left to the decision making of parents. It is in those cases in which science cannot provide an answer that human evaluation—by parents—is most needed; it is those cases, moreover, that are most *inappropriate* to be regulated by abstract standards of justice which mask the dilemma and blunt the incommensurability of the moral issues at stake. See Farley, *The Importance of Moral Quibbles*, 5 HASTINGS CENTER REP., Apr. 1975, at 6; cf. J. GOLDSTEIN, A. FREUD & A. SOLNIT; Goldstein, *supra* note 69, at 654-57 (psychological and social connection of parent and child makes parent the best decision maker). Such cases might include ones in which (a) there is lack of experience in treatment which renders insufficient prognostic guidance; (b) serious problems are expected by the treating physician to arise which cast uncertainty about whether the immediate treatment or intervention is advisable; and (c) the field is too new to make predictions of reasonable medical certainty about the benefits of treatment. They also include cases in which appropriate medical management has been subject to controversy and thus is unsettled. This position is one provoked by my conversation with Dr. Duff.

tions which affect a sense of certainty about prognosis, a factor which should not be ignored in identifying cases of *uncertainty*, although in the individual case it need not be an appropriate factor of decision-making by the doctor—or parents.

Because it cannot be categorically determined in these cases of uncertainty whether a decision to withhold or withdraw treatment is in the child's interest, I advocate that decision making should be left to *informed* parents, who, I argue, must directly confront the moral consequences of the decision, regardless of choice, and who are generally best suited to make decisions in the interest of the infant. States should require that before any life or death decision is made in cases within the contours of the gray zone of uncertainty, parents be counseled concerning choices, as described in Part C, below. Moreover, in cases where it appears that the decision ultimately preferred by the parent may be inappropriate because it does not meet the interest of the child and thus is one that any reasonable parent under the circumstances would not make, the state should provide for investigation by the child protection agency, and, if necessary, judicial intervention.

Determining how to define the contours of the "gray zone," however, is problematic. I propose that the broad contours initially be drawn, on the one hand, by guidelines developed by local hospitals from their prior cases involving decisions to withdraw or withhold life supporting treatment of infants, and, on the other hand, from developing state law that will certainly eventually emerge because of public awareness of the cases and which will refine the conditions under which a decision to terminate life cannot medically be determined.¹⁷⁶

The contours of the "gray zone" can also be refined by identifying cases which clearly are *not* to be considered uncertain—cases in which:

- (1) reasonable doctors would not disagree about the certainty of the prognosis in which a certain set of conditions is present, such that a recommendation to with-

¹⁷⁶ See Tribe, *supra* note 77, at 26 & n.64.

draw or withhold treatment clearly would not be indicated;

- (2) there has been substantial agreement among parents who have been faced with treatment decisions related to a particular set of conditions in which a withdrawal request would not be made; and
- (3) clergy and ethicists substantially agree that withdrawal of treatment under the set of conditions would violate available guidelines for decision making.¹⁷⁷

To make this determination, data from hospital records and reports from medical professionals and other interest groups should be solicited and views presented in public hearings sponsored by state abuse agencies or community hospitals with the aim of identifying cases for which there is clear consensus that treatment is required. In those cases, a decision by parents and their doctors to refuse treatment will automatically be referred to the state child abuse agency for investigation and intervention.

Through the entire process described above there may be established broad areas in which individual treatment decisions can be located:

¹⁷⁷ This aspect of my proposal is most problematic from the standpoint that it risks the imposition of coercive public morality that is at odds with individual decision making which may be justified in the particular case. It is offered, however, in recognition that there may be a social need for line-drawing which rationally delineates the contours of the gray zone in which decision making generally should be left to parents. As an alternative, Dr. Duff, for example, has suggested that the line demarcating the boundaries of parental discretion might be drawn by hospital administrators, such as members of the Board of Trustees, who are concerned with the economic considerations of providing health services. Conversation with Dr. R. Duff at Yale New-Haven Hospital (March 22, 1985). An alternative to Dr. Duff's utilitarian approach, more consistent with my arguments, is to assign a team of doctors and other medical personnel the task of delimiting the boundary of prognostic certainty (and thus, the zone of parental discretion) through hospital guidelines developed from past cases involving conditions frequently confronted by the infant care facility. Thus, for example, doctors could set the minimum weight and other vital conditions of premature infants for whom a life decision must be made; see Todres, *supra* note 5. On the other hand, because medical management of illnesses such as spina bifida has been subject to shifts in treatment, those infirmities may be best left within the gray zone since they are vulnerable to error and conflict in decision making. See Gallo, *Spina Bifida: The Stage of the Art of Medical Management*, 14 HASTINGS CENTER REP., Feb. 1984, at 10; see also *Focus: Current Issues in Medical Ethics*, *supra* note 92.

- (a) cases in which there is clear societal consensus that treatment must be administered;
- (b) cases of uncertainty in which parents have principal decision-making responsibility which can be more closely scrutinized by the state only if, in the individual case, it can be said no reasonable parent would decide to withhold or withdraw treatment; and
- (c) cases in which treatment is not medically indicated but may be requested by parents in an individual instance because of their life-preserving views.

C. Parental Decision Making in the Face of Uncertainty

In the uncertain cases that have been located in category “(b),” the parent ought to be recognized as the principal decision maker. But society can nonetheless assert some interest in the outcome of decision making, even in those cases, because the decisions affect other institutions and values that it insists should be protected. Thus, at a minimum, there ought to be some assurance that the decision making process is deliberative and reflective. Of course, it is impossible to insist upon rational decision making; the intent in this decisional framework is rather to encourage some reflection and avoid undue coercion of choice in the morally troublesome gray area.

In addition, the technical advancement in medicine combined with the professional commitment of doctors have, in effect, created the benefits and burdens of the survival of the profoundly infirm, and thus the profession has an interest in decision making beyond simply providing technical assistance. Though privacy in individual decision making has often been the focus with respect to autonomy, it need not mean that decision making must be made in isolation or that merely passive technical assistance is best. To cast the alternatives available as isolated privacy or pervasive public regulation is to suggest that decision making precludes “exhortation, argument and advice”¹⁷⁸ of others. Rather, the focus should be on affording some assurance that communication is made in an

¹⁷⁸ H.L.A. HART, *supra* note 13, at 75.

environment that encourages informed choice and does not repress it.

1. The Counseling Obligation

It is conceivable that hospital committees similar to those which have been recommended by the HHS Secretary in the final rules and linked to tertiary neonatal care facilities could be established to provoke conversation among parents, doctors, and others who may have some interest in a decision to withhold or withdraw treatment. But the use of those committees for that purpose is, in my view, troublesome for at least two reasons. First, it does not seem consistent under the above analysis for such committees to both provoke conversation in a noncoercive environment while supporting self reflective, deliberative decision making, and, on the other hand, to make judgments about the appropriateness of the ultimate decision, as called for by the HHS recommendations. Instead, the function of counseling for the purpose of ensuing deliberate, reflective choice should, if possible, be separated from the kind of committee intervention that can countermand decision making. Second, it may well be that some community and expert representatives on a committee see themselves not as counselors but as *decision makers* reflecting an aspect of the community interest involved in the decision to withhold or withdraw treatment. Thus it may be that a supportive role in provoking conversation, enabling reflective parental decision making, may be lost by requiring hospital committees to become both a sounding board for raising and discussing issues related to parental decision making in the first instance, and also a reviewer of appropriate decision making in the second. I propose, however, that each hospital engaged in providing neonatal care have available trained counselors who are on staff, are representatives of the hospital review committee, or are drawn from local resource organizations recognized by the state child abuse agency and who can counsel parents and mediate discussion between medical personnel and parents in particular cases involving life and death decisions.

When a dispute occurs between doctor or medical staff member and parents, either could insist that the counselor or counseling

committee be utilized before a life threatening decision is made. If the doctor or other medical personnel refuses to attend a counseling session, but continues to treat the infant, he could be subject to hospital sanctions and possible litigation by the parent. The doctor who is confronted with a noncommunicative parent, on the other hand, would be faced with deciding whether to withdraw from the case, administer treatment despite the lack of parental consent,¹⁷⁹ or refer the case to the hospital review committee for proceedings described below.

The purpose of the counseling meeting is to ensure that the parents' ultimate choice is an informed one. Ideally this aim is satisfied if there is some assurance that a treatment decision is not the result of duress or undue influence, is consistent with personal attitudes and values held by the parents, is made with awareness of alternatives and consequences to the infant and to the family, and is based upon acceptance of the moral values acted on.

2. The Role of Hospital Review Committees

I propose that hospital ethics or review committees¹⁸⁰ be established within the hospitals and utilized in two distinct ways. The

¹⁷⁹ Compare J. KATZ, *supra* note 13, at 154-64; R. BURT, *supra* note 35, at 124-143.

¹⁸⁰ The utilization of hospital ethics or infant review committees has rapidly become a favored way of resolving at least some of the troublesome cases, and is supported by most interest groups. Committee review has been approved both by the pediatricians who challenged the intrusive HHS rules in *Heckler* as well as by advocates of the handicapped who supported the HHS position in that case. See 561 F. Supp. at 401 n.6. Committees were endorsed by the President's Commission. *Deciding to Forego Life Sustaining Treatment*, *supra* note 80, at 597-98; see generally Fleishman & Murray, *Ethics Committees for Infants Doe?*, 13 HASTINGS CENTER REP., Dec. 1983, at 5 (ethics committees may prove sensible alternative to federal investigators).

The rapid rise in popularity of review committees should not diminish the concern that there is, practically, neither evidence of success nor indications of shortcomings to assess their effectiveness. Committee decision making was used in the twenties to consider the appropriateness of sterilizations, and, prior to *Roe*, abortions. But those committees functioned in an environment unaffected by the shift in patient-doctor relationships provoked by the informed consent doctrine. See Levine, *Questions and (Some Very Tentative) Answers About Hospital Ethics Committees*, 14 HASTINGS CENTER REP., June 1984, at 9.

At the time that the *Quinlan* court first recommended the usage of committees in determining whether withdrawal of treatment for incompetents is appropriate there were few committees in existence. As of 1983 only about 1% of the nation's nearly 7,000 acute care

committees can be convened to consider prospectively whether ap-

hospitals had functioning ethics committees. Randal, *Are Ethics Committees Alive and Well?*, 13 HASTINGS CENTER REP., Dec. 1983, at 10. In the interim, however, much had been written about the value of lay participation and group decision making in health policies. See, e.g., *Lay Participation and Health Policy: Introduction*, 5 HASTINGS CENTER REP., Oct. 1975, at 22; Veatch, *Hospital Ethics Committees: A Guarded Prognosis*, 5 HASTINGS CENTER REP., Oct. 1975, at 25. There is now positive data available concerning the somewhat analogous institutional review boards which examine research proposals. See, e.g., Veatch, *The National Commission on IRB's: An Evolutionary Approach*, 9 HASTINGS CENTER REP., Feb. 1979, at 22, 22-23..

There are clearly problems which may arise in the prospective committee function of mediating disputes among doctors and parents related to withholding treatment and recommending appropriate treatment. Committees may tend to be protective of institutions and the medical staff with which they are affiliated, particularly after becoming more familiar with the troubling contexts of the cases under review. The committee's collective involvement with the cases may provoke a tone of "authoritarian moral superiority," Randal, *supra*, at 12, which would be counterproductive to the committee's purpose and functioning. Indeed, a problem with the ICRCs which have been recommended by HHS is that they are advised to follow the dubious conception of medical certainty envisioned by the regulations and thus are not seen as engaged in mediation of moral uncertainty and conflict.

Finally, there are obvious problems associated with privacy that can be anticipated to follow the increased use of committees. It is in part because of these concerns that counseling should be preferred and prospective committee decision making should only be used in the extreme case where it appears that parents have made or are making a decision which no reasonable, caring parent would make and thus one that is contrary to the interest of the child. Even though the intrusion of a committee with power, in effect, to countermand parents' positions and to subject parental decision making to state scrutiny is troubling, it is preferable to more immediate intervention by the state. Practically, the committee can become the buffer between the state and family.

Several considerations, nevertheless, qualify my endorsement of infant review committees. First, I believe that the committee should not become the de facto, substitute decision maker in the gray area cases. Rather, the committee should assert a view contrary to parents about treatment only in circumstances where, upon review, it appears that the parents clearly are not acting in the child's interest. For this reason, I have proposed that the standard of committee evaluation should be *whether no reasonable parent would make the decision in the interest of the child*. It is my view that a collective body composed of individual representatives drawn from multiple disciplines as well as lay representatives, can serve as an effective "second best" decision maker about appropriate treatment if it appears that the parent is clearly acting contrary to the child's interest. The application of the standard from the collective perspective of what reasonable parents would decide for this child, given all the facts and information for decision making, comes closest to addressing the interest of the voiceless child present by emphasizing the child's connectedness with others—the parents. I believe, on the other hand, that the "best interest of the child" standard has no meaning without reference to the parents because the child is newborn and has no life experience separate from the parents. It does not adequately encapture the distinction between the child and other incompetents who have had some experience in life, however minimally. Because the parents (who can be present at the hearing of the case by the committee) do have life experiences and can offer their views, this standard appropriately

appropriate treatment is being made or about to be made in gray zone cases where it is questionable that the parent is exercising reasonable judgment. Any medical or other hospital affiliated person who believes that a treatment decision which has been, or is about to be made, is one that is contrary to what a reasonable parent in similar circumstances would decide could refer the case to the committee for immediate consideration. In the meeting of the committee, at which the parent, counselor, and any interested medical or hospital affiliated personnel could attend, the committee would hear the views of the participants and, upon reflection, make a recommendation about the appropriate treatment to be undertaken under the circumstances. If the parent refuses to consent to the committee's recommended course of treatment, the case can be referred to the child protection agency for investigation with a report from the committee and, if necessary, court action can be taken to sever the parental ties and to order treatment. The committee's recommendation favoring treatment should be prima facie evidence of appropriate treatment in the judicial determination.

Retrospectively, the hospital review committee in regular meetings can evaluate treatment undertaken in gray zone cases involving disputes as well as agreement about the treatment alternative taken in order to develop normative guidelines to inform the committee's future decision making as well as to further refine the contours of the gray area of uncertainty. These guidelines can be made available to parents and doctors and also can be assigned reading

emphasizes more than is otherwise possible: there may be morally significant considerations that justify different treatment in each case. Therefore, nonagreement about appropriate parental decision making should not be grounds for state intervention.

Second, I believe that the committee should predominantly be concerned with retrospective information gathering for the purpose of setting prospective guidelines for decision making by parents and doctors, and verifying and clarifying facts—rather than arrogating to itself decision making power. Only in extreme cases should the committee make a recommendation contrary to the decision of parents and doctors which would require the investigation of the state child-abuse agency and, possibly, judicial intervention. This allocation of responsibility is possible only if there is the recognition that the proper bounds of parental decision-making within the gray zone are established by moral principles which may be subject to disagreement. See Farley, *supra* note 175; Tribe, *supra* note 77, at 30-31 & n.77; see also Arras, *Toward an Ethic of Ambiguity*, 14 HASTINGS CENTER REP., Apr. 1984, at 25.

for staff involved in decision making and in training. In this manner, there can develop a continuous refinement of treatment norms, a slow evolution of the contours based on a cumulation of cases and not related to one particular doctor's treatment philosophy.

As the recommendation in the rulemaking of the HHS regarding the creation of ICRCs suggests, the effectiveness of the committee process may well depend to a large extent on the diversity of views reflected by its composition. Thus, I, too, support the inclusion of members drawn not only from medically related areas, but also from the ethics and legal fields, as well as representatives from the child protection agency, and parents who have made life threatening decisions, and perhaps an advocate of the handicapped and disabled. Moreover, the benefits of having the committee will be enhanced by a selection process aimed at identifying a cross section of views represented in the affected community. Although there is some speculation about the desirability of such committees, under this proposal it can be argued that a review body composed of experts and lay people holding a collection of informed views reflective of the multiple dimensions involved makes logical sense: a determination can be made as to whether the parent's decision appropriately favors the interest of the child. Because of its developing experience in considering prospective cases, the committee also appears to be practically suited to the task of considering what appropriate guidelines can be drawn for future cases from past decision making practices within the hospital. Since any intrusion into the area of medical decision making involving life and death is problematic, it can be argued that the committee's utilization only in cases where, arguably, parental judgment has foundered forges a proper balance in respect of private decision making and social responsibility.

D. Substantive National Guidelines for Decision Making

Whereas the political response has been to reach a compromise which purports to eliminate quality of life factors that often have come to play a role in Baby Doe cases, I believe that this compromise will not prove satisfactory. Indeed it is to be expected that

the question of whether the anticipated quality of life of the infant can affect decision making about withdrawing or withholding treatment will resurface in committee deliberations and in court cases as a result of the medical rationality standard of the congressional legislation. That expectation is increased by the HHS rules which interpret the statutory provisions in a manner that narrows medical discretion.

As has been suggested earlier, ultimately the question of what "life" means bears on a conclusion about what treatment is appropriate. Because normative data affecting that conclusion has only begun to emerge, I have proposed that national substantive guidelines for decision making be postponed and that state regulation be founded on a process of decision making that allows great flexibility for the parents. It is at present preferable for there to be judicial resolution of conflict in decision making in individual cases. This judicial resolution should be based on the extreme cases that would be recognized as outside the reasonable judgment of any parent rather than constricting choices to those based on politically defined categorical delimitations of a "right" to refuse treatment.¹⁸¹ Substantive standards that focus on such a right necessarily draw into question the meaning of life, which has been raised in the bioethical and legal literature responding to earlier Baby Doe cases, but which has not been seriously considered in any political response or clearly confronted in the cases.¹⁸² There are in-

¹⁸¹ See Tribe, *supra* note 77, at 26.

¹⁸² See Arras, *supra* note 180 (whether child can anticipate distinctively human benefits); Fletcher, *supra* note 91 (neocortical functioning is cardinal human trait); McCormick, *supra* note 97 (potential for human interaction; condition itself is negation of truly human potential); Paris, *Terminating Treatment of Newborns: A Theological Perspective*, I BIOETHICS REP. 1188 (potential for future relationships, for living, and for being loved does not exist or is submerged in the mere struggle to survive); Robertson, *supra* note 93 (social consensus should establish substantive criteria specifying class or group of patients for whom medical treatment may be withheld, in terms of mental functioning and physical condition or prognosis); see also *Deciding to Forego Life Sustaining Treatment*, *supra* note 80, at 589-93 (net benefit to the infant: if burdens imposed on the patient by a disability or its treatment would lead a competent decision maker to forego treatment); Smith, *supra* note 84 (no person can say that voiceless, defenseless infant should be legitimate victim of protective killing). Consistent with its tendency in other life-and-death decision making, however, the federal legislation focuses on identifying the decision maker and limits recognition of quality of life considerations which necessarily come into play to pain and suffering.

deed several problems that challenge the proposition that quality of life factors *can* successfully be applied in a general way to develop substantive criteria for decision making by courts or the legislature. Social and economic factors, for example, obviously affect the quality of life that can be anticipated. Yet the explicit consideration of those consequences in determining whether treatment can be withheld may run afoul of constitutional principles of equality. In some circumstances, moreover, it may be impossible to separate physical or mental dimensions of disability, thus rendering it impossible to articulate satisfactory classifications that do not unduly infringe on the rights of the handicapped. Finally, despite other innovations, in tort law courts have generally refused to compare the advantages of life against the state of nonbeing initiated by death, indicating some reluctance to more clearly formulate the contours of society's life preserving impulse in substantive, legally cognizable terms.¹⁸³

¹⁸³ In addition, in the case of Baby Doe, more acutely than in the case of other competent or incompetent patients who have had some life experience, it is problematic to determine what burdens of life count, as well as from whose viewpoint. Thus, even if there can be agreement that, in some cases, biological human life is pointless from a moral standpoint, and that certain basic human capacities (beyond pain and suffering) are morally significant features, it is still difficult to articulate substantively what factors lead to such a decision in given cases. There lurk problems of abuse from any standpoint and there is no present persuasive solution as to how best to control abuse by the decision maker. See *Deciding to Forego Life Sustaining Treatment*, *supra* note 80, at 584-95; Arras, *supra* note 180, at 26; Ellis, *supra* note 1, at 406. Indeed, it can be said that the attempt to compare advantages of life, even with a severe disability, against the state of "nonbeing" dictated by death is a "moral blind alley" if considered in terms of abstract justice and good. *Id.*

In *Tragic Choices*, Calabresi and Bobbitt describe the deceptive ways in which we artfully choose methods of allocating resources to avoid confrontation with morally troublesome, first order decisions about the availability or limit of resources as well as to mask the conflict of values which are involved when these decisions are important ones. It thus may be preferable, under this analysis, to affirm the value of life by conferring on the medical profession the responsibility of making life and death decisions related to infants, even though nonscientific values come in to play. But as the authors concede, there is a price to be paid for sacrificing honesty in a tragic choice. I would further add that there is some human benefit in confronting the tragic, moral dilemma, for in the anguish of decision making, we confirm the human experience and connectedness that makes life worth valuing.

Considered in this light, the controversy of withdrawing or withholding treatment for Baby Does not only underscores the inadequacy of concepts like autonomy in decision making, it makes more compelling further exploration and reconsideration of theories of human development. It may be that the shortcomings of existing decisional framework could relate to the absence of alternative perspectives concerning moral orientation and value presup-

In short, it may ultimately be concluded that the development of quality of life criteria is undesirable because of the impossibility of providing an effective voice for the newborn with profound disabilities. Society may conclude that the fundamental value of life and the interest of liberty from interference justify the broadest reading of "life" despite the importance of other competing values that come into play in a decision to withhold treatment and that no one can make the decision to withdraw or withhold treatment for the profoundly infirm infants. But that decision should be made reflectively and deliberately, with full appreciation of the consequences, for the sake of the child as well as for other members of society who are affected by this most troublesome issue, and not through compromise action as was the case in the federal regulatory action relating to Baby Doe.

positions which has been identified most notably by recent writings of Carol Gilligan. See Gilligan, *Remapping Development: The Power of Divergent Data*, to be published in *VALUE PRESUPPOSITIONS IN THEORIES OF HUMAN DEVELOPMENT*.

