Hastings Law Journal

Volume 37 | Issue 5 Article 3

1-1986

Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection

Steven R. Smith

Follow this and additional works at: https://repository.uchastings.edu/hastings_law_journal

 Part of the Law Commons

Recommended Citation

Steven R. Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 Hastings L.J. 765 (1986).
Available at: https://repository.uchastings.edu/hastings_law_journal/vol37/iss5/3

This Article is brought to you for free and open access by the Law Journals at UC Hastings Scholarship Repository. It has been accepted for inclusion in Hastings Law Journal by an authorized editor of UC Hastings Scholarship Repository. For more information, please contact wangangela@uchastings.edu.

Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection

By STEVEN R. SMITH*

The changing place of children in our society has had a significant impact on the legal relationship between parent and child. Although parents previously enjoyed great latitude in decisions involving their children, limitations on parental authority recently have been expressed through child abuse and child abuse reporting laws.[1] Ironically, one area of parental decision-making that in the past has been relatively unaffected by child abuse laws is the withholding of lifesaving treatment from seriously impaired infants. The recent adoption of amendments to the federal child abuse statutes and related regulations was an effort to provide for protection of disabled newborns through state child abuse laws.[2]

Child abuse laws are an appropriate interference with parental child-rearing interests and represent one legitimate mechanism for dealing with the problem of withholding lifesaving treatment from infants. The new federal law was apparently intended to impose new obligations on states, hospitals, individual physicians, and other medical personnel to protect disabled newborns. It is likely, however, that the current federal approach will be inadequate to influence significantly decisions to withhold lifesaving treatment from infants. Under the new federal law most decisions to withhold lifesaving treatment from infants will continue to be hidden from any review and the impact of the new law will be limited.

---

* Professor of Law, University of Louisville School of Law; Associate Professor, University of Louisville School of Medicine. B.A., 1968, Buena Vista College; J.D., M.A., 1971, University of Iowa.

1. *See* Besharov, *Child Protection: Past Progress, Present Problems, and Future Directions*, 17 FAM. L.Q. 151, 151 (1983); Paulsen, *The Legal Framework for Child Protection*, 66 COLUM. L. REV. 679, 679-80 (1966).

2. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified at 42 U.S.C.A. §§ 5102-5106, 5111-5113, 5115 (West Supp. 1985)). The implementing regulations are contained in the Child Abuse and Neglect Prevention and Treatment Program, 45 C.F.R. § 1340 (1985). Hereafter, unless otherwise noted, the citations to provisions of the Child Abuse Amendments of 1984 will be to the codified provisions in the United States Code Annotated.

The mechanism suggested by the federal regulations, hospital ethics committees, may not be the best way of meeting these obligations. For example, such committees may be cumbersome and unworkable in emergencies. Furthermore, because of the way the new federal law is written, in those cases that are reviewed, state courts may not apply the treatment standards of the new federal law. The scope and clarity of the federal statute and regulations must be expanded if they are to be effective in curtailing the improper withholding of treatment from infants.

States, of course, have primary responsibility for implementing child protection laws, and they are free to adopt clearer standards and greater review of nontreatment decisions than federal law requires. One solution is for states to institute interdisciplinary teams to review all decisions to withdraw lifesaving treatment from infants to ensure that the appropriate legal and medical standards have been applied properly. This review could be conducted relatively quickly, unobtrusively, and confidentially. Like all child abuse laws, this review would interfere with parental child-rearing decision-making. The decision to withhold medical treatment from infants, however, involves questions of life and death for individuals incapable of representing their own interests. In addition, parents' decisions to withhold treatment are made during an emotional crisis and may rest on factors irrelevant to the best interest of the child.[3] Such critical decisions, made by highly emotional decision-makers for the weakest members of society, surely warrant careful scrutiny.

This Article first explores the scope of the problem of withholding lifesaving treatment from seriously impaired infants. Next, the Article examines the interests involved in decisions to withhold treatment and the rationales for them. It contends that there are limitations on parental child-rearing rights and suggests standards to define when treatment may be withheld. The Article then reviews recent efforts to protect disabled newborns and points out a shift in the focus of these efforts toward a reliance on child abuse and neglect laws. Next, the Article surveys the development of federal and state child abuse and neglect statutes. The Article then considers the new federal Child Abuse Amendments and analyzes the ways in which definitional and functional problems impede statutory efforts to protect against improper withholding of treatment.

3. *See* Fost, *Counseling Families Who Have A Child With Severe Congenital Anomaly*, 67 PEDIATRICS 321, 321-22 (1981); Kindregan, *The Court as Forum for Life and Death Decisions: Reflections on Procedures for Substituted Consent*, 11 SUFFOLK U.L. REV. 919, 933 (1977); Marks & Salkovitz, *The Defective Newborn: An Analytic Framework for a Policy Dialogue*, in ETHICS OF NEWBORN INTENSIVE CARE 97, 114-15, 117-18 (A. Jonsen & M. Garland eds. 1976); Note, *Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. REV. 157, 162 (1983).

Finally, the Article proposes an alternative method of review of nontreatment decisions through the use of interdisciplinary teams that could provide more effective protection than is required under current law.

The Problem of Withholding Treatment

Scope of the Problem

Withholding lifesaving treatment from infants is not a recent development.[4] Although generally considered unlawful,[5] nontreatment of dis-

4. *See* D. HORAN & M. DELAHOYDE, INFANTICIDE AND THE HANDICAPPED INFANT (1982); INFANTICIDE AND THE VALUE OF LIFE (M. Kohl ed. 1978). Modern decisions to withhold treatment from infants are seen as raising some of the same ethical issues that ancient infanticide raised. Lund, *Infanticide, Physicians and the Law: The "Baby Doe" Amendments to the Child Abuse Prevention and Treatment Act,* 11 AM. J.L. & MED. 1, 1-21 (1985).

5. Legal principles regarding withholding medical care from infants are analyzed in Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice?*, 27 BAYLOR L. REV. 76, 78-85 (1975); Mueller & Phoenix, *A Dilemma for the Legal and Medical Professions: Euthanasia and the Defective Newborn*, 22 ST. LOUIS U.L.J. 501, 504-17 (1978); Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, in LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS 213, 214-22 (A. Doudera & J. Peters eds. 1982) [hereinafter cited as Robertson, *Withholding Medical Treatment];* Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 217-43 (1975) [hereinafter cited as Robertson, *Involuntary Euthanasia*]; Note, *Birth Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599, 613-19 (1978). For discussions of the legal principles regarding euthanasia in general, see Foreman, *The Physician's Criminal Liability for the Practice of Euthanasia*, 27 BAYLOR L. REV. 54 (1975); Sharp & Crofts, *Death with Dignity: The Physician's Civil Liability*, 27 BAYLOR L. REV. 86 (1975).

In the past, commentators generally have agreed that withholding lifesaving treatment from infants violates current legal standards. This, however, may be changing. *See* Book Note, 83 MICH. L. REV. 894, 896 (1985) (reviewing R. WEIR, SELECTIVE INVOLUNTARY TREATMENT OF HANDICAPPED NEWBORNS (1984)). At least one commentator believes that an alternative "medical-feasibility standard" is permitted under current laws, *see* Note, *supra*, at 623-32, although this is close to a futile treatment standard and represents only a slight variation in the interpretation of current legal standards.

According to some commentators, those who withhold lifesaving treatment from infants might be guilty of murder, involuntary manslaughter, conspiracy, child abuse and neglect, or violations of the child abuse reporting laws. *See, e.g.*, Foreman, *supra*, at 54; Robertson, *Involuntary Euthanasia, supra,* at 222-44. It is also suggested that civil liability might be imposed for wrongful death, negligence, abandonment, and violations of federal civil rights. *See* Mueller & Phoenix, *supra*, at 512-17.

Under certain conditions, parents have been found guilty of homicide for failing to provide adequate medical care for their children. *See, e.g.*, Stehr v. State, 92 Neb. 755, 139 N.W. 676, *aff'd*, 94 Neb. 151, 142 N.W. 670 (1913); State v. Williams, 4 Wash. App. 908, 484 P.2d 1167 (1971); *see also* State v. House, 260 Or. 138, 489 P.2d 381 (1971) (indictment alleging that parents caused child's death by willfully withholding food and care sufficient to charge first degree murder). The history of parental obligation to provide medical care is reviewed in State v. Clark, 5 Conn. Cir. Ct. 699, 261 A.2d 294 (1969). For a survey of child neglect statutes in the United States, see generally Katz, Howe & McGrath, *Child Neglect Laws in America*, 9 FAM. L.Q. 1 (1975).

abled newborns is probably not a rare event.[6] One study, for example, found that fourteen percent of all infant deaths in the studied hospital were related to withdrawal or withholding of medical treatment.[7] Congress has been presented with evidence indicating that several hundred to several thousand infants die each year in hospitals as a result of the withdrawal or withholding of medical treatment.[8] Some physicians have suggested that these data are outdated and that the number of infants from whom treatment is withheld has decreased in the last decade.[9] It is possible, however, that the number has actually increased because improved, more aggressive treatment techniques may now enable more infants to survive.

Attitude surveys have demonstrated that a significant number of physicians are willing to withhold lifesaving treatment from infants even though the action will result in the death of the child.[10] For example, one study revealed that eighty-five percent of the pediatric surgeons and sixty-five percent of the pediatricians surveyed would be willing to honor parental wishes not to perform necessary surgery on a Down's syndrome child, but less than six percent would deny similar treatment for a child

6. *But see* PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983) [hereinafter cited as PRESIDENT'S COMMISSION], which suggests that "*seriously* erroneous" decisions about the nontreatment of newborns occur very rarely. *Id.* at 208-09 (emphasis added). Given the data it cites, the Commission's basis for the conclusion that these events are rare is unclear. *See, e.g., id.* at 207-09.

7. Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890, 891 (1973); *see also* Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 398-99 (1982) (citing two studies showing that 61% and 80% of selected groups of physicians knew of, or participated in, withholding treatment).

8. Estimates given before a congressional subcommittee of the number of infant deaths resulting from the withdrawal of lifesaving treatment ranged from a few thousand to several thousand each year. *Medical Ethics: The Right to Survival, 1974: Hearings Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare*, 93d Cong., 2d Sess. 26 (1974) (testimony of Dr. Robert E. Cooke and Dr. Raymond S. Duff estimating that perhaps a couple of thousand infants a year would have survived if treatment had not been withdrawn) [hereinafter cited as *Medical Ethics Hearings*].

9. *See Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1983: Hearings Before the Subcomm. on Family and Human Services of the Senate Comm. on Labor and Human Resources*, 98th Cong., 1st Sess. 57-60 (1983) (testimony of Dr. George Little, American Academy of Pediatrics); PRESIDENT'S COMMISSION, *supra* note 6, at 208-09.

10. Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588, 590 (1977) [hereinafter cited as Shaw]. These and similar studies may have had a significant impact on Congress. The Congressional Conference Report on the Child Abuse Amendments of 1984 noted these studies. *See* S. REP. NO. 246, 98th Cong., 2d Sess. 8-9, *reprinted in* 1984 U.S. CODE CONG. & AD. NEWS 2918, 2925-26. Regarding more recent interviews expressing similar attitudes, see Rhoden, *Treatment Dilemmas for Impaired Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1309 n.168. (1985).

without the disability.[11] Similar statistics were obtained for the treatment of disabled children who had other disorders.[12] In addition, it appears that some physicians make the decision not to treat an infant without even consulting the parents. This is done, apparently, to avoid forcing the parents to make extremely difficult decisions, and perhaps in some cases, when the physician opposes treatment he believes the parent will demand.[13]

Complexity of the Problem

Lifesaving treatment decisions for infants are of a greater variety and complexity than is often recognized.[14] The decision may depend upon the nature and severity of any disability and upon the kind of treatment or other support that the child needs. In addition, the probability of the child's survival even with very aggressive treatment serves to complicate the decision. In at least some circumstances, the less likely a treatment is to save the life of an infant, the stronger the case is for permitting refusal of the treatment. This is particularly true if the treatment is risky or extremely painful. For example, a treatment that carries only a one percent chance of saving the life of an infant, is extremely painful, and has a high mortality rate might be rejected.[15]

General Assumptions

Two common assumptions exist concerning the treatment of children. One assumption is that parents should make the final decision about what treatment their children will receive. The second assumption is that, generally, lifesaving treatment should be given to children. Neither of these assumptions is absolute. Rather, each states the point

11. Shaw, *supra* note 10, at 590.

12. Collester, *Death, Dying and the Law: A Prosecutorial View of the* Quinlan *Case*, 30 RUTGERS L. REV. 304, 305 (1977) (similar attitudes concerning keeping a permanently nonsapient patient alive); Todres, Krane, Howell & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977); *see Treating the Defective Newborn: A Survey of Physicians' Attitudes*, HASTINGS CENTER REP., Apr. 1976, at 2 (More than half of the obstetricians and pediatricians surveyed approved of active or passive euthanasia for Down's syndrome children.) (reporting research and paper delivered by Dr.McKilligan at the annual meeting of the Canadian Pediatric Association).

13. *See* Longino, *Withholding Treatment from Defective Newborns: Who Decides, and on What Criteria?*, 31 U. KAN. L. REV. 377, 400 (1983); Marks, *supra* note 3, at 118-19; Waldman, *Medical Ethics and the Hopelessly Ill Child*, 88 J. PEDIATRICS 890, 890-91 (1976).

14. For a matrix demonstrating the complex ways in which infant treatment decisions may arise, see Smith, *Life and Death Decisions in the Nursery: Standards and Procedures for Withholding Lifesaving Treatment from Infants*, 27 N.Y.L. SCH. L. REV. 1125, 1146-53 (1982).

15. *See infra* notes 80-81 & accompanying text.

from which the consideration of whether to treat begins. The inquiry must continue by determining whether there is adequate cause not to act in accordance with the general assumptions. Moreover, these assumptions are not necessarily consistent. When parents refuse lifesaving treatment for a child, the assumptions are in conflict. The disagreement over these assumptions arises out of the strength or value assigned to each of them and the nature of interests that will overcome them. The following sections consider these issues and discuss the reasons for overcoming the presumptions of requiring lifesaving treatment and parental decision-making.

The presumption in favor of parental decision-making has strong constitutional and common law protection, and expresses values and public policies of long standing. These are discussed at length in the next section.[16]

The presumption in favor of lifesaving treatment reflects the strong social interest in preserving human life, which is generally as strong as any interest the state has. Such a "compelling" interest may justify interference with fundamental individual rights.[17] The fact that life is a sine qua non for the exercise of virtually all other rights, and that death is an irreversible event, contribute to the preservation of life assumption. When the life of a child or incompetent person is involved there is a particularly strong presumption in favor of preserving life. These are the weakest members of society and the least able to protect themselves. Therefore, society has a special obligation to protect the lives of children.[18]

There is, then, little disagreement about the general assumption favoring lifesaving treatment or about the propriety of state intervention in parental decision-making when such intervention is necessary to prevent serious harm to the child. The disagreement concerns the exceptions to these broad assumptions and generally focuses on two issues. First, is it appropriate to withdraw lifesaving treatment from an infant based on the quality of life the infant is likely to have?[19] Second, is it appropriate to withhold treatment based on the burdens the infant's life

16. *See infra* notes 21-60 & accompanying text.

17. *E.g.*, Roe v. Wade, 410 U.S. 113, 155-56 (1973); Branzburg v. Hayes, 408 U.S. 665, 700-01 (1972); *see also* Smith, *Constitutional Privacy in Psychotherapy*, 49 GEO. WASH. L. REV. 1, 32-41 (1980); Note, *Of Interests, Fundamental and Compelling: The Emerging Constitutional Balance*, 57 B.U.L. REV. 462 (1977).

18. *See* Comment, *Withholding Lifesaving Treatment from Defective Newborns: An Equal Protection Analysis*, 29 ST. LOUIS U.L.J. 853, 864-67 (1985).

19. *See infra* note 67 & accompanying text.

will place on others?[20] Each of these issues is considered in detail later in the Article. The questions may, of course, be complicated by disagreement about the applicability of standards to any given infant because of disagreements about medical prognosis, including chances of survival. Their resolution requires a consideration of the appropriate decision-making procedures.

Parental Decision-Making and Withholding Treatment

Nontreatment decisions have an impact on a broad range of interests, including those of parents and families, the infant, and the state.[21] It is sometimes implicitly assumed that it is possible to total the interests of these groups and thereby calculate, in some "total utilitarian" manner, whether treatment may be withdrawn from an infant.[22] Such calculations are too broad, however, because they consider some factors that are not appropriate in making these decisions. For example, the fact that a child may have an adverse effect on the family cannot be a legitimate basis for refusing life-saving treatment. Therefore, caution must be exercised in considering what factors are appropriate in making infant care decisions.

Parental Interests

The right of parents to make medical decisions for their children is rooted in the common-law and constitutional right of privacy in child-rearing. The common-law right was based on the concept of parental ownership of children[23] and on the very practical notion that children were incompetent to make medical decisions for themselves.[24] Underlying these concepts was the presumption that parents would always have the greatest possible interest in the physical and emotional well being of

20. *See infra* notes 67-81 & accompanying text.

21. *E.g.*, Bennett, *Allocation of Child Medical Care Decision-making Authority: A Suggested Interest Analysis*, 62 VA. L. REV. 285, 306-29 (1976); Ewald, *Medical Decision Making for Children: An Analysis of Competing Interests*, 25 ST. LOUIS U.L.J. 689, 691-726 (1982); Note, *supra* note 5, at 602-05.

22. See Strong, *Defective Infants and their Impact on Families: Ethical and Legal Considerations*, 12 L. MED. & HEALTH CARE 168 (1983); Note, *Life-Prolonging Treatment Decisions for Defective Newborns: Who Should Make the Choice?*, 17 SUFFOLK U. L. REV. 675, 680-88 (1984).

23. For a review of the history of the status of children and their relationships to their family, see generally C. SOMMERVILLE, THE RISE AND FALL OF CHILDHOOD (1982).

24. In Bonner v. Moran, 126 F.2d 121 (D.C. Cir. 1941), a leading child treatment consent case, the court noted that young children are often incapable of making intelligent decisions. Hence, surgeons have no right to operate upon them without parental consent. *Id.* at 122.

their children and that they therefore would make careful medical decisions that advance the health of the child.[25] This presumption is sometimes inappropriate because parents' medical decisions for their children may in some instances be influenced by factors that are not consistent with the best interests, or at least the best medical interests, of the child.

The Constitution also protects the parents' privacy right in child-rearing. The United States Supreme Court, in its decisions discussing the right of privacy, has stressed repeatedly that child-rearing falls within the scope of this privacy freedom.[26] As early as 1923, for example, the Court noted that the concept of liberty includes the right to establish a home and to raise children.[27] A few years later, the Court stated that liberty also includes parents' right to "direct the upbringing and education of children under their control."[28] The Court later affirmed the right of parents to direct the education of their children at home based on religious beliefs.[29]

There are several reasons for recognizing common law and constitutional rights in child-rearing, although courts seldom identify these interests specifically. Historically, the concept of the child as the parents' property probably played a role in this development because parental de-

25. *See In re* Phillip B., 92 Cal. App. 3d 796, 801, 156 Cal. Rptr. 48, 51 (1979), *cert. denied*, 445 U.S. 959 (1980); Zoski v. Gaines, 271 Mich. 1, 9, 260 N.W. 99, 101-02 (1935); Friedrichsen v. Niemotka, 71 N.J. Super. 398, 402, 177 A.2d 58, 60 (1962); *In re* Hofbauer, 47 N.Y.2d 648, 654-55, 393 N.E.2d 1009, 1013, 419 N.Y.S.2d 936, 940 (1979); Rogers v. Sells, 178 Okla. 103, 105, 61 P.2d 1018, 1019-20 (1936); *In re* Green, 220 Pa. Super. 191, 195, 286 A.2d 681, 683 (1971); Weston's Adm'x v. Hospital of St. Vincent de Paul, 131 Va. 587, 592, 107 S.E. 785, 786 (1921); *In re* Hudson, 13 Wash. 2d 673, 693-94, 126 P.2d 765, 775-76 (1942); *see also* RESTATEMENT (SECOND) OF TORTS § 892A comment b (1979).

26. Although formal recognition of a constitutional right of privacy is relatively new, some aspects have a long history. *See* Griswold v. Connecticut, 381 U.S. 479 (1965); Prince v. Massachusetts, 321 U.S. 158, 166 (1944). The historical development of the right of privacy has been documented. *See generally* Clark, *Constitutional Sources of the Penumbral Right to Privacy*, 19 VILL. L. REV. 833 (1974); Emerson, *Nine Justices in Search of a Doctrine*, 64 MICH. L. REV. 219 (1965); Griswold, *The Right to be Let Alone*, 55 NW. U.L. REV. 216 (1960); Henkin, *Privacy and Autonomy*, 74 COLUM. L. REV. 1410 (1974); O'Connor, *The Right to Privacy in Historical Perspective*, 53 MASS. L.Q. 101 (1968); Note, *Formalism, Legal Realism, and Constitutionally Protected Privacy Under the Fourth and Fifth Amendments*, 90 HARV. L. REV. 945 (1977). Child-rearing is protected by the constitutional right to privacy. *See, e.g.*, Carey v. Population Servs. Int'l, 431 U.S. 678, 684-85 (1977); Paul v. Davis, 424 U.S. 693, 713 (1976); Paris Adult Theatre I v. Slaton, 413 U.S. 49, 65 (1973).

27. Myer v. Nebraska, 262 U.S. 390, 399 (1923) (parental interest in the teaching of foreign languages).

28. Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925) (involving the requirement that children attend public schools rather than private schools).

29. Wisconsin v. Yoder, 406 U.S. 205, 234 (1972); *see* Quillan v. Walcott, 434 U.S. 246, 255 (1978).

cision-making was an extension of property rights.[30] In addition, another reason could be that because parents are responsible for supporting and providing for their children, they also should have the authority to make decisions related to that responsibility and to direct the development of their children's values and beliefs. Finally, recognition of the right of privacy in child-rearing might also promote the concept of the family as a central or fundamental social value.

Child's Interests

It is possible to view children as having privacy rights that are exercised for them by their parents.[31] Parents making the medical decision to withhold or withdraw treatment from their children might, therefore, claim to exercise a privacy right belonging to the child. The question is whether parents, in addition to exercising their *own* privacy rights in child-rearing, also are capable of exercising their *child's* right of autonomy privacy in making medical decisions, a kind of "substituted privacy" right.

The recognition of substituted privacy exercised by parents on behalf of their children potentially would limit the ability of the state to require lifesaving treatment. State child abuse and neglect laws and federal laws seeking to ensure provision of lifesaving treatment might be challenged on the ground that they unconstitutionally interfere with the right of the child, through the child's parents or guardian, to refuse treatment. For example, a state law requiring that treatment be given to a Down's syndrome baby if necessary to save the child's life may be seen as interference with the child's right to refuse treatment, even if the decision will result in the death of the child. Or the new federal law, to the extent it is effective in requiring that treatment be provided regardless of the decision of parents, also could be seen as an unconstitutional interference with the child's autonomous decision-making. A child's right of privacy, protected through substituted privacy, might be particularly important because the privacy right to make medical decisions for oneself seems to be of greater weight than the child-rearing privacy interest of parents.[32]

30. *See* Note, *Unequal and Inadequate Protection Under the Law: State Child Abuse Statutes*, 50 GEO. WASH. L. REV. 243, 243 & n.4 (1982) (citing D. BAKAN, SLAUGHTER OF THE INNOCENTS 26-32 (1971)).

31. *See generally* Keiter, *Privacy, Children, and Their Parents: Reflections On and Beyond the Supreme Court's Approach*, 66 MINN. L. REV. 459 (1982); Levy, *The Rights of Parents*, 1976 B.Y.U. L. REV. 693.

32. *See* United States v. George, 239 F. Supp. 752 (D.C. Conn. 1965); *In re* Estate of Brooks, 32 Ill. 2d 361, 372-74, 205 N.E.2d 435, 442-43 (1965). *But see* Application of President of Georgetown College, 331 F.2d 1000, 1008 (D.C. Cir.), *cert. denied*, 377 U.S. 978

Some support for the existence of substituted privacy arises from several cases establishing the right to refuse medical treatment. In *In re Quinlan,*[33] for example, the New Jersey Supreme Court noted that people do not lose their privacy rights when they become incompetent.[34] On the basis of the *patient's* privacy rights, the court permitted a decision to refuse lifesaving treatment to be made by a guardian. Similar language has been repeated in other state court cases such as *In re Storar,*[35] *Severns v. Wilmington Medical Center,*[36] and *In Re Conroy.*[37] It is important to note that in these cases, the patients had expressed judgments about what medical treatments they wished to receive if they ever became incompetent.[38] Therefore, these cases can be seen as merely implementing the decisions made by the patients while still competent. There is, however, some danger that these cases may be mistaken as establishing a substituted autonomy principle for children.[39]

(1964); People v. Labrenz, 411 Ill. 618, 625, 104 N.E.2d 769, 773-74 (1952); State v. Perricone, 37 N.J. 463, 472-73, 181 A.2d 751, 756-57 (1962). *See generally* Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337 (1981).

33. 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied*, 429 U.S. 922 (1976). In *Quinlan*, the court permitted the parents of a 22-year-old woman in a nonsapient state to remove her from a respirator, even though it was possible that the removal would result in her death.

34. *Id.* at 25, 355 A.2d at 664. The New Jersey Court later emphasized that even statements made to others concerning the general topic of artificially prolonging life are relevant in making substituted consent treatment decisions. *In re* Conroy, 98 N.J. 321, 362, 486 A.2d 1209, 1230 (1985).

35. 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981). In *Storar*, Brother Joseph Fox, while undergoing surgery, suffered cardiac arrest and substantial brain damage, resulting in a nonsapient state from which there was no hope of recovery. Father Eichner sought permission to have Brother Fox removed from the respirator that was keeping him alive. Noting that Brother Fox had expressed such wishes while he was competent, the court granted permission for removal from the respirator. *Id.* at 376, 420 N.E.2d at 70, 438 N.Y.S.2d at 272. The court expressly stated, however, that it was not reaching the issue of the patient's right to privacy. *Id.* at 376-77, 420 N.E.2d at 70, 438 N.Y.S.2d at 272-73.

36. 421 A.2d 1334 (Del. 1980). In this case, the court held that a guardian may vicariously assert the rights of a comatose patient, including the right to refuse or discontinue medical treatment. *Id.* at 1347.

37. 98 N.J. 321, 486 A.2d 1209 (1985). In this case, the court emphasized the broad range of evidence that should be considered in determining the wishes of a once competent patient. *Id.* at 362-63, 486 A.2d at 230-31.

38. As a practical matter, it is often very difficult to know with any degree of certainty whether a patient would refuse treatment if actually faced with the real decision. Her offhanded remarks about important decisions may not reflect what she would do when actually confronted with the question.

39. In *In re* P.V.W., 424 So. 2d 1015 (La. 1982), for example, the Louisiana Supreme Court held that "a permanently comatose child has an *independent right* to discontinuance of artificially sustained life . . . and that an appropriate representative may judicially assert that right on behalf of the child. . . ." *Id.* at 1020. The right noted by the court apparently existed in a state statute, but the court seemed to depend on *Quinlan*, *Storar*, and similar decisions. *Id.* at 1017-19. *See* Gostin, *A Moment in Human Development: Legal Protection, Ethical Stan-*

There are different considerations when parents attempt to exercise a child's privacy right on the child's behalf, rather than claim their own privacy interests in child-rearing. Because the concept of individual choice forms the core of the privacy right, the values, goals, beliefs, and feelings of the individual are essential to the privacy. Therefore, it is improper to allow another person, who holds different interests or values, to exercise the privacy interest of a patient. As *Conroy* and *Storar* demonstrate, guardians may implement decisions expressed earlier by the patient, in a form of so-called "substituted judgment."[40] Unlike the patients in those cases, however, an infant cannot have the established beliefs, values, preferences, and goals upon which privacy decisions depend. Parents may exercise their *own* privacy rights in child-rearing. They may also be able to protect the child's interest in life or to make decisions in the child's "best interest." Parents cannot claim, however, to be exercising the child's autonomy privacy rights. To allow this sort of "substituted privacy" exercise would be the same as allowing parents to exercise the infant's religious rights to refuse lifesaving treatment. Courts have universally recognized that parents cannot exercise the religious beliefs of a child who is currently unable to hold such beliefs. Just as the parents could not refuse a blood transfusion based on the infant's beliefs as a Jehovah's Witness,[41] they cannot refuse the transfusion based on the infant's right of privacy.

Although an infant cannot have an autonomy privacy interest in refusing treatment, the child does have other legal interests in treatment decisions. Theoretically, a child could have an interest in *refusing* treatment to which parents wished to consent and which might be described as an "interest in avoiding harmful bodily invasions." The right of children to avoid harmful bodily invasions might arise out of the fourteenth amendment concept of ordered liberty (the *state* gives parents legal authority to act for their children and parents are limited in the exercise of this power), from a common-law right of bodily integrity, or from statutory protection, such as child abuse and neglect laws. Arguably, in the

dards and Social Policy on the Selective Treatment of Handicapped Neonates, 11 AM. J.L. & MED. 31, 52-58 (1985).

40. *Conroy*, 98 N.J. at 359-74, 486 A.2d at 1229-37; *Storar*, 52 N.Y.2d at 367, 372, 420 N.E.2d at 67-68, 71-73, 438 N.Y.S.2d at 268, 270.

41. *See* Jehovah's Witnesses v. King County Hosp., 278 F. Supp. 488, 504-05 (W.D. Wash. 1967), *aff'd per curiam*, 390 U.S. 598 (1968); *In re* Ivey, 319 So. 2d 53, 58-59 (Fla. Dist. Ct. App. 1975); People v. Labrenz, 411 Ill. 618, 625-26, 104 N.E.2d 769, 773-74, *cert. denied*, 344 U.S. 824 (1952); Morrison v. State, 252 S.W.2d 97, 103 (Mo. Ct. App. 1952); State v. Perricone, 37 N.J. 463, 472-74, 181 A.2d 751, 756-57, *cert. denied*, 371 U.S. 890 (1962); Application of Brooklyn Hosp., 45 Misc. 2d 914, 915, 258 N.Y.S.2d 621, 622 (N.Y. Sup. Ct. 1965); *In re* Clark, 90 Ohio Op. 2d 21, 25-26, 185 N.E.2d 128, 131 (1962).

same way a child has an interest independent of its parent in being free of harmful, brutal beatings, the child may have a legal interest in avoiding harmful treatment.

If a child has a right to avoid "harmful" treatment, the question becomes how to define what harmful treatment is. Can life-saving treatment ever become harmful? Proponents of a quality of life position might argue that treatment which forces an infant to live a life of low quality is "harmful" and therefore not reasonably "in the best interest" of the child. Resolution of this question, however, depends on an analysis of several factors described below, such as how to evaluate the quality of life, the risks of treatment, and the trade-offs between the quality and quantity of life.[42] Claims that parents and physicians are abusing a child by providing too much life-saving treatment are virtually unknown.[43] In part, this reflects a fairly strong legal presumption in favor of lifesaving treatment. If a strong quality of life position is taken, however, then it might be possible to assert that the parents of disabled newborns are abusing them by providing treatment that will force them to live undesirable lives. If such legal claims were taken seriously, difficult due process problems would arise in reviewing claims of overtreatment made "on behalf of" disabled newborns.

Limits on Child-Rearing Rights

The United States Supreme Court has noted that parental child-rearing rights, even though constitutionally protected, may be limited when the "parental decisions will jeopardize the health or safety of the child."[44] The Court in another context stated that "parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children . . . ."[45]

Traditionally, courts have been willing to interfere with parental rights when the parent's decision threatens the child's life or when the child's constitutional rights may be involved. Parents' decisions to withhold necessary blood transfusions for religious reasons[46] or to refuse consent for children to receive vaccinations against childhood diseases[47]

42. *See infra* notes 67-81 & accompanying text.

43. Claims of harmful overtreatment could be made against parents who consented to treatment that others saw as undesirable. Theoretically, then, child abuse and neglect laws could be invoked to stop treatment.

44. Wisconsin v. Yoder, 406 U.S. 205, 233-34 (1972).

45. Prince v. Massachusetts, 321 U.S. 158, 170 (1944).

46. *See supra* note 41.

47. *See* Zucht v. King, 260 U.S. 174 (1922); Wright v. DeWitt School Dist., 238 Ark. 906, 385 S.W.2d 644 (1965); Auten v. Board of Directors of Special School Dist., 83 Ark. 431,

illustrate the range of medical determinations by parents that are subject to close scrutiny. The general trend seems to be toward increased review of these important medical decisions, although parents are still granted great latitude in making non-life-threatening decisions that do not significantly infringe upon the fundamental rights of minors.[48]

This trend toward review of unrestricted parental decision-making is expressed in *Parham v. J.R.*,[49] in which the court held that parental decisions regarding commitment of minors to mental institutions must be reviewed by independent professionals at institutions.[50] Courts have similarly upheld the rights of minors to obtain constitutionally protected medical treatment, such as abortion and contraception, despite the absence of parental consent.[51] Even when a minor is not sufficiently mature to decide whether or not to have an abortion, a state court may authorize the procedure without the consent of the minor's parents.[52] Child abuse laws and child abuse reporting laws are further examples of state interference with parental decision-making.[53] These statutes ordinarily provide for state intervention in a very wide range of areas of parental abuse or neglect and also require that those knowing of potential abuse or neglect report it to the state.

Thus, there has been a modern trend toward increasing state review of, and interference with, parental decision-making for children when those decisions may significantly harm the child. This is particularly true when the parents' decision could put the infant's life in unnecessary jeopardy.[54] Should this state interference be used to protect all children, including disabled newborns? It might be argued that the state's interest in protecting the life of a disabled infant is less compelling than its interest in protecting the life of a "normal" infant.[55] If this claim is based on a

104 S.W. 130 (1907); Board of Educ. v. Maas, 56 N.J. Super. 245, 152 A.2d 394 (1959), *aff'd*, 31 N.J. 537, 158 A.2d 330, *cert. denied*, 363 U.S. 843 (1960); *In re* Marsh, 140 Pa. Super. Ct. 472, 14 A.2d 368 (1940); *cf.* Jacobson v. Massachusetts, 197 U.S. 11, 37-38 (1905) (upholding statute requiring smallpox vaccinations for residents).

48. *See* PRESIDENT'S COMMISSION, *supra* note 6; Ewald, *supra* note 21.

49. 442 U.S. 584 (1979).

50. *Id.* at 606-07. In *Parham,* the Court demonstrated a preference for permitting the review of the medical decisions to be made by medical specialists rather than by courts.

51. *See* Bellotti v. Baird, 443 U.S. 622, 646-47 (1979); Carey v. Population Servs. Int'l, 431 U.S. 678, 692-94 (1977); Planned Parenthood v. Danforth, 428 U.S. 52, 74-75 (1976).

52. Planned Parenthood v. Ashcroft, 462 U.S. 476, 492-93 (1983).

53. Child abuse and child abuse reporting laws are discussed in detail *infra* notes 114-32 & accompanying text. For discussion of the application of child abuse laws to withholding treatment from physically impaired newborns, see *infra* notes 133-81 & accompanying text.

54. Comment, *Baby Doe Decisions: Modern Society's Sins of Omission*, 63 NEB. L. REV. 888 (1984).

55. For example, one commentator has argued that lifesaving treatment for infants

view of the relative value to the state of normal and disabled life, the distinction is inappropriate. It would alter seriously the traditional legal view of the value of human life.[56] Consider the result if someone enters a hospital nursery and stabs two infants at random, and both infants die. It would be inappropriate to punish the person only for killing the normal infant. It also would be improper to punish him less severely for killing the disabled infant based on the theory that the state has a stronger interest in the life of the normal infant. The attacker is equally guilty of homicide for causing the death of the normal child and the severely disabled child. If instead those children are only injured, but required blood transfusions over parental objections, it would be unacceptable to order treatment for the normal child, but not for the disabled child based on the claim that the state does not have as strong an interest in preserving the life of the disabled child. Neither can the life expectancy of each child be used to define the state interest in preserving that life. Just as the state has a strong interest in avoiding the death of the very elderly who have a very short remaining life expectancy,[57] so too must it protect the children who are born with a severe disability. Thus, the state's interest in preserving life should not be reduced either by some perception of the value of life or by the length of life expectancy.

There has been some criticism that government intervention in life-saving treatment cases is inappropriate because it interferes with family autonomy.[58] If there is ever an appropriate time for state interference in parental decision-making, however, it is when the parents' decision may result in the death of the child. Indeed, child abuse laws currently permit state intervention in a wide range of decision-making that will have

should not be ordered when "there is less than a high probability that the . . . treatment will enable the child to pursue either a life worth living or a life of *relatively normal healthy growth* toward adulthood." Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, 86 YALE L.J. 645, 653 (1977) (emphasis added).

56. *See* Phillips v. United States, 508 F. Supp. 537 (D.S.C. 1980); P. RAMSEY, ETHICS AT THE EDGES OF LIFE 224-26 (1978).

Most courts have not recognized a cause of action for wrongful life. *See, e.g.*, Alquijay v. St. Luke's-Roosevelt Hosp., 53 N.Y.2d 978, 473 N.E.2d 244, 483 N.Y.S.2d 994 (1984); Nelson v. Krusen, 678 S.W.2d 918 (Tex. 1984). Those that have recognized such a cause of action have not permitted general damages for the pain of experiencing life as opposed to having no life at all. *See* Turpin v. Sortini, 31 Cal. 3d 220, 643 P.2d 954, 182 Cal. Rptr. 337 (1982) (en banc); Procanik v. Cillo, 97 N.J. 339, 478 A.2d 755 (1984); Harbeson v. Parke-Davis, 98 Wash. 2d 460, 656 P.2d 483 (1983).

57. The underlying assumptions of such a claim of reduced state interest in a disabled newborn are considered *infra* notes 61-79.

58. *See, e.g.*, Goldstein, *supra* note 55, at 649-50; Steinfels, *Children's Rights, Parental Rights, Family Privacy, and Family Autonomy*, in WHO SPEAKS FOR THE CHILD 223, 257-63 (W. Gaylin & R. Macklin eds. 1982); Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV. 1383, 1386-87 (1974).

far less serious consequences.[59] For example, most states require intervention in cases of severe emotional abuse or sexual molestation.[60] Neither is likely to result in the death of the child, but both are appropriate bases for state intervention in parental decision-making. In sum, the state is justified in interfering with parental decision-making when a child may die or be seriously harmed, and the fact that a child is disabled does not increase the parent's privacy interest in child-rearing nor does it decrease the state's interest in protecting the child.

State and Other Interests

The primary interest of the state is commonly identified as a strong dedication to preserving human life. This interest is usually considered so compelling that it outweighs even fundamental personal rights, including the right of privacy.[61] This statement of the interest in preserving life, however, is too broad. For example, the state does not necessarily have such a strong interest in preserving life that it can always require a fully competent adult to accept lifesaving treatment over her objections.[62] In some circumstances, therefore, even the compelling state in-

59. *See* Areen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Neglect and Abuse Cases*, 63 GEO. L.J. 887, 920-28 (1975); Bennet, *supra* note 21, at 294-306; Ewald, *supra* note 21, at 722-26; Note, *supra* note 58, at 1399-1402.

60. *E.g.*, ALA. CODE § 26-14-1(1) (Supp. 1985); MD. FAM. LAW CODE ANN. § 5-901 (1984); R.I. GEN. LAWS § 40-11-2(2) (Supp. 1985).

61. Roe v. Wade, 410 U.S. 113, 153-54 (1973).

62. Competent adults generally have a right, at least partially based on the right to privacy, to refuse medical treatment for themselves even though doing so might seriously endanger their lives. *See, e.g.*, Holmes v. Silver Cross Hosp., 340 F. Supp. 125, 129-30 (N.D. Ill. 1972); Satz v. Perlmutter, 379 So. 2d 359 (Fla. 1980); Suenram v. Society of Valley Hosp., 155 N.J. Super. 593, 601-03, 383 A.2d 143, 147-48 (1977).

In many instances, however, the courts have found reason to compel the treatment. Courts commonly identify the protection of the rights of innocent third parties as their reason for ordering medical treatment. *See, e.g.*, Application of President of Georgetown College, 331 F.2d 1000, 1008 (D.C. Cir. 1964), *cert. denied*, 377 U.S. 978 (1964); United States v. George, 239 F. Supp. 752, 754 (D. Conn. 1965); Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964). In many of these cases, it appears that the courts' main reason for ordering treatment is their reluctance to permit even a competent adult to die for the lack of relatively risk-free treatment when this treatment is refused for what the courts view as insignificant reasons. *See generally* Byrn, *Compulsory Lifesaving Treatment for the Competent Adult*, 44 FORDHAM L. REV. 1 (1975); Cantor, *A Patient's Decision to Decline Life-Saving Medical Treatment: Bodily Integrity Versus The Preservation of Life*, 26 RUTGERS L. REV. 228 (1973) (suggesting that no state interest is sufficient to force an adult patient to undergo treatment); Paris, *Compulsory Medical Treatment and Religious Freedom: Whose Law Shall Prevail?*, 10 U.S.F.L. REV. 1 (1975) (In their zeal to protect lives, courts have avoided complex emotional, legal, and moral-theological issues raised when a competent adult refuses treatment.); Note, *Compulsory Medical Treatment and Constitutional Guarantees: A Conflict?*, 33 U. PITT. L. REV. 628 (1972) (Courts should objectively identify the individual's interests before deciding that the state's interests are superior.).

terest in preserving human life is not absolute, although exceptions to it tend to be few and narrowly limited. Any number of state interests, such as maintaining the efficient operation of its court system, reducing the cost of medical care, promoting a general respect for life, and promoting family integrity have been identified.[63] These interests are less important and generally are not sufficiently strong to justify significant interference with fundamental rights.

There are, of course, a large number of other people and groups with interests in lifesaving treatment decisions. For example, hospitals may have an interest in reducing the cost of care and promoting the smooth operation of the hospital. Similarly, doctors have an interest in making medical judgments without the interference of the government. Doctors may also have an interest in not providing care that unnecessarily causes the death of their patients. In addition, insurance companies have an interest in the cost of treatment, or nontreatment, of a child.[64]

The many interests that can be identified in nontreatment decisions are secondary to the primary interests of the parents and child. Even the government's interest essentially revolves around protecting the child's interests and parental decision-making. The common-law and constitutional rights of privacy are central to these interests.

Parental Decisions to Withhold Lifesaving Treatment and Proper Decision-Making Standards

Most of the reasons parents refuse lifesaving treatment can be divided into six broad categories: (1) religious belief; (2) quality of life; (3) burdens on others; (4) pain of treatment; (5) short life expectancy; and (6) futility of treatment. Although this Article discusses these reasons in terms of parental refusal of treatment, the same categories also would apply to other entities, such as physicians, hospitals, and courts involved in lifesaving treatment decisions.

Reasons for Withholding Lifesaving Treatment

A parent may wish to refuse treatment to the child because the treatment violates the parent's religious beliefs. When medical treatment is necessary to save the life of the child, however, courts have almost unanimously ordered that treatment be given even though it violates the

63. Bennett, *supra* note 21, at 317-19.

64. The insurance interests in treatment decisions may be conflicting. Health insurance carriers may want to avoid expensive long term lifesaving treatment, but life insurance carriers might have as clear an interest in maintaining the lifesaving treatment.

parent's religious convictions.[65] As important as the parent's religious beliefs are, they cannot legitimately be the basis for causing the death of another person who has not explicitly adopted and accepted those beliefs. Put another way, the child's right to life is of greater importance than the parent's interest in implementing religious beliefs on the child's behalf.

Much of the debate about withholding lifesaving treatment really concerns the question of whether the refusal of treatment can legitimately be used to cause the death of a severely impaired newborn. For example, the refusal of a blood transfusion or surgery to correct a life-threatening defect in a Down's syndrome child is likely to be based on dissatisfaction with the child's impaired life rather than with the intrusiveness of the treatment. This refusal may be based on a feeling that the child will not have a life worth living or that the life of the child will be highly disruptive to others. In either case, it is not the treatment itself that is feared, but rather the nature of the life the infant will lead if it survives.[66] The effort in such cases is not to improve the quality of life or trade some quantity of life for increased quality of life. Rather, the effort is to shorten a life of uncertain or unknown quality.

This rationale has potentially disastrous ramifications. If it is appropriate to terminate treatment and thereby end a life on the theory that it is not worth living or that it will have too many adverse effects on others, why should we have to wait for a life-threatening condition in order to end that life? Why permit the "benefits" of an early death only to those infants who suffer from a life-threatening illness?[67] The same arguments supporting the withholding of treatment could be invoked to permit the withdrawal of food and water or the direct killing of the infant. Indeed, it seems that direct euthanasia would be more humane in many instances than a prolonged, painful period of illness resulting from nontreatment. Nor is the distinction between action (harm) and inaction (failure to rescue) applicable here, when there is a duty to care for another.[68]

65. *See supra* note 41.

66. The question also may be stated in terms of parental autonomy; for instance, should the family of a severely retarded child be permitted to withhold lifesaving treatment when the family of a normal child is not permitted to do so?

67. In considering these questions imagine four infants. All require simple surgery to remove a bowel obstruction. Death, often occurring after a long and painful period of time, is the certain result without treatment. Suppose one of the infants is normal, the second is born without legs, the third is profoundly retarded, and the fourth has life expectancy of five or six years, much of which will be spent in pain. The law surely would require that the first child be given treatment to save its life. But should the second, third, or fourth child be treated differently because of the abnormalities?

68. *See* R. WEIR, *supra* note 5, at 98-100. *See generally* Goldstein, *supra* note 55, at 645; PRESIDENT'S COMMISSION, *supra* note 6, at 76.

Terminating another's life because of a feeling that that life is not worth living may reflect a subjective desire to do what is best for the person. A major fallacy of this approach, however, is that it rests on the assumption that reasonable judgments about the quality of another's life can be made.[69] It also rests on the highly debatable assumption that the life of a disabled child is less acceptable or meaningful than that of a normal child. The assumption that those with disabilities, even serious disabilities, do not have lives worth living is inconsistent with our increased acceptance of the value of disabled citizens. The legitimacy of these assumptions is open to question. Views regarding the value and quality of life vary greatly. Even illegitimacy has been seen as making life not worth living.[70] Thus, it seems unlikely that an objective set of criteria by which to gauge the quality of life can ever be established.

We often do not know enough about the potential quality of the life of an impaired newborn to make such judgments. Some may view the quality of life for a child born to a large, uncaring family living in poverty to be quite limited, but it certainly does not seem proper to withhold lifesaving treatment on that basis.[71] Yet it is not clear that the subjective

69. "Slavery, witch-hunts and wars have all been justified by their perpetrators on the grounds that they held their victims to be less than fully human." Bok, *Ethical Problems of Abortion*, HASTINGS CENTER STUD., Jan. 1974, at 33, 41. One commentator suggests that equal treatment need only apply to those with a capacity for a "sense of self" or a sense of "being a continuing entity." This view is dangerous, however, because the right to treatment is subject to the definition of a "sense of self." Tooley, *Abortion and Infanticide*, 2 PHIL. & PUB. AFF. 37, 49 (1972). Under this concept of equal protection, "sense of self" could be defined broadly to remove legal protection from many groups. A recent article, which heroically claims to establish a principled standard that will avoid a slippery slope, proposes that lifesaving treatment need not be provided if the infant will not develop the capacity to relate to others. Rhoden, *supra* note 10, at 1318-23. Although this is an admirable effort to establish a quality of life standard, it depends on relations to others very much like ourselves and thereby may define the valuable functions of human life too narrowly.

70. The case of Zepeda v. Zepeda, 41 Ill. App. 2d 240, 190 N.E.2d 849 (1963), *cert. denied*, 379 U.S. 945 (1964), illustrates the extreme to which such judgments can be taken. In *Zepeda*, an illegitimate child sought damages from his biological father for having caused his birth, suggesting that it would be better never to have been born than to be born illegitimate. While the court denied relief in deference to the legislature's role of establishing this type of tort action, it did recognize that the child's argument was the logical result of allowing actions for prenatal injuries. *Id.* at 243, 190 N.E.2d at 853.

If the Zepeda child had needed lifesaving treatment at birth, could the mother have appropriately refused the treatment because it would be better for the infant not to survive than to survive as an illegitimate child? That illegitimacy might be thought to make "no life at all" better than living demonstrates the potential range of the "life worth living" decisions.

71. The prospect for an acceptable, or even happy, life varies from person to person. To some people, albeit a very few, "normal" human life is unhappy. In People v. McQuiston, 12 Cal. App. 3d 584, 90 Cal. Rptr. 687 (1970), the defendant killed his wife and then his two normal children. He described the killing of the children as acts of mercy that he would repeat because he believed the children would be better off dead than to continue living with their

quality of life of a profoundly mentally retarded infant is any less than it is for a normal child. Even a child born with pain or with a relatively short life expectancy cannot be said, with certainty, to lack all capacity to enjoy life or to have a life without any meaning or value. In sum, opinions regarding the value of life are so disparate, and our ability to calculate an infant's capacity to enjoy life so feeble, that withholding treatment on the basis of the "quality of life" rests life and death decisions on pure speculation.

It is also unacceptable to withhold lifesaving treatment from an infant because the child will have a negative impact on her family, the medical community, or others. The potential burdens of a disabled newborn include psychological, social, and financial harm to the family and a potential economic drain on society if the parents do not or cannot care for the child. The proposition that one person's life should be ended by others to avoid potential social or economic harm is contrary, however, to the most fundamental concepts of individual rights and protection central to our laws and Constitution.[72] Once applied to the disabled, such a general principle easily could expand to reach others who become a financial, social, or psychological drain to their families or to society.[73] Indeed this principle would seem to have immediate application to the mentally ill, the seriously disabled, and the elderly. The fact that a seriously impaired child may place substantial burdens on a family argues for permitting the family to give up responsibility for the child through adoption. It does not argue for permitting the parents to cause the death of the infant by withdrawing treatment.

Here, too, there are impossibly complex practical problems involved

mother dead and their father in prison. *Id.* at 590, 90 Cal. Rptr. at 689-90. Additionally, one psychiatrist has described to the author a case in which he feared that a patient who was very caring and even loving toward his child might try to kill the child to protect it from the great pain and suffering associated with living. It was difficult for the patient/father to understand what pleasure the child might find in life.

As these cases illustrate, the perspective from which one person views the value of a life can be quite different from that of the person actually experiencing that life. Similarly, it is difficult for us to appreciate what the life of a severely impaired newborn is like.

72. Courts generally permit the taking of life only to protect another life. Thus, the protection of property is ordinarily of insufficient importance to justify the use of life-threatening force. *See* Katko v. Briney, 183 N.W.2d 657, 660-61 (Iowa 1971) (use of spring-loaded gun to protect against trespassers not justified).

73. Society does permit some interference with individual rights in order to protect others. For example, involuntary civil commitment may be justified because a person is mentally disabled and dangerous to himself or to others. The tendency in most states, however, has been to require serious dangerousness, generally a serious threat to personal safety, to justify commitment. S. SMITH & R. MEYER, LAW, BEHAVIOR, AND THE MENTAL HEALTH PROFESSION (in press).

in the calculations required to gauge the burden created by the infant's disability.[74] To begin with, such an approach calls for not merely a calculation, but also a prediction about future costs and utilities. In part, this prediction requires a calculation of the "net utility," loosely defined as pleasure less displeasure, that the infant will experience from life. This "net utility" must be calculated on the basis of how the infant himself or herself will perceive pleasure and pain. Next, the net pleasure and pain that the infant will bring to the family, to others, and to society, must be calculated from the perspective of those people. Finally, the two calculations of net utilities must be compared. This calculation thus rests on gross speculation.

It is precisely the extraordinarily speculative nature of the "life not worth living" and "too costly to others" principles that makes them so dangerous.[75] Without any reliable information on which to make these decisions, they will be based on hunches, fears, suspicions, and prejudices. Decisions of this type often will reflect the feeling that lives substantially different from our own or from "normal" standards are imperfect and of low value. These are generally inappropriate bases on which to make life and death decisions and may often cause us to undervalue considerably the lives of those who are different.

The very speculative nature of these decisions might, on the other hand, be seen as a reason for leaving these decisions within the range of parental child-rearing decision-making. Arguably, when we cannot predict with certainty which alternative is best for the child or the family, we should leave that decision to the parents.[76] When the parental decision-making may result in serious harm to a child, however, the fact that there is some uncertainty ought not to give the family unlimited authority. While uncertainty does create substantial latitude in the family, it does not create a general power to withhold lifesaving treatment from the

74. Ramsey suggests that if these extremely difficult calculations and decisions are to be made, divine wisdom is necessary. "If physicians are going to play God under the pretense of providing relief for the human condition, let us hope they play God as God plays God." P. RAMSEY, *supra* note 56, at 203; *see* Silving, *Euthanasia: A Study in Comparative Criminal Law*, 103 U. PA. L. REV. 350, 356-58 (1954). *But see Medical Ethics Hearings, supra* note 8, at 7-8.

75. To avoid the use of grossly inappropriate criteria in withholding treatment based on quality of life, the standards for any such decision should be precise, unambiguous, and widely known. Such acceptable "quality of life" standards have not been established, and it is debatable whether they could ever be written. *See* Sherlock, *Liberalism, Public Policy and the Life Not Worth Living: Abraham Lincoln on Beneficent Euthanasia*, 26 AM. J. JURIS. 47, 56-57 (1981).

76. *See* Smith, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 NEB. L. REV. 709, 729-31 (1984).

child.[77] Furthermore, the parents of seriously impaired infants may be in a particularly bad position to make such calculations when faced with life and death decisions; they may have conflicting interests or be emotionally unfit to consider all factors equally.[78]

Therefore, the law should not accept, as a basis for denying lifesaving treatment, claims that a life is not worth living or that an infant will have a negative impact on others. Basing life and death decisions on physical or mental abnormalities is inconsistent with the belief that human life should be protected without regard to status or defects.[79] This utilitarian analysis would establish a most dangerous precedent and challenge our most basic concepts of individual rights and freedoms. It invites abuse, and it is impractical because it requires calculations that are so uncertain and speculative as to be impossible.

Another reason parents may wish to refuse treatment is that the pain the treatment causes is not worth enduring because the value of the infant's life following treatment will be so low. For example, it might be claimed that a spina bifida baby will require a very substantial and painful treatment and that, even then, the child will have only a very limited quality of life. This reason for refusal of treatment is very closely related to the "life not worth living" approach discussed above, because it requires a decision-maker to compare the value of impaired life with the existence of no life at all.[80] It suffers from the same serious difficulties noted in the prior discussion.

A fifth reason for refusing treatment is that the treatment itself is very painful and it probably will provide only a very short extension of life. Unlike the prior reason for refusing treatment, this reason is based on an exchange of some *quantity* of life for an improved *quality* of life. If treatment can only modestly prolong life and is so painful that what life

77. For example, a parental belief that it is better for a child to die from blood loss than to violate religious precepts by accepting a transfusion cannot be disproved. The long-term best interests of the child are speculative. Nevertheless, the fact that there is uncertainty cannot be the basis for withholding a transfusion even if that means the child's death. Nor should we be willing to permit the parents to withhold a transfusion when the parents believe that a child's life will not be worth living because of serious deformities or profound mental retardation.

78. *See supra* note 3.

79. Contemporary legal authorities often reject quality or value of life criteria, especially when broadly defined, as a basis for treating infants and incompetents. In Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 754, 370 N.E.2d 417, 432 (1977), the court rejected quality of life as the basis for withholding treatment of a mentally retarded adult. *See* Maine Medical Center v. Houle, No. 74-145 (Cumberland County Sup. Ct., Me. Feb. 13, 1974), *cited in* Brant, *supra* note 32, at 366 n.150; Robertson, *Involuntary Euthanasia, supra* note 5, at 252-61; Note, *supra* note 5, at 620-23; cases cited *supra* note 56.

80. *See supra* notes 61-74 & accompanying text.

there is would be considerably less enjoyable, then treatment is refused in order to improve the quality of remaining life. In this circumstance, there can be a reasonable trade-off between the quality and quantity of life. For example, if a child suffers from cancer and painful chemotherapy can prolong the life of the young patient for a short time, but not cure the disease, then it may be reasonable to reject the therapy on quality of life grounds. This kind of refusal, of course, depends on there being some reasonable trade-off between length and quality of life.

Finally, treatment also may be refused because it is of no value. When treatment cannot meaningfully prolong life, it is ultimately futile.[81] Additionally, treatment may be so risky that it has greater potential for shortening life than for lengthening it. In these circumstances, the decision not to undertake the treatment does not shorten the life of the newborn and therefore is not really the refusal of effective treatment.

Proper Standards to Be Applied

Many proposals have been made concerning the appropriate standards to be applied in considering the refusal of lifesaving treatment.[82]

81. The new federal law, discussed *infra* notes 139-55 & accompanying text, provides for a treatment exception when the treatment would "merely prolong dying." 42 U.S.C.A. § 5102(3)(B)(i) (West Supp. 1985).

82. Among the standards that have been suggested for withholding treatment are the following: (1) the treatment's cost and the disruption of the family are greater than the value of the life of the child, *see Medical Ethics Hearings*, *supra* note 8, at 5-7, 18, 27-28 (testimony of Dr. Raymond Duff, Dr. Robert Cooke, Dr. Warren Reich, and Dr. Lewis Scheiner); Lorber, *Results of Treatment of Myelomeningocele*, 13 DEV. MED. & CHILD NEUROLOGY 279, 300 (1971); (2) the treatment would impose "grave burdens," *see* Note, *Withholding Treatment from Defective Newborns: Substituted Judgment, Informed Consent, and the* Quinlan *Decision*, 13 GONZ. L. REV. 781, 801 (1978) (citing R. Veatch, Guardian Refusal of Lifesaving Medical Procedures 5-7 (1976) (unpublished manuscript, Institute of Society Ethics and Life Sciences, N.Y.)); and (3) if there is no *proven* medical procedure available, there is conflicting medical opinion concerning the treatment procedure to be used, or there is less than a high probability that the treatment will enable the child to pursue relatively normal growth toward adulthood or a life worth living. *See* Goldstein, *supra* note 55, at 653. This, of course, is an extraordinarily permissive standard which would allow treatment to be withheld from a wide range of sick children.

In addition, one commentator suggests that care should not be required for defective children for whom no known therapy could prevent multisystem handicaps, a short life expectancy, and a low quality of life. Lorber, *supra*, at 288. Essentially this appears to be a "life worth living" standard. A similar proposal would permit withholding lifesaving treatment if the infant can live only a few years, can live only with the aid of highly restrictive technology, or "lacks potential for human interaction as a result of profound retardation." Rhoden, *supra* note 10, at 1323. Another commentator would permit active or passive euthanasia in cases in which the infant will not survive the first several years of life, the life would be of no value or of negative value, and death will confer a "significant net benefit" to those most directly affected by it. Active or passive euthanasia also would be permitted if the life would not be worth living or if the infant would have to undergo significant suffering in order to reach "the age of

On the basis of the above analysis, with one minor addition, the following standards are proposed to define when lifesaving treatment may be properly withheld from children.[83] Parents should be permitted to withhold lifesaving treatment from children in any of the following circumstances:

1. The treatment will be of no value. Treatment may be of no value either because it would be ultimately futile (it would not extend the life of the infant), because it is too risky, or because it poses a great threat of shortening the life of the infant.
2. The treatment will inflict severe pain and is unlikely to provide any significant extension of the child's life. Refusing treatment in this setting creates a reasonable trade-off between quality of life and quantity of life.[84]
3. The treatment is experimental. This third exception is meant to protect the infant by ensuring that she will not be an experimental human subject.[85]

Low Birth-Weight Infants

Considerable attention has been given to treatment issues regarding Down's syndrome and spina bifida babies. There are, of course, a variety of other life-threatening conditions and circumstances in which lifesaving treatment decisions must be made. Among the most common, and most difficult, are the low birth-weight babies. Medical advances have dramatically improved the prognosis for small neonates so that it is now possible to save smaller and smaller babies.

Although low birth-weight infants present special medical

reason." Coburn, *Morality and the Defective Newborn*, 5 J. MED. & PHIL. 340, 354 (1980). These standards would permit active and passive euthanasia in a broad range of situations.

It also has been suggested that treatment always should be required "if the medical profession agrees on a proper course of treatment, if treatment will enable the child to make progress in growth and development, *and* if the failure to treat would result in the child's death." Shatten & Chabon, *Decision-Making and the Right to Refuse Lifesaving Treatment for Defective Newborns*, 3 J. LEGAL MED. 59, 74 (1982). For a discussion of other standards that have been proposed, see *id.* at 73.

83. For a somewhat different statement of these standards, see Smith, *supra* note 14, at 1174.

84. This "exception" also would justify *action* that might shorten life somewhat. For example, giving pain medication might reduce life functions and cause death a little sooner than would be the case without the pain palliative. This life-shortening action can be justified on the ground that it reasonably increases the quality of life even though it may somewhat shorten the length of life.

85. The decision to accept lifesaving treatment that is truly experimental should be within the range of decisions properly left to the parents. There are, of course, limits on the experimentation that can be done on children even with the consent of their parents. When the experimental treatment may save or prolong the life of the infant, parents should have broad authority to consent to that treatment. *See* NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL BEHAVIORAL RESEARCH, RESEARCH INVOLVING CHILDREN 73-118 (1977).

problems,[86] the treatment standards suggested above for other neonates with life-threatening conditions are fully applicable to low birth-weight infants as well. No blanket rule can be stated requiring that every low birth-weight neonate be given every conceivable treatment, nor should there be a rule making the provision of lifesaving treatment to these neonates discretionary or unnecessary. The standards suggested in this Article may be applied to low birth-weight infants with appropriate medical consideration of their conditions. For example, neither purely experimental treatment, nor treatment that has no realistic possibility of saving the life of the infant should be required. On the other hand, because death will almost certainly result without aggressive treatment, seldom should nonexperimental treatment be refused if it holds any real possibility of being lifesaving. Moreover, treatment should not be withheld merely because after treatment the infant will have disabilities that will make its life different from that of normal infants.

In some circumstances the decision to withhold treatment may be the most appropriate one. One such circumstance is when the pain of treatment may be so great that it may not be justified by the length of life that can be expected to result from the treatment. The likelihood of success or of improving life expectancy depends on several factors, however, including the facilities and quality of neonatal care in the hospital or the region in which the infant is born. Treatment legitimately can be refused or withdrawn when adequate lifesaving treatment is not available. These circumstances illustrate the importance of reliable medical information in considering nontreatment decisions. Because of the critical nature of the decision and the importance of the information upon which it must be based, decisions not to treat low birth-weight infants should be reviewed carefully. The interdisciplinary team suggested later in this Article[87] is intended to provide an effective method of review of both the medical and legal bases for withholding treatment.

Parental decision-making is an important value in our society, but interference with that right is acceptable when parental choices will significantly harm the child. Although there may be circumstances in which treatment may be withheld, parents' perceptions that their child will not have a life worth living or will be too great a burden on others cannot form a legitimate basis upon which to withhold lifesaving treatment. The Article next considers efforts to ensure that inappropriate decisions to withhold lifesaving treatment are reviewed and corrected.

86. PRESIDENT'S COMMISSION, *supra* note 6, at 199-201.

87. *See infra* notes 277-79 & accompanying text.

Recent Efforts to Protect Disabled Newborns

Infant Doe Case

Seldom in American law has such a small case had such an immediate impact as did Indiana's *Infant Doe* case.[88] It lasted less than six days, but led to various lawsuits, several state statutes, a new federal statute, and new federal regulations. *Infant Doe* was the first case of its kind to attract significant national attention.

The full facts of the *Infant Doe* case are not known because the court records in the case were sealed. In addition, press reports, discussions with the court officials, and autopsy findings are not always consistent in their descriptions of the medical condition of the infant.[89] Infant Doe apparently was born with two serious defects: no connection between the esophagus and the stomach and a connection between the trachea and the esophagus.[90] Corrective surgery was possible. Without treatment, death was certain either from lack of food and water, which could not be provided because there was no connection to the stomach, or from suffocation. Infant Doe also suffered from Down's syndrome. The child's parents refused to consent to surgery and decided to withhold food and water. The state court refused to order treatment, and the Indiana Supreme Court declined to overturn the lower court's ruling.[91] Six days after birth the infant died, as certiorari was being sought from the United States Supreme Court.[92] This case is notable because it got to court at all. Ordinarily such decisions are made in private.[93] Only if the

88. *In re* Infant Doe, No. GU 8204-004A (Monroe County Cir. Ct., Ind. Apr. 12, 1982) (declaratory judgment), *cert. denied sub nom.*, Infant Doe v. Bloomington Hosp., 464 U.S. 961 (1983). The *Infant Doe* case was certainly not the first of its kind. *See supra* notes 4-11 & accompanying text. Only a few cases involving nontreatment of infants, however, have come to the attention of the public. During the 1970's, two cases at Johns Hopkins received attention. In both cases refusal of simple surgery for infants with Down's syndrome resulted in death of the infants. In 1972, a similar case was reported. *See* Ellis, *supra* note 7, at 399-400.

89. The confusion caused by the newspaper accounts of the event is noted in Kuzma, *The Legislative Response to Infant Doe*, 59 IND. L.J. 377, 377 n.2 (1984). There also has been some confusion about the seriousness of Infant Doe's other, possibly uncorrectable, defects. For example, it has been reported that the child had a minor heart defect. Pless, *The Story of Baby Doe*, 309 NEW ENG. J. MED. 664 (1983). Others have indicated that the defect was serious. Smith, *supra* note 14, at 1136 n.41.

90. The medical conditions were esophageal atresia and tracheoesophageal fistula. Pless, *supra* note 89.

91. For a procedural history of the case, see Note, *Withholding Treatment from Defective Infants: "Infant Doe" Postmortem*, 59 NOTRE DAME L. REV. 224, 234-35 (1983).

92. Note, *supra* note 91, at 235. The Supreme Court eventually denied certiorari. State *ex rel.* Infant Doe v. Baker, 52 U.S.L.W. 3369 (U.S. Nov. 8, 1983) (No. 83-437).

93. In *Infant Doe*, a hospital representative informed the court of the parents' decision. Note, *supra* note 91, at 234.

physician seriously disagrees with the decision to withhold treatment is any court activity likely.[94]

Initial Federal Response

At the time the *Infant Doe* case arose, no federal law explicitly prohibited withholding of treatment from infants. The federal government endeavored to use section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against the disabled by federally funded programs, to fill this void.[95] About a month after Infant Doe's death, the Department of Health and Human Services ("HHS") sent a "Notice to Health Care Providers" concerning "discriminating against the handicapped by withholding treatment or nourishment."[96] The notice warned hospitals that they risked the loss of federal funding by failing to treat infants because of their mental or physical handicap.[97] HHS pointed to current regulations implementing section 504[98] and informed hospitals that they should counsel parents against refusing treatment and refuse to aid parents who decide to withhold treatment or nourishment.[99]

94. If the physician and hospital personnel do not disagree with the parents' decisions, it is unlikely that anyone else will even know of the withholding of treatment. If others, such as religious advisors, are informed they may be required or inclined to maintain the confidentiality of the parents. In short, there is usually no party with interests adverse to the parents or medical personnel who is likely to be in a position to know about and react to withholding lifesaving treatment. For a different viewpoint, see Vitiello, *Baby Jane Doe: Stating a Cause of Action Against the Officious Intermeddler,* 37 HASTINGS L.J. 863 (1986).

95. 29 U.S.C. § 794 (1982); *see* Note, *Life Prolonging Treatment Decisions for Defective Newborns: Who Should Make the Choice,* 18 SUFFOLK U.L. REV. 675, 692-93 (1984).

96. Notice to Health Care Providers from Betty Lou Dotson, Director, Office for Civil Rights, Department of Health & Human Services (May 18, 1982) [hereinafter cited as Notice to Health Care Providers].

97. The notice provided, in part:

> In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:
>
> Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.
>
> Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.
>
> Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.
>
> The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance.

Notice to Health Care Providers, *supra* note 96.

98. 45 C.F.R. pt. 84 (1981).

99. Notice to Health Care Providers, *supra* note 97.

This notice was followed in 1983 by a formal HHS "interim final" regulation.[100] The regulation provided that withholding food or customary medical treatment from disabled infants violated section 504 of the Rehabilitation Act. It further required that hospitals post a notice indicating that such discrimination is prohibited by federal law. This notice had to include a "hotline" number that anyone could use to report known or suspected withholding of treatment. The regulations also provided for federal investigation and intervention to protect the life of a disabled individual.

Hospitals and medical groups immediately challenged these regulations in federal court,[101] and the court invalidated the regulations essentially on procedural grounds. HHS had adopted the rule without the public notice or thirty-day delay required by the Administrative Procedure Act[102] and also apparently had neglected to consider a number of important factors, including the disruptive effect of the regulations, the harm that could result from removing an infant from a hospital, the malpractice risks, and the allocation of scarce medical and economic resources.[103]

Shortly after the invalidation of the initial procedure, HHS proposed new procedures that, with very modest changes, were the same as the earlier interim final regulations.[104] After receiving nearly 17,000 comments on the proposed regulations, HHS modified and adopted them early in 1984.[105] The new regulations continued the hotline and posting of notice requirements, but they still suffered from considerable ambiguity about what factors could be considered in deciding to withhold treatment. The regulations permitted medical factors to be taken into account, but prohibited "nonmedical considerations from being injected into the decision-making process."[106] The final regulations also encouraged hospitals to establish infant care review committees ("ICRCs"). These committees were only to be advisory and were not authorized to permit the withholding of treatment from infants.[107]

While the process of adopting federal regulations was underway, another case arose in New York that put them to rest. This case was con-

100. 48 Fed. Reg. 9630 (1983) (codified at 45 C.F.R. pt. 84 (1985)).

101. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983), *aff'd sub nom.*, Bowen v. American Hosp. Ass'n, 106 S.Ct. 2101 (1986).

102. *Id.* at 400-01.

103. *Id.* at 395-400.

104. 48 Fed. Reg. 30,846 (1983).

105. 49 Fed. Reg. 1622 (1984) (codified at 45 C.F.R. 84 (1985)).

106. *Id.* at 1630 (codified at 45 C.F.R. 84 (1985)).

107. *Id.* at 1622, 1651 (codified at 45 C.F.R. 84 (1985)).

siderably different from the Indiana *Infant Doe* case. While the New York infant, "Baby Doe," did suffer from a variety of mental and physical abnormalities, her situation was not as clearly life-threatening as had been Infant Doe's situation in Indiana. This child ultimately left the hospital and went home with her parents.[108] Both private individuals and the federal government sought to intervene to require treatment on the child's behalf. These private efforts were unsuccessful, however. The New York court held that, given the record in this case, as a matter of procedure, only the appropriate state agency could bring the action; private individuals could not.[109] The federal government attempted to enter the case under the new federal discrimination provisions contained in section 504.[110] After a careful review of the Rehabilitation Act's legislative history, the Second Circuit ultimately rejected this attempt, concluding that Congress had not intended to authorize HHS to become involved in decisions to refuse treatment for seriously ill infants.[111] The Supreme Court has reviewed the issues raised in this case and has agreed with the Second Circuit's holding.[112]

A Change of Focus

With the decision of the Second Circuit in the Baby Jane Doe case, the government's focus has changed from regulatory approaches interpreting section 504 to the establishment of new statutory authority dealing directly with life-saving treatment for infants. Its focus also has changed from protecting newborns under legislation intended to prohibit discrimination against the disabled to legislation intended to reduce the abuse and neglect of children. Although the withholding of treatment from a seriously impaired newborn may very well be discrimination on the basis of disability, section 504 was not intended to serve this purpose, and its use in this manner was inappropriate.[113] Hence, the issue is more appropriately raised in the context of child abuse and neglect.

The shift in focus toward protecting disabled newborns under child abuse and neglect statutes also has shifted the focus of enforcement from the federal government to the states. Under section 504, the federal gov-

108. *See* Vitiello, *The Baby Jane Doe Litigation and Section 504: An Exercise in Raw Executive Power*, 17 CONN. L. REV. 95, 106 (1984).

109. Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *cert. denied*, 464 U.S. 1026 (1983).

110. United States v. University Hosp., 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

111. United States v. University Hosp., 729 F.2d 144, 157 (2d Cir. 1984).

112. Bowen v. American Hosp. Ass'n, 106 S.Ct. 2101 (1986).

113. Vitiello, *supra* note 108, at 108-21, 159-60.

ernment would have been responsible for investigating and pursuing cases of nontreatment. Under child abuse and neglect laws, however, states will have that responsibility. This may be appropriate because the care and protection of children traditionally has been a state function. Furthermore, the harm resulting from nontreatment occurs solely within a single state. On the other hand, when the death of an infant is at stake, important federal rights, including the protection of life, are involved. In addition, for some time the federal government has sought to require states to meet federal standards for preventing the abuse and neglect of children even when the threat of harm to the child is considerably less severe than death.[114]

Even before this shift in emphasis to state child abuse statutes, some states acted directly to prevent withholding of lifesaving treatment. A number of states already have passed "Infant Doe" laws for this purpose.[115] These statutes vary considerably, but they typically include the denial of lifesaving treatment within the definition of "neglect," and give courts authority to order treatment in such cases.[116] Adoption of a federal statute may remove some of the political pressure on states to adopt their own statutes. Because the new federal law depends on state child protective services agencies, however, it ultimately may encourage more states to consider adopting their own infant lifesaving treatment statutes. In any event, the focus of attention now will be state abuse and neglect laws. After a brief review of those laws, the Article will turn to the new federal requirements.

Child Abuse and Neglect Laws

Since 1974, federal law has encouraged states to adopt child abuse and neglect laws.[117] The federal law sets minimum standards that states must meet in order to qualify for federal funds for state programs designed to protect against child abuse. Virtually all states now meet

114. For example, federal law requires that to qualify for certain federal funds, states must intervene to prevent "mental injury" or "sexual exploitation" of children. 42 U.S.C. §§ 5102, 5103(b)(2) (1982).

115. *E.g.*, ARIZ. REV. STAT. ANN. §§ 13-3260, 36-2281-84 (Supp. 1985); IND. CODE ANN. § 31-6-4-3 (West Supp. 1985); LA. REV. STAT. ANN. §§ 40:1299.36.1-.3 (West Supp. 1986). *See* Feldman & Murry, *State Legislation and the Handicapped Newborn: A Moral and Political Dilemma*, 12 LAW, MED. & HEALTH CARE 156 (1984); Goichman, *A Critique of Louisiana's Approach to Withholding Medical Treatment from Defective Newborns*, 9 S.U.L. REV. 157 (1984); Kuzma, *supra* note 89, at 400-05; Comment, *Legal and Ethical Issues Concerning Treatment of Seriously Ill Newborns*, 30 LOY. L. REV. 925, 945-48 (1984).

116. *See infra* notes 134-38.

117. Child Abuse Prevention and Treatment Act of 1974, 42 U.S.C. §§ 5102-5107 (1984). (originally enacted as Act of Jan. 31, 1974, Pub. L. No. 93-247 § 2, 88 Stat. 4).

these federal standards, although child abuse statutes vary considerably from state to state.[118] State statutes typically include provisions for mandatory and permissive reporting of known or suspected child abuse, investigation of potential abuse by child protective services agencies, and intervention to prevent further abuse or neglect.[119] Child protective services agencies are permitted to seek court orders to protect children from abuse and to provide necessary shelter, food, and medical treatment.

Development of State Abuse and Neglect Laws

In 1963, the United States Children's Bureau proposed principles and suggested language for legislation on reporting incidents of child abuse,[120] and states adopted abuse and neglect statutes at an astonishing rate.[121] Within four years, all fifty states had adopted such laws.[122] These statutes have been modified frequently, and the current laws are sometimes referred to as the third or fourth generation of child abuse reporting statutes.[123] The tendency during the past twenty years has been to expand these laws by broadening the definition of abuse and neglect and by increasing the groups of persons required to report known or suspected abuse.[124] In addition, statutes now require the reporting of abuse to child protective services agencies rather than to law enforcement agencies.[125] Furthermore, the laws commonly provide for central registries of child abuse within the state.[126]

Since the adoption of early child abuse and neglect laws, physicians and other medical personnel have been required to report known or sus-

118. As of April 1985, HHS noted that "[f]ifty-one of fifty-seven eligible jurisdictions meet the requirements of the Act and the regulations and currently receive State grant funds." 50 Fed. Reg. 14,878 (1985).

119. Federal law requires these features in state laws for states to qualify for federal financial support. 42 U.S.C. § 5103(b) (1982).

120. UNITED STATES CHILDREN'S BUREAU, THE ABUSED CHILD: PRINCIPLES AND SUGGESTED LANGUAGE FOR LEGISLATION ON REPORTING OF THE PHYSICALLY ABUSED CHILD (1963). The medical community made its own proposed model act. AMERICAN MEDICAL ASSOCIATION, PHYSICAL ABUSE OF CHILDREN—SUGGESTED LEGISLATION (1965).

121. Paulsen, *supra* note 1, at 711-12.

122. Besharov, *supra* note 1, at 153-54.

123. *See* Fraser, *A Glance at the Past, A Gaze at the Present, A Glimpse at the Future: A Critical Analysis of the Development of Child Abuse Reporting Statutes*, 54 CHI.-KENT L. REV. 641, 649-50 (1978).

124. *See* Smith & Meyer, *Child Abuse Reporting Laws and Psychotherapy: A Time for Reconsideration*, 7 INT'L J.L. & PSYCHIATRY 351, 353 (1985).

125. *E.g.*, ALASKA STAT. § 47.17.020 (1984); CONN. GEN. STAT. ANN. § 17-38a(b) (West Supp. 1985); ILL. ANN. STAT. ch. 23, § 2054 (Smith-Hurd Supp. 1985).

126. An excellent review of the provisions of state reporting statutes is contained in Fraser, *supra* note 123, at 651-67 (these state statutes, however, have been modified frequently); *see* Smith & Meyer, *supra* note 124, at 353.

pected abuse or neglect. It is now common for all medical personnel, teachers, social service workers, and law enforcement officers to be required to report.[127] Reporting of abuse or neglect is required even if the information comes to the professional in a confidential relationship, such as physician-patient, and otherwise would be privileged.[128] A number of states now require that anyone suspecting or knowing of child abuse must report it.[129] Reporting in good faith is protected by immunity from civil liability.[130]

Failure to report known or suspected child abuse or neglect is a misdemeanor in most states, although prosecution for failure to report is very rare. Some states, however, specifically provide civil liability for failure to make a required report.[131] Thus, a physician with knowledge of abuse or neglect who fails to report it may be subject to liability for damages that result from subsequent abuse or neglect. Even without express statutory provisions, the failure to diagnose or report child abuse may result in liability either on the basis of negligence per se[132] or ordinary negligence.[133]

The Definition of Abuse and Neglect

Early statutes defined child abuse in terms of serious physical inju-

127. Early statutes defined abuse as "non-accidental" injuries. Fraser, *A Pragmatic Alternative to Current Legislative Approaches to Child Abuse*, 12 AM. CRIM. L. REV. 103, 106 (1974); *see* Daly, *Willful Child Abuse and State Reporting Statutes*, 23 U. MIAMI L. REV. 283 (1969). This definition has been broadened to include neglect and sexual and emotional abuse. Fraser, *supra*, at 114.

128. *See* Smith & Meyer, *supra* note 124, at 358-60.

129. *See, e.g.*, DEL. CODE ANN. tit. 16, § 903 (1983); FLA. STAT. ANN. § 415.504 (West Supp. 1986); IDAHO CODE § 16-1619 (Supp. 1986).

130. Besharov, *The Legal Aspects of Reporting Known and Suspected Child Abuse and Neglect*, 23 VILL. L. REV. 458, 470 (1978).

131. *E.g.*, IOWA CODE ANN. § 232.75(2) (West Supp. 1984); N.Y. SOC. SERV. LAW § 420(2) (McKinney 1983).

132. The failure to adhere to a duty described in a criminal or similar statute may result in negligence liability if the statute was designed to protect the class of persons of which the plaintiff is a member and to prevent the risk of harm and injury which occurred. W. KEETON, D. DOBBS, R. KEETON & D. OWEN, PROSSER AND KEETON ON THE LAW OF TORTS § 36, at 229-31 (5th ed. 1984).

133. For a discussion of the negligence liability for the failure to report child abuse, see Isaacson, *Child Abuse Reporting Statutes: The Case for Holding Physicians Civilly Liable for Failing to Report*, 12 SAN DIEGO L. REV. 743, 747-55 (1975); Paulsen, *Child Abuse Reporting Laws: The Shape of the Legislation*, 67 COLUM. L. REV. 1, 34-36 (1967); Note, *Civil Liability for Teachers' Negligent Failure to Report Suspected Child Abuse*, 28 WAYNE L. REV. 183, 191-95 (1981); Note, *Physician's Liability for Failure to Diagnose and Report Child Abuse*, 23 WAYNE L. REV. 1187 (1977). Civil liability has not yet become a major issue in child abuse and neglect. *See* Landeros v. Flood, 17 Cal. 3d 399, 551 P.2d 389, 131 Cal. Rptr. 69 (1976); Brown & Truitt, *Civil Liability in Child Abuse Cases*, 54 CHI.-KENT L. REV. 753 (1978).

ries. This definition has now been expanded considerably, and in most states the following also constitute abuse or neglect: physical injury; sexual molestation; emotional injury; failure to provide supervision; and failure to provide adequate shelter, clothing, food, or medical care.[134] The statutes ordinarily require that the threat of injury from abuse or the abuse itself be "serious" or a "serious threat" to the welfare of the child.

Many of the terms in child abuse and neglect laws are left undefined or are defined so broadly that the definitions serve little useful purpose.[135] The natural result of this uncertainty is great confusion about what child abuse and neglect includes. This, of course, creates great difficulties for professionals who are required to report known or suspected abuse or neglect.

In 1980, it was estimated that between 1.1 and 1.2 million children were reported to child protective services agencies as being abused or neglected.[136] In 1983, it was estimated that the number had increased to 1.5 million children.[137] No recent evidence indicates that this increase in the reporting of abuse and neglect has abated.

Paradoxically, there is probably both significant underreporting and overreporting of abuse and neglect. For example, the National Study of Child Abuse found that nearly sixty percent of abuse and neglect reports to social service agencies could not be confirmed, suggesting substantial over reporting.[138] On the other hand, child protective services agencies are often understaffed and are hard pressed to investigate claims of abuse or neglect adequately.

The Federal Statute

The new federal approach to withholding lifesaving treatment from infants depends heavily on the child protective services agencies of the states. Recognizing the need for new legislation dealing with the denial of lifesaving treatment to infants, Congress enacted the Child Abuse Amendments of 1984.[139] The Act represents a compromise between in-

134. Smith & Meyer, *supra* note 124, at 354.

135. *See* J. GIOVANNONI & R. BECERRA, DEFINING CHILD ABUSE 4-13, 257-59 (1979).

136. *See* CHILDREN'S BUREAU, NATIONAL CENTER ON CHILD ABUSE AND NEGLECT, UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, NATIONAL STUDY OF THE INCIDENCE AND SEVERITY OF CHILD ABUSE AND NEGLECT 39 (1981) [hereinafter cited as NATIONAL STUDY OF CHILD ABUSE].

137. D. WHITCOMB, E. SHAPIRO & L. STELLWAGEN, WHEN THE VICTIM IS A CHILD: ISSUE FOR JUDGES AND PROSECUTORS 2 (1985).

138. NATIONAL STUDY OF CHILD ABUSE, *supra* note 136, at 39-40.

139. Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West 1983 & Supp. 1985)). Sections that refer specifically to withholding of treatment are codified at 42 U.S.C.A. §§ 5102(3), 5103(b)(2)(k) (West Supp. 1985).

terested medical organizations, organizations supporting disabled newborns, the administration, and interested members of Congress. The final bill, overwhelmingly approved in both houses of Congress,[140] had the support of most child support groups and most medical groups, except, notably, the American Medical Association.

The major provision of the legislation regarding withdrawal of lifesaving treatment from infants was the addition of a new clause to the federal child abuse law.[141] Existing federal law required states to meet certain criteria to qualify for federal child abuse and neglect prevention funds.[142] The 1984 amendment provided that, beginning in October 1985, states must have procedures or programs within the state child protective services to respond to instances of withholding medical treatment from disabled infants. States must provide for the appointment of someone in hospitals with whom the state can deal when nontreatment questions arise, who also must provide for prompt notification of instances of suspected medical neglect.[143] Finally, the new law requires

140. House approval of the final bill came on a voice vote, 130 CONG. REC. H10,338 (daily ed. Sept. 26, 1984), after a short debate praising the bill. *Id.* at H10,327-38. The Senate also adopted the final bill by voice vote, 130 CONG. REC. S12,392 (daily ed. Sept. 28, 1984), again after a short affirmative debate. *Id.* at S12,382-92.

In considering separate bills before the Conference Report, the House adopted the bill by a vote of 396 to 4. 130 CONG. REC. H376-77, 379-423 (daily ed. Feb. 2, 1984). The Senate unanimously approved the preconference measure it adopted. 130 CONG. REC. S9307-29 (daily ed. July 26, 1984).

Both the House and the Senate held hearings concerning the amendments to the child abuse law. The Senate hearings dealt in detail with issues of withholding lifesaving treatment from infants. For the House hearings, see *To Amend the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978: Hearing on H.R. 1904 Before the Subcomm. on Select Education of the House Comm. on Education and Labor*, 98th Cong., 1st Sess. (1983). The Senate subcommittee devoted one day of its hearings on the proposed amendments to the Child Abuse Act to the issue of withholding lifesaving treatment from infants. *Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1983: Hearings Before the Subcomm. on Family and Human Services of the Senate Comm. on Labor and Human Resources*, 98th Cong., 1st Sess. 1-195 (1983) [hereinafter cited as *Child Abuse Hearings*]. The Senate provisions were generally accepted by the Conference Committee. Child Abuse Amendments of 1984, H. CONF. REP. NO. 1038, 98th Cong., 2d Sess. 18, *reprinted in* 1984 U.S. CODE CONG & AD. NEWS 2947.

141. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984) (codified as amended at 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985)).

142. The Act also contained a variety of provisions relating to child abuse and adoption. It authorized continued funding for state and other grants for child abuse treatment and prevention, 42 U.S.C.A. § 5104 (West Supp. 1985), and contained a number of new provisions regarding sexual abuse of children and improved adoption procedures. *Id.* §§ 5106, 5113, 5115.

143. 42 U.S.C.A. § 5103(b)(2)(K) (West Supp. 1985). To qualify, by October 1985, the state must

> have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled in-

that states allow the state child protective services system "to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions."[144]

Central to the new provision is the term "withholding of medically indicated treatment," defined as the failure to "respond to the infant's life-threatening condition" in a way that is "most likely to be effective in ameliorating or correcting" all life-threatening conditions.[145] Appropriate or necessary treatment must be determined according to the treating physician's "reasonable medical judgment"[146] and specifically includes food, water, and medication.[147] Presumably, treatment also includes surgery and the broad range of all forms of medical intervention.

The statute recognizes several categories in which treatment "other than appropriate nutrition, hydration, or medication" need not be provided to infants.[148] These exceptions to the requirement that lifesaving

---

fants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disable infants with life-threatening conditions.

Id.

144. *Id.* § 5103(b)(2)(K)(iii).

The authority of the child protective services agencies may be illusory because they must be *authorized* to begin these proceedings. More critical, however, is what standards state courts will use in making the decisions. States apparently are not required to change state law to reflect federal requirements, so it is entirely possible that state courts will not apply the federal rules.

145. The definition provides, in part:

[T]he term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions . . . .

42 U.S.C.A. § 5102(3) (West Supp. 1985); *see* H. CONF. REP. NO. 1038, *supra* note 140.

146. 42 U.S.C.A. § 5102(3) (West Supp. 1985).

147. *Id.*

148. *Id.* For interpretation of the meaning of the term "appropriate," see *infra* notes 218-20 & accompanying text. The permitted exceptions to withholding of medically indicated treatment are technically stated as follows:

the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or

treatment be given are:

1. When the child is irreversibly comatose.[149]
2. When treatment would "merely prolong dying."[150]
3. When the treatment would not be effective in ameliorating or correcting all of the life-threatening conditions.[151]
4. When the treatment would "otherwise be futile" in terms of the survival of the infant.[152]
5. When imposing the treatment would be "virtually futile" in terms of survival and the treatment itself "under such circumstances would be inhumane."[153]

The statute apparently excludes the provision of "appropriate" food, water, and medication from the treatment permitted to be withdrawn under these exceptions; therefore, these basic necessities must be provided even if one of the above treatment exceptions is present. Of course, by including the qualifying word, "appropriate," the statute implies that there are undefined conditions in which food, water, or medication are "inappropriate."

The Act also does not authorize the government to "establish standards prescribing specific medical treatment for specific conditions" and does not affect any rights or protections under section 504 of the Rehabilitation Act.[154] Neither of these provisions should have a major impact on the Act's implementation. They merely leave open the question of whether the government may continue to push for the treatment of disabled newborns through section 504 of the Rehabilitation Act. The new statute also requires HHS to establish model guidelines concerning infant care review committees.[155]

HHS Regulations

On December 10, 1984, HHS published its proposed regulations to

---

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

Id.

149. *Id.* § 5102(3)(A).

150. *Id.* § 5102(3)(B)(i).

151. *Id.* § 5102(3)(B)(ii).

152. *Id.* § 5102(3)(B)(iii).

153. *Id.* § 5102(3)(C).

154. Child Abuse Amendments of 1984, Pub. L. No. 98-457 § 127(a)-(b), 98 Stat. 1754-55 (1984) (construction of Child Abuse Amendments of 1984 with other laws).

155. *Id.* § 124(b), 98 Stat. 1754 (1984).

implement the Child Abuse Amendments of 1984.[156] Through these regulations, HHS attempted to define the statute's concept of "withholding of medically indicated treatment."[157] The regulations were intended to specify circumstances in which it might be appropriate to withhold treatment. At the same time, HHS also published "interim" model guidelines for health care providers to establish infant care review committees.[158]

HHS received what was described as an "unprecedented" 116,000 letters during the comment period.[159] "[M]ore than 115,000 letters from concerned citizens . . . strongly endorsed the compelling objective of assuring the provision of medically indicated treatment to disabled infants with life-threatening conditions."[160] HHS also received comments from medical groups, particularly the American Academy of Pediatrics, which strongly resisted the regulations on the ground that they would require treatment in cases not specified by the statute.[161] The six principal sponsors of the Senate bill also wrote a letter urging modification of the proposed regulations.[162] Among other concerns, the Senators objected to incorporation of the word "imminent" in defining the phrase "merely prolong dying" as well as to other phrases that would permit the termination of treatment that would be futile or would extend life only slightly.[163]

Final regulations were adopted on April 15, 1985.[164] In response to the many comments concerning the proposed regulations, HHS omitted most of the regulatory definitions and largely echoed the language of the statute in the final version of the regulations. These regulations contain four parts: the general regulations,[165] an appendix containing "interpre-

156. Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48,160 (1984) (codified as amended at 45 C.F.R. pt. 1340).

157. 42 U.S.C.A. § 5102(3) (West Supp. 1985).

158. Interim Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 49 Fed. Reg. 48,170 (1984) (interim regulations Dec. 10, 1984).

159. Nicholson, *Final Federal "Baby Doe" Rule Released,* 9 MENTAL & PHYSICAL DISABILITIES L. REP. 227, 227 (1985).

160. Child Abuse and Neglect Prevention and Treatment Program, Summary of Final Rule, 50 Fed. Reg. 14,878-79 (codified at 45 C.F.R. pt. 1340 (1985)).

161. *Id.* at 14,879, 14,881.

162. *Id.* at 14,879-80.

163. *Id.* The Senate sponsors noted that the words used in the statute had been carefully considered. Apparently they thought that HHS was being too specific in defining "merely prolonging dying" and similar concepts. It is possible that part of the compromise that produced the bill was to leave these terms ambiguous.

164. *Id.* at 14,878.

165. Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14,878 (1985) (codified at 45 C.F.R. pt. 1340).

tive guidelines" to the regulations,[166] Model Guidelines for Health Care Providers to Establish Infant Care Review Committees,[167] and an appendix analyzing the model guidelines.[168]

The general regulations are little more than a recitation of the statutory definitions and a list of the documents that states must provide to prove eligibility. HHS, however, did provide regulatory definitions of the terms "infant" and "reasonable medical judgment." An "infant" is defined as someone less than one year of age.[169] The regulations also imply that "infant" status extends beyond the first year if the child has been "continuously hospitalized since birth, and was born extremely prematurely or . . . has a long term disability."[170] The definition of "reasonable medical judgment" essentially tracks the common-law tort definition and requires that such judgments "be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved."[171] Both of these definitions were taken directly from the congressional conference report.[172]

The appendix to the regulations is four times the length of the interpretive guidelines, and its length suggests the difficulty that HHS had in trying to establish acceptable but clear regulations. In this appendix, HHS notes that it "does not seek to establish these interpretive guidelines as binding rules of law."[173] Instead, the guidelines are "intended to assist in interpreting the statutory definition so that it may be rationally and

166. Appendix to Part 1340, Interpretive Guidelines Regarding 45 C.F.R. § 1340.15 (1985).

167. Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893 (1985).

168. Appendix [to Model Guidelines], 50 Fed. Reg. 14,896 (1985).

169. 45 C.F.R. § 1340.15(b)(3)(1) (1985).

170. The regulatory definition of infant is as follows:

> The term 'infant' means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in paragraph (b)(2) of this section should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

Id.

The discussion of this section by HHS does not provide great clarification. *See* 50 Fed. Reg. at 14,882.

171. 45 C.F.R. § 1340.15(b)(3)(ii) (1985).

172. *See* H. CONF. REP. NO. 1038, *supra* note 134, at 41, 1984 U.S. CODE CONG. & AD. NEWS at 2970.

173. 50 Fed. Reg. 14,889 (1985) (codified at 45 C.F.R. Appendix to pt. 1340).

thoughtfully applied in specific contexts in a manner fully consistent with the legislative intent."[174] Because the regulations presumably "assist in interpreting the statutory definition . . . in specific contexts in a manner fully consistent with the legislative intent,"[175] the appendix is in some ways a regulation without the force of law. Yet, because HHS claims that the guidelines' interpretation of the definitions in the statute are consistent with the legislative intent, they are more than simply general suggestions or comments.

Among the noteworthy points made in the appendix are the following:

(1) Decisions to withhold medically indicated treatment may *not* be based on "subjective opinions about the future 'quality of life' of a retarded or disabled person."[176]

(2) Even when the statute permits the withholding of medically indicated treatment, "the infant must nonetheless be provided with appropriate nutrition, hydration, and medication."[177]

(3) "Life-threatening" conditions include conditions that "significantly increase the risk of the onset of complications that may threaten the life of the infant."[178]

(4) "Treatment" includes adequate evaluation, the referral of the infant to other physicians when necessary, and multiple medical or surgical procedures over a period of time.[179]

(5) "Merely prolong dying" and related provisions that refer to treatments that would extend life only a short time do not apply only when death is "imminent." Treatment must be provided, however, when "many years of life will result from the provision of treatment or where the prognosis is not death in the near future but rather in the more distant future."[180] It is up to the physician's exercise of reasonable medical judgment "to determine whether the prognosis of death, because of its nearness in time, is such that the treatment would not be

174. *Id.*

175. *Id.*

176. *Id.*

177. *Id; see also id.* at 14,892 ("[T]he statute is completely unequivocal in requiring that all infants receive 'appropriate nutrition, hydration, and medication,' regardless of the condition or prognosis."). For discussion of the meaning of the term "appropriate," see *infra* notes 205-08 & accompanying text.

178. *Id.* at 14,889. HHS states that it was unnecessary to state this interpretation as part of the regulation because "reasonable medical judgment . . . commonly deems the condition described as life-threatening and responds accordingly." *Id.*

179. *Id.* at 14,890.

180. *Id.* at 14,891. This discussion in the appendix is somewhat confusing. HHS notes that it was not part of the negotiations that resulted in the final bill and that it had mistakenly believed that "imminent" described the appropriate time during which treatment might not be necessary. However, the sponsors of the bill disagreed with this language in the final bill. HHS was finally left, even in the interpretive guidelines, with the ability to define the relevant time only as somewhere between "the near future" and "the more distant future," or at least not extending to "several years." *Id.* at 14,890-91.

medically indicated."[181]

(6) The term "virtually futile" treatment means treatment that is highly unlikely to prevent death in the near future.[182]

The regulations also propose model guidelines for establishing infant care review committees.[183] Although the regulations encourage hospitals to establish ICRCs, they are not required to do so. If hospitals do establish them, the committees are not bound to conform to the guidelines suggested by HHS.[184] The purposes of the ICRCs are: to offer counseling in specific cases involving disabled infants; to recommend institutional policies concerning disabled infants; and to educate hospital personnel and families of disabled infants concerning counseling, rehabilitative services, and support organizations.[185] The regulations urge that the ICRC be able to be convene within twenty-four hours or less when there is disagreement between the infant's family and physician concerning withholding treatment or when the decision is made to withhold life-sustaining treatment "in certain categories of cases" identified in ICRC policies.[186] The ICRC may "meet" by telephone when it cannot convene quickly enough in person.[187]

Seven categories make up the suggested core membership of the ICRC. These are a practicing physician, a nurse, a hospital administrator, a social worker, a representative of a disability group, a lay community member, and a member of the medical staff (to serve as chair).[188] Interestingly, the revised regulations dropped from the list of core members a representative of the legal profession on the ground that the ICRC should have legal counsel available when needed, and therefore a legal profession member was unnecessary.[189] The ICRC also may supplement its core membership with other permanent members or advisors. This would allow the addition to the ICRC of clergy, medical specialists, legal authorities, and others with valuable knowledge or special

181. *Id.*

182. *Id.* at 14,892.

183. Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, *id.* at 14,896. Such Ethics Committees had been suggested by the President's Commission, *supra* note 6, at 160-70, 227-28. *See* Capron, *Borrowed Lessons: The Role of Ethical Distinctions in Framing Law on Life-Sustaining Treatment*, 1984 ARIZ. ST. L.J. 647; *see also infra* notes 216-22 & accompanying text. For a detailed discussion of the operation of ICRC's elsewhere in this symposium, see Shapiro & Barthel, *Infant Care Review Committees: A More Effective Approach*, 37 HASTINGS L.J. 827 (1986).

184. Model Guidelines, 50 Fed. Reg. at 14,896.

185. *Id.* at 14,894.

186. *Id.* at 14,895-96.

187. *Id.* at 14,896, 14,900.

188. *Id.* at 14,894.

189. *Id.* at 14,894, 14,897.

perspectives.[190]

Analysis of the Federal Approach

The federal law requires that, to qualify for certain federal funds, a state's child protective services system must have written procedures or programs designating one or more people within appropriate health care facilities as consultants regarding nontreatment,[191] to require these individuals to notify the system of medical neglect,[192] and to have authority to pursue legal remedies to prevent the withholding of medically indicated treatment.[193] These requirements were intended to ensure that disabled newborns receive treatment and to prevent a recurrence of the *Infant Doe* situation.[194] This expectation concerning the federal law is unwarranted, however. Certain technical aspects of the statutes and regulations, the practical operation of hospitals and child protective services agencies, and the authority of juvenile and other state courts may prevent the effective implementation of many of the goals expressed in the federal law. The Article next examines why the current federal approach may not change current practices concerning withholding of lifesaving treatment from disabled newborns.

Values Expressed in the Federal Approach

Congressional documents[195] and the commentary to the regulations themselves[196] make clear that the Child Abuse Amendments express a desire to protect the lives of impaired newborns. In its commentary to the regulations, HHS described the new federal law as firmly rejecting the refusal of treatment based on a finding that an infant is not going to have a life worth living.[197] The language and structure of the Act and regulations, however, already have led one commentator to conclude that

190. *Id.* at 14,894.

191. 42 U.S.C.A. § 5103(b)(2)(K)(i) (West supp. 1985).

192. *Id.* § 5103(b)(2)(k)(ii).

193. *Id.* § 5203(b)(2)(k)(iii).

194. For a discussion of the *Infant Doe* case, see *supra* notes 89-113 & accompanying text. The congressional committee reports noted the *Infant Doe* and similar cases as a reason the legislation was needed. S. REP. NO. 246, 98th Cong., 1st Sess. 4-11, *reprinted in* 1984 U.S. CODE CONG. & AD. NEWS 2920-28.

195. S. REP. NO. 246, 98th Cong., 1st Sess. 4-11, *reprinted in* 1984 U.S. CODE CONG. & AD. NEWS 2920-28.

196. 50 Fed. Reg. 14,889 (1985).

197. *Id.* (suggesting that the legislature's definition of "withholding of medically indicated treatment makes clear that it does not sanction decisions based on subjective opinions about the future 'quality of life' of a retarded or disabled person").

the federal law really does recognize quality of life considerations.[198] The inadequacies of the federal law invite this kind of confusion. Implicitly the Act also rejects the burdens created by an infant's disability as a basis for refusing lifesaving treatment. Neither the statute, nor the regulations (except in an appendix) specify that these are unacceptable factors.[199] The law does recognize several situations in which lifesaving treatment may be withheld. The provisions have severe problems, however, resulting from the definitional deficiencies of some of their terms and from the omission of factors that should have been addressed. Unless corrected, the effectiveness and efficiency of the new law will suffer.

Definitional Problems

Comatose Infants

Under the new law, lifesaving treatment may be withheld from chronically and irreversibly comatose infants, as long as "appropriate" food, water, and medication are still provided.[200] The administration and the Surgeon General took a similar position in congressional hearings[201] and during the earlier discussion of the section 504 regulations.[202] The reason for allowing refusal of treatment for these infants is not stated. One possible justification might have been that comatose infants do not have a life worth living. Such an approach, however, would be entirely inconsistent with the whole thrust of the federal law, which rejects quality of life as the basis for refusal of lifesaving treatment, and probably does not explain this provision.[203]

An alternative explanation is that Congress believed that the permanently comatose are not alive at all. Most states now accept whole brain death, the total cessation of brain function, as a definition of death.[204]

198. Rhoden, *supra* note 10, at 1313.

199. 50 Fed. Reg. 14,889 (1985) (codified at 45 C.F.R. app. to pt. 1340).

200. 42 U.S.C.A. § 5102(2)(B)(3); 50 Fed. Reg. 14,888, 14,891 (1985).

201. *See Child Abuse Hearings*, *supra* note 140, at 7-9, 14-16 (Statement of C. Everett Koop, M.D., Surgeon General).

202. Singer & Kuhse, *The Future of Baby Jane Doe*, N.Y. REV. BOOKS, Mar. 1, 1984, at 17, 18-19 (Dr. Koop's testimony in federal court).

203. Of course, it is possible that the federal government in fact adopts a "quality of life" approach. *See* Rhoden, *supra* note 10, at 1313. Given the strenuous objections to the quality of life approach by those who proposed the "comatose" exception, however, imputing a quality of life exception to the treatment requirement suggests a fundamental inconsistency of such magnitude that it is highly unlikely.

204. The permanent cessation of all brain activity is now commonly considered to be the definition of death. Many states have adopted brain death by statute, e.g., ALASKA STAT. § 09.65.120 (Supp. 1984); KAN. STAT. ANN. § 77-205 (1977 & Supp. 1980); MD. HEALTH-GEN. CODE ANN. § 5-202 (Supp. 1985); *see* Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337, 338-40 (1981); Capron & Kass, *A Statu-*

Even permanently comatose infants would have some brain activity, however, so technically they would not fall within this definition.[205] Although not generally accepted, there is much to be said for a definition of death in terms of permanent cessation of all higher brain activity that irrevocably precludes any possibility of any form of consciousness.[206] Under such a "higher brain function" definition, the presence of some lower brain or brain stem function would not be sufficient to indicate[207] that human life exists. A higher brain function standard would be entirely consistent with rejection of quality of life as the basis for withdrawing treatment from infants. The distinction is between a life of unknowable quality and no life at all.[208] Because a higher brain death

tory Definition of Standards for Determining Human Death: An Appraisal and a Proposal, 121 U. PA. L. REV. 87 (1972); Charron, *Death: A Philosophical Perspective on the Legal Definitions*, 1975 WASH. U.L.Q. 979; Compton, *Telling the Time of Human Death by Statute: An Essential and Progressive Trend*, 31 WASH. & LEE L. REV. 521 (1974); Schneck, *Brain Death and Prolonged States of Impaired Responsiveness*, 58 DEN. L.J. 609 (1981).

205. *A Definition of Irreversible Coma, Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 J. A.M.A. 337 (1968); *see also An Appraisal of the Criteria of Cerebral Death, A Collaborative Study*, 237 J. A.M.A. 982 (1977).

206. It has been suggested that the definition of death should be based on higher brain function. Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 UCLA L. REV. 386, 403-06 (1981); Kluge, *The Euthanasia of Radically Defective Neonates: Some Statutory Considerations*, 6 DALHOUSIE L.J. 229, 244-54 (1980); *see* R. VEATH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION, OUR LAST QUEST FOR RESPONSIBILITY 55-76 (1976); Olinger, *Medical Death*, 27 BAYLOR L. REV. 22 (1975). Some states implicitly may accept a higher brain death standard for infants by prohibiting parents from withholding lifesaving treatment from physically impaired infants, but permitting the treatment to be withheld from permanently comatose infants. *E.g.*, LA. REV. STAT. ANN. § 40:1299.36.1 (West Supp. 1985). The new federal law may also accept implicitly the concept of higher brain death. *See supra* note 203.

207. The "higher brain death" definition of death correctly recognizes some consciousness as the essential element of human life. Therefore, treatment should be allowed to be rejected for the permanently comatose on the ground that they are, for legal purposes, not alive.

208. The distinction between claiming that there is not life at all and that there is low quality of life is more than an insignificant semantic distinction. *See* Vitiello, *supra* note 108, at 137. The question whether there is human life at all requires a discussion of the minimum functional qualities required to make a homo sapiens a "person" with rights worth protecting. The decision to withhold treatment on the basis of a person's low quality of life is a much broader treatment principle that could result in the denial of lifesaving to a much larger group of patients. Defining death, however, does present some of the same potential problems as does the decision to withdraw lifesaving treatment. The danger is to define "out" of human life and legal protection those who are significantly different than ourselves. For example, definitions of "human person" have been proposed, although not generally seriously considered or approved, that would further narrow the group of beings given the full protections of the law. One such suggestion is for a "delayed personhood policy" under which the state would delay recognizing the child's personhood until its potential for development and growth is established. Marks & Salkovitz, *The Defective Newborn: An Analytic Framework for a Policy Dialogue*, in ETHICS OF NEWBORN INTENSIVE CARE, *supra* note 3, at 110-11. At the other extreme, legislation has been introduced to define human life as beginning at conception. *See*

definition is not generally accepted, such a definition should be explicit if it is to be accepted for withdrawal of treatment purposes.[209]

The Short Life Exceptions

The statute and the regulations contain four exceptions to the general requirement of lifesaving treatment that all permit the refusal of treatment if it would be futile in prolonging life for any significant time. Those exceptions are as follows: First, the treatment would "merely prolong dying";[210] second, the treatment would not be effective in resolving all of the life-threatening conditions;[211] third, the treatment would be "otherwise futile in terms of the survival of the infant";[212] and fourth, the treatment "would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."[213]

These provisions are essentially redundant and confusing. Consider, for example, the third and fourth exceptions. The third provides that the treatment may be withheld if it would be "futile in terms of survival of the infant," and the fourth allows nontreatment if it would be "virtually futile in terms of the survival of the infant." The latter, however, also requires that the "treatment itself under such circumstances would be inhumane." There is such a slight difference, if any at all, between these provisions that separate statements are not warranted.

A much more serious problem with all four exceptions is the failure to describe the life expectancy that will justify life-prolonging treat-

e.g., S. 1741, 97th Cong., 1st Sess., 127 CONG. REC. 11,514 (daily ed. Oct. 14, 1981); H.R. 900, 97th Cong., 1st Sess., 127 CONG. REC. 128 (daily ed. Jan. 19, 1981); *see also* Hyde, *The Human Life Bill: Some Issues and Answers*, 27 N.Y.L. SCH. L. REV. 1077 (1982). See *supra* notes 67-80 & accompanying text for a discussion of quality of life issues.

209. The legal definition of human life always differs from total biological death. Even cardiovascular or "heart" death defines the end of life considerably before all of the cells of the body have died. The legal definition of death essentially is based on the death of a specified group of cells, such as heart muscle, total brain, or cerebrum. All legitimate definitions of death, however, have in common an effort to define death in terms of "nothingness" rather than quality of life.

It is possible, of course, to claim to define the existence of human life as something well beyond nothingness. *See* Fletcher, *Indications of Humanhood: A Tentative Profile of Man*, HASTINGS CENTER REP., Nov., 1972, at 1 (defining human criteria as including such factors as minimum I.Q. of 40, self-control, a sense of the past, concern for others, and curiosity). Such an approach is not, however, truly a definition of life, but a commentary on the quality of life that does exist.

210. 42 U.S.C.A. § 5102(3)(B)(i) (West Supp. 1985).

211. *Id.* § 5102(3)(B)(ii).

212. *Id.* § 5102(B)(iii).

213. *Id.* § 5102(3)(C).

ment.[214] In the proposed regulations, HHS suggested that life-prolonging treatment should be delivered unless death was "imminent," but this language was dropped because of objections from the medical community and some of the bill's Senate sponsors.[215] As noted above, in the appendix to the regulations, HHS indicated that "futile treatment" or "merely prolong dying" means something less than many years of life and is somewhere between "the near future" and "more distant future."[216] These are very vague standards that go to the heart of the "short life" exceptions. Defining a period of time as being between the near future and the more distant future gives no guidance at all. And yet, a definition of the length of life expectancy that will permit the refusal of treatment is critical to any understanding of the four "short life exceptions" contained in the statute.

Another problem is the lack of clarity concerning the basis for permitting the refusal of treatment in "short life" circumstances. When lifesaving treatment cannot prolong life, it is, of course, not lifesaving treatment at all. It is completely consistent with the goals of the federal legislation not to require the imposition of treatment that is futile in this sense. Treatment that will extend life for only a very short time also might be rejected because, as a practical matter, whether it can really extend life cannot be determined with an acceptable degree of certainty. It is also possible that extremely short periods of life may be seen as of somewhat trivial value and, therefore, not worth arguing about. The law, however, has viewed this last argument with some suspicion.[217]

Additional confusion is engendered by the exception that treatment need not be provided if it would "merely prolong dying." In one sense, any form of medical treatment can, at best, only delay death and, therefore, is not *absolutely* lifesaving. In this sense, all treatment only "prolongs dying" because the recipient ultimately will die later. With the other "futile" treatment exceptions, there really is no need for the confusing "merely prolong dying" provision.

The absence of the definition of "futile" or "short life" is a signifi-

214. Even when lifesaving treatment may be withdrawn, "appropriate" food, water, and medicine must be given to the infant. *Id.* § 5102(3). *See supra* notes 146-53 & accompanying text.

215. 50 Fed. Reg. 14,890-91 (1985); *see supra* note 155 & accompanying text.

216. 50 Fed. Reg. 14,891 (1985) (app.).

217. In criminal law, for example, any shortening of life is considered homicide if it directly causes death. *See* W. LAFAVE & A. SCOTT, HANDBOOK ON CRIMINAL LAW § 35 (1972). However, even in homicide, some real reduction of life would be necessary. At an absurd level, it is unlikely that a homicide prosecution could proceed for shortening life a fraction of a second.

cant problem in providing clear understanding of the critical terms in the statute and regulations. If they are to have any practical, consistent meaning, these exceptions require clearer definition.

Defining "Appropriate" Care

The statute twice refers to "*appropriate* nutrition, hydration, and medication."[218] The precise meaning of "appropriate" is highly important because it is used to define the treatment that must be provided. Neither the statute nor the regulations provide a clear definition of this term, however. Even the appendix provides only vague assistance in deciphering what factors should be used in defining "appropriate."[219] This ambiguity leaves open the question of whether factors such as the cost of treatment, the inconvenience imposed on the family, the ability of family to pay for the lifesaving treatment, or the "extraordinary" nature of the treatment can be considered in deciding what is "appropriate." Except for some language in the appendix to the regulations, which does not carry the force of law, there is no explicit prohibition against consideration of the quality of life in deciding what constitutes appropriate food, water, and medication.[220] At a minimum, the regulations should specify the factors that are properly considered in defining this phrase.

Defining "Infants" Covered by the Standards

There is also confusion concerning the definition of "infant."[221] The regulations state that the standards "should be consulted fully in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who is born extremely prematurely, or who has a long-term disability."[222] The "should be consulted" language of the regulation, however, makes it unclear whether the latter group is covered by the regulations or whether

218. 42 U.S.C.A. § 5102(3) (West Supp. 1985) (emphasis added). One reference is in the definition of what constitutes lifesaving treatment. The other reference is to nonlifesaving treatment that must be provided to infants even if an infant falls within one of the exceptions under which lifesaving treatment may be withheld. *Id.*; *see supra* notes 146-53 & accompanying text.

219. *See* 50 Fed. Reg. 14,892 (1985) (app.).

220. *Id.* Another ambiguous use of the phrase "appropriate" in the statute and regulations requires that the state protective services system work with, and receive, reports from "appropriate health care facilities" concerning suspected medical neglect. Undoubtedly, this term applies to any facility that cares for infants as defined in the regulations. 45 C.F.R. § 1340.15(C)(2) (1985).

221. *See supra* notes 169-71 & accompanying text.

222. 45 C.F.R. § 1340.15(b)(3)(i) (1985).

the department proposes that hospitals merely act as though they were covered.

Other Issues

Parents

It is particularly noteworthy that there is virtually no mention of parents in the statute and regulations.[223] Yet, it is the parents' decision-making authority that is most directly affected by the federal law. Parents, not physicians or hospitals, have the authority to consent to, or refuse, treatment for their children.[224] Although it is not critical to the implementation of the federal policy, the new law appears to limit only physician decision-making rather than parental decision-making.

Ordinary and Extraordinary Treatment

Some courts and commentators have suggested that "extraordinary treatment" need not be provided when considering life-sustaining treatment.[225] Fortunately, neither the statute nor the regulations specifically use the term "extraordinary treatment." Even if the term "extraordinary treatment" were included in the standards, it refers to such a wide variety of concepts that it is virtually worthless in describing forms of treatment that need not be accepted. It might mean experimental treatment, treatment not accepted by the general medical community, treatment that is not customary under the circumstances, treatment with a very high cost/benefit ratio, very invasive treatment, or treatment that most people would reject. Because of the term's multifaceted definition, its use has been confusing and dangerous.[226] Therefore, while this issue may warrant coverage, great caution should be used in developing terminology.

Neither the statute nor the regulations speak in terms of ordinary or extraordinary treatment. Because of the careful use of the concept of "reasonable medical judgment," that term should not pose the problems that "extraordinary" has. However, the reference to treatment as "including *appropriate* nutrition, hydration, and medication" carries the potential for the same problems in defining "appropriate" as exist with

223. The guidelines dealing with ICRC's do mention parents. The general explanation that accompanies the final regulations, but is not part of them, also notes the importance of family decision-making. 50 Fed. Reg. 14,880 (1985).

224. *See supra* notes 23-29 & accompanying text.

225. *See, e.g., In re* Severns, 425 A.2d 156, 156-60 (Del. Ch. 1980); Satz v. Perlmutter, 379 So. 2d 359, 360 (Fla. 1980); *In re* Quinlan, 70 N.J. 10, 48, 355 A.2d 647, 667-68, *cert. denied*, 429 U.S. 922 (1976); Horan, *supra* note 5, at 82-85; Note, *supra* note 82, at 787-89.

226. *See generally* PRESIDENT'S COMMISSION, *supra* note 6, at 82-89.

"extraordinary" treatment. Indeed it would not be surprising to see claims made that appropriate treatment in the statute means that "extraordinary" treatment, however defined, need not be given. This is potentially a serious problem with the use of "appropriate" in the statute and in the regulations.[227]

Action and Inaction

The 1984 amendments explicitly prohibit only nontreatment[228] and do not directly speak to the issue of active euthanasia. Presumably, such a prohibition is unnecessary because active euthanasia is fully covered by the original child abuse law and by state laws. Parents undoubtedly may consent to treatment that would shorten the life of a child if the treatment were considered "appropriate." For example, pain palliatives may carry the risk of suppressing life functions, thereby causing an earlier death than would occur without the medication. Nothing in the statute or regulations appears to prohibit this or any direct form of treatment.

Medicine, Food, and Water

When one of the exceptions that permits the refusal of treatment is present, the statute provides that treatment "other than appropriate nutrition, hydration or medication" need not be given.[229] Thus, the law draws a distinction between food, water, and medication and other forms of medical service. Presumably, this distinction was meant to require that a child be made as comfortable as possible even if lifesaving treatment would be futile.[230] However, the reason for this distinction in these circumstances is not immediately apparent from the face of the statute.

If concern for the comfort of a dying infant was the reason for the special provisions regarding those kinds of care, the federal law should have specified the obligation as one to provide for the reasonable comfort of the child. If the distinction was drawn because the provision of food, water, and medicine is less invasive than most other forms of treatment, then the statute should have added some provision for other relatively noninvasive treatments. If food, water, and medication were seen as more basic to life, then the distinction between provision of those and other lifesaving treatment is basic to the life of the patient. Perhaps the provisions deserve special consideration because the failure to provide

227. *See supra* notes 218-20 & accompanying text.
228. *See supra* notes 141-55 & accompanying text.
229. *See supra* notes 218-19 & accompanying text.
230. *See* 50 Fed. Reg. 14,891-99 (1985) (app.).

food and water may evoke images of starving a child to death and raises the specter of a gross breach of long-standing parental obligations.

The federal Child Abuse Amendments are intended to protect disabled newborns by limiting the circumstances in which lifesaving treatment may be withheld from the infants. Several of the statute's definitional problems and ambiguous terms discussed in this section threaten to reduce the protection the statute can provide. Protection is additionally reduced, however, because enforcement of the new federal law depends on state child abuse and neglect laws. The Article next explores difficulties with this approach to implementation of the federal statute that further threatens to weaken its effectiveness in protecting infants.

Functional Problems in Implementation of the Federal Approach

Reporting Requirements

Another potential problem with the Child Abuse Prevention and Treatment Act is that it does not provide explicitly that states must require the same broad reporting of withholding of lifesaving treatment that they require for other kinds of abuse and neglect.[231] The federal statute imposes strict reporting and enforcement standards on the states, requiring that states "provide for the reporting of known and suspected instances of child abuse and neglect."[232] It also requires that states ensure immunity for persons reporting child abuse and neglect[233] and that, after an investigation revealing abuse or neglect, immediate steps be taken to protect the health and welfare of the child.[234] States also must ensure that a guardian *ad litem* is appointed in judicial proceedings involving an abused or neglected child.[235] These standards may not have a significant effect on nontreatment decisions, however, because the statute

231. This commitment was omitted despite the fact that the statute's sponsors emphasized, and the Congressional Conference Committee seemed to accept, the proposition that "the same reporting mechanism and standards set forth in the Child Abuse Prevention and Treatment Act and *existing* regulations would be applicable to reporting of cases of medical neglect." Joint Explanatory Statement by Principal Sponsors of Compromise Amendment Regarding Services and Treatment for Disabled Infants, H. CONF. REP. NO. 1038, 98th Cong., 2d Sess. 40, 41 (app.), *reprinted in* 1984 U.S. CODE CONG. & AD. NEWS 2969-70 (emphasis added); *see id.*, at 20, U.S. CODE CONG. & AD. NEWS at 2949-50.

232. 42 U.S.C.A. § 5103(b)(2)(B) (West Supp. 1985). The related regulations require that states "provide by statute that *specified persons must* report and . . . that all other persons are permitted to report known and suspected instances of child abuse and neglect. . . ." 45 C.F.R. § 1340.14(c) (1985) (emphasis added).

233. 42 U.S.C.A. § 5103(b)(2)(A) (West Supp. 1985).

234. *Id.* § 5103(b)(2)(C).

235. *Id.* § 5103(b)(2)(G).

does not clearly include withholding of medically indicated treatment in its definition of child abuse and neglect.

The definition of child abuse and neglect in the federal statute includes only "the physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a child. . . ."[236] The new statute does include a definition of the term "withholding of medically indicated treatment," but it does not clearly provide that the withholding of such treatment is child abuse or neglect as defined in the statute.[237] If the definition of child abuse and neglect does not include withholding lifesaving treatment, states would not necessarily be required to apply all of the statute's provisions concerning reporting, immunity for persons who do report, and appointment of guardians *ad litem* to situations involving withholding medically indicated treatment.

HHS apparently takes the position that the definition of child abuse and neglect does include withholding medically indicated treatment from disabled infants with life-threatening conditions. Its reasoning is that the pre-1984 child abuse statute included "negligent treatment or maltreatment" as forms of child abuse or neglect.[238] HHS previously had defined maltreatment as "failure to provide adequate food, clothing, shelter or medical care."[239] In commentary to the regulations implementing the new statute, HHS suggests that "medical neglect" includes the withholding of medically indicated treatment from infants.[240] In additional commentary accompanying the regulations, it further states that "[t]he *new law* and its legislative history *make clear* that Congress understood and intended that 'medical neglect' is a form of 'child abuse and neglect' within the meaning of the Act and the present regulations. . . ."[241] The legislative history also suggests that Congress intended to include withholding treatment from disabled infants as a form of child abuse and neglect required to be reported.[242] The language of the Act and the regulation, however, do not make this clear. In fact, quite the contrary conclusion could be drawn from the language of the Act; a strong argument could be made instead that it was intended to *avoid* broad reporting re-

236. *Id.* § 5102.

237. *Compare* 42 U.S.C.A. § 5102(1) (West Supp. 1985) (not including "withholding of medically indicated treatment" within the definition of "child abuse and neglect") *with id.* § 5102(3) (carefully defining "withholding of medically indicated treatment") *and id.* § 5103(b)(2)(K) (imposing only limited obligations on states to prevent improper withholding of medically indicated treatment).

238. *Id.* § 5102.

239. 45 C.F.R. § 1340.2(d)(3)(i) (1985).

240. *Id.* § 1340.15(b)(1).

241. 50 Fed. Reg. 14,881 (1985) (commentary) (emphasis added).

242. *See supra* note 114.

quirements.[243] If the legislation were as clear as HHS has indicated, considerable potential confusion could be avoided. The new statute should place medical neglect, including the absence of medically indicated treatment, in its definition of neglect.[244]

A more critical issue is whether state child abuse and neglect reporting statutes will require reporting of medical neglect. The obligation of individuals, including medical professionals, to report arises out of state laws, not out of the new federal law. Therefore, if state statutes do not require reporting medical neglect, including withholding of lifesaving treatment, there will be no obligation to do so.[245] In commentary, HHS noted that it was not requiring states to adopt the federal definition of withholding treatment. "States currently *can* receive reports concerning, and provide protection to, disabled infants with life-threatening conditions under present [state statutes] and definitions."[246] The question, however, is whether states will be forced to require that such abuse or neglect *must* be reported. Therefore, the failure to require states to adopt reporting standards equal to the federal standards essentially defeats the purpose of establishing federal minimum standards.[247] Furthermore, if states already receive nontreatment reports, as the commentary seems to imply, the new federal requirement seems to serve little purpose. This problem becomes even more significant when viewed in the context of the standards that may be applied by state courts.[248]

243. The argument would be that Congress failed to provide a sufficiently broad reporting obligation. The language of the statute speaks only to the obligation of state child protective services agencies to provide for specific individuals within hospitals to report medical neglect. 42 U.S.C.A. § 5103(b)(2)(K) (West Supp. 1985). It says nothing about the obligation of anyone else to report. If hospital officials already were under reporting obligations, there would be very little need for state statutes to specify that designated individuals within the hospital are required to report. It also could be argued that the new federal statute represents a compromise supported by some medical groups dissatisfied with the broad reporting responsibility that the administration had tried to impose under section 504 of the Rehabilitation Act. *See supra* notes 96-113 & accompanying text. Furthermore, the fact that states are not required to modify their child abuse and neglect reporting statutes, *see* 50 Fed. Reg. 14,883 (1985), indicates that there was no expectation that states would change their general reporting requirements.

244. *See* 45 C.F.R. § 1340.2(d) (1985).

245. *See supra* notes 124-33 & accompanying text.

246. 50 Fed. Reg. 14,883 (1985) (emphasis added). HHS described this as the understanding and intent of Congress. *Id.*

247. The regulations covering other forms of child abuse and neglect require the state to define abuse and neglect in accordance with the federal definitions. 45 C.F.R. § 1340.14(b) (1985). Those regulations also require that states must provide by statute that specified persons must report known and suspected abuse and neglect. *Id.* § 1340.14(c).

248. *See infra* notes 251-54 & accompanying text.

Designated Reporter

The new statute provides that child protective services agencies should be notified of suspected medical neglect, including withholding lifesaving treatment, "by individuals *designated by* and *within* appropriate health care facilities. . . ."[249] Under this provision, hospitals may appoint certain members of their staff to report suspected withholding of lifesaving treatment. Apparently, states must require only that hospitals designate one or more persons (administrators or nursing directors, for example) within the hospital to report to the state their concerns about the withholding of treatment.[250] Even if these individuals do report suspected medical neglect of which they are aware, there will be few reports made overall because the reporters will have only limited knowledge of the cases. This is likely to be a particular problem in some institutions because the law allows the hospitals themselves to appoint the individuals who shall bear the obligation to report. It is not hard to imagine that many institutions, wanting to avoid the intrusion of child protective services agents investigating their care of infants, will not appoint particularly aggressive reporters. More fundamentally, the federal statute requires only reporting procedures or programs within the child protective services system of states, and in many states those agencies may not be authorized to require that the designated individuals report suspected medical neglect.[251] The legal authority to *require* reporting may reside in state statutes rather than child protective services regulation. Therefore, a state regulation might have no legal effect.

Standards Applied by Courts

The most fundamental failure of the federal law is that it does not provide a means to ensure that state courts will implement federal standards in deciding whether to order the treatment. The federal statute requires that child protective services agencies have authority under state law "to pursue any legal remedies" that may be necessary to prevent the withholding of medically indicated treatment.[252] A state must document in writing that the child protective services agency is *authorized* to take legal steps to protect a child who may be a victim of medical neglect. This does not guarantee that those agencies will be successful in having the federal standard applied in state courts.[253] Indeed, the 1984 amend-

249. 42 U.S.C.A. § 5103(b)(2)(K)(ii) (West Supp. 1985) (emphasis added).
250. *Id.*
251. *See supra* notes 244-47 & accompanying text.
252. 42 U.S.C.A. § 5103(b)(2)(K)(iii) (West Supp. 1985).
253. Interestingly, the state child protective services agency must be able to demonstrate

ments do not require that state courts follow the federal definition of withholding of medically indicated treatment.[254] More likely, state courts will follow state law in considering a child protective services application for orders to provide lifesaving treatment. Most child protective services agencies do not have authority by regulation to change the criteria for state court intervention,[255] and most states have not changed their juvenile or child abuse statutes to reflect the federal law. Federal law supremacy doctrines probably would not apply because the federal child abuse statute does not claim to establish law, but only to provide criteria for states to meet in order to qualify for certain federal funding. The failure of the federal government to require states to adopt the new definition of medical neglect and to use that definition in judicial proceedings involving withholding treatment means state courts may implement existing state law rather than the new federal criteria. This omission, in turn, will be a major obstacle in accomplishing the goals set for the federal statute.

Ethics Committees

The law's proposals for infant care review committees[256] follow the recommendations of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.[257] In some respects, these ethics committees are like the institutional review boards that are now used to review human experimentation.[258] The

that it can obtain a court order for a medical examination of an infant. 45 C.F.R. 1340.15(c)(4)(ii) (1985). It does not have to demonstrate, however, that it can obtain a court order to provide treatment consistent with the federal definitions of providing lifesaving treatment.

254. The statute requires only that social services agencies have authority to "initiate legal proceedings in a court of competent jurisdiction." 42 U.S.C.A. § 5103(b)(2)(K)(iii) (West Supp. 1985). It does not require that courts apply the federal standards concerning withholding treatment. This concern is raised by the statute's failure to require that states adopt by statute the new federal definition of medical neglect, including withholding treatment. *See supra* notes 244-47 & accompanying text. The federal statute sets criteria for federal funding of state programs. It does not purport to set legal standards independent of state law. Rather it is intended to provide minimum guidelines for states to qualify for funding. Therefore, the federal standards generally would not be applied under a federal supremacy theory.

255. The definition of child abuse and neglect generally is set by state statute rather than by state regulation.

256. 50 Fed. Reg. 14,893-14,901 (1985).

257. PRESIDENT'S COMMISSION, *supra* note 6, at 153-65, 439-57.

258. *See* 45 C.F.R. §§ 46.103-.108 (1985); PRESIDENT'S COMMISSION, *supra* note 6, at 160-70, 439-42; *see also* Cowan, *Human Experimentation: The Review Process in Practice*, 25 CASE W. RES. 533 (1975); DuVal, *The Human Subjects Protection Committee: An Experiment in Decentralized Federal Regulation*, 1979 AM. B. FOUND. RESEARCH J. 571; Robertson, *The Law of Institutional Review Boards*, 26 UCLA L. REV. 484 (1979).

ICRCs, however, do not have authority to make treatment decisions. Even under the federal guidelines, the committees are purely advisory.

ICRCs can be of considerable value, however, as a means for establishing institutional policies concerning withholding treatment and in educating hospital personnel and parents about resources and alternatives.[259] They are likely to be of less value in reviewing and resolving individual nontreatment cases because the committees are not likely to be consulted very often unless there is serious disagreement between the parents and physicians concerning the desirability of treatment and because they can offer advice, but little else. A physician or hospital receives no legal immunity from such a review, and, in fact, the review itself may increase the risk that nontreatment will be reported to the state.[260]

Beyond this, if the ICRC is to help implement the federal law, its members must thoroughly understand fairly ambiguous legal definitions and complex legal standards concerning nontreatment. Although legal counsel should be provided to the committee, the revised model regulation has removed the requirement that an attorney *member* be appointed to the ICRC.[261] Therefore, the committees may find it difficult to focus on the necessary legal issues in individual cases.[262] Finally, any committee of this size (seven or more members) is somewhat cumbersome when decisions must be made quickly. The regulations suggest that telephone consultation or other emergency forms of meeting may be necessary in individual cases.[263] Telephone consultation and emergency meetings, however, are inadequate when complex legal and ethical questions must be considered.[264] Ethics committees, therefore, will be of limited value in

259. These are included in the duties the suggested guidelines propose for ICRC's. Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893, 14,894-96 (1985).

260. *Id.* at 14,899-14,901.

261. *Id.* at 14,894, 14,897; *see supra* notes 188-90 & accompanying text.

262. *Id.* at 14,894.

263. *Id.* at 14,896.

264. The author's experience with institutional review committees indicates that there are a number of difficulties with telephone consideration of complex ethical problems. The interaction of the various disciplines is virtually impossible because there is no group deliberation. It is often very difficult for each member of the committee to be given all of the facts on which a decision must be based or to consult with many of the members within an hour or two.

The author's experience is that emergency meetings are similarly inadequate and often result in very light attendance, especially by those away from the medical center. It is often difficult for the committee to obtain sufficient facts in the face of the emergency. The deliberation tends to be limited or haphazard. *See generally* Cowan, *supra* note 258; DuVal, *supra* note 258. For a contrary view expressed elsewhere in this symposium, see generally Shapiro & Barthel, *supra* note 183.

reviewing decisions to withhold treatment. Institutions may wish to supplement the educational and policy-making functions of the ICRC with an interdisciplinary team composed of an attorney and a physician to review specific cases.[265]

Will the Federal Law Work?

Current Problems

The *Infant Doe* case[266] was the driving force behind the new federal effort to protect disabled infants. Throughout the process of adopting the new federal law, the plight of the child was noted as evidence of the need for law reform. The first inquiry into whether the federal law achieves its purposes, therefore, is whether it would have made a difference in the *Infant Doe* case. One commentator has claimed it would have, noting that "if the amendment had been in effect on April 9, 1982, Infant Doe would be celebrating his third birthday this year."[267] Such optimism may be unwarranted. In the *Infant Doe* case, the child protective services agency knew that treatment was being withheld; thus, the reporting requirements of the new law would have had little impact on the case. Also, the question of treatment was litigated in state courts. Even if the new law had been in effect, therefore, the Indiana courts may have applied the same state law criteria concerning withholding lifesaving treatment, since the federal law does not require states to adopt the federal standards. It is certainly possible that the Indiana courts could have come to the same conclusion in the *Infant Doe* case even if the new federal law had been in operation at the time.[268]

It also seems unlikely that the federal law will have a significant impact in cases similar to Infant Doe's. Either the new law must encourage all parents and their physicians to provide treatment voluntarily, except when withdrawal is permitted by federal law, or the following chain of events must occur to ensure that treatment is provided:[269]

265. *See infra* notes 275-78 & accompanying text.

266. *In re* Infant Doe, No. GU 8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment), *cert. denied*, 52 U.S.L.W. 3369 (U.S. Nov. 8, 1983) (No. 83-437); *see supra* notes 89-113 & accompanying text.

267. Comment, *The Child Abuse Amendments of 1984: The Infant Doe Amendment*, 18 AKRON L. REV. 515, 536 (1985).

268. Subsequent to the *Infant Doe* case, Indiana adopted an infant treatment statute. IND. CODE ANN. § 31-6-4-3 (West Supp. 1985). It is possible, although far from certain, that the Indiana courts would have ordered treatment had the *Infant Doe* case been decided under the new Indiana statute.

269. It is, of course, possible that several of these links could be skipped under unusual circumstances. For example, if a child protective services worker happens to learn of an in-

1. Someone at the hospital must know or suspect that lifesaving treatment is being withheld improperly from an infant.
2. That person must inform (or be) the designated internal reporter of the suspected child neglect or voluntarily inform the child protective services agency of the neglect.
3. The designated person (or other knowledgeable person) must inform the agency of the suspected abuse.
4. The agency must adequately investigate to determine whether treatment is being withheld improperly.
5. If treatment is being withheld improperly, the agency must either convince the parents to accept the treatment or seek a court order to provide the treatment.
6. The court must order the treatment, applying criteria similar to those in the federal statute.

All these events ordinarily must occur in a relatively short time period because of the infant's urgent needs.

In short, a number of problems make tenuous the federal law's protection for disabled newborns. These problems include ambiguity in the federal statute and regulations, especially the failure clearly to define medical neglect, including withholding lifesaving treatment, as a part of child abuse and neglect; the failure to require broad reporting of medical neglect; the unclear exceptions to the treatment obligation; and the failure to require states to adopt federal treatment standards. It is thus virtually certain that states will continue to act upon nontreatment cases as they have in the past. Moreover, these problems, as well as the practical truth that nontreatment decisions are often hidden and very difficult to discover, suggest that the federal law will have only limited impact in addressing the problem of withholding lifesaving treatment.

Future Directions

Some ambiguity and inconsistency are, of course, often necessary by-products of political compromises in emotionally charged areas. One cannot examine the congressional and regulatory history of this federal law without developing a great respect for the tremendous efforts that went into resolving a most difficult question. Sadly, the current federal law is not likely to accomplish very much in ensuring that lifesaving treatment is provided to infants. Some modest changes probably would improve the federal law considerably. States should be required to recognize the federal definition of medical neglect as a form of child abuse and neglect for purposes of the mandatory reporting laws. The definition also

stance of withholding treatment (e.g., while visiting a friend in the hospital), treatment would not necessarily depend on a report from someone at the hospital. For a discussion elsewhere in this symposium of possible tort liability when nontreatment decisions are reported outside statutorily mandated routes, see Vitiello, *supra* note 94.

should serve as a criterion for state courts to use in ordering treatment. This modification would ensure that the federal definition of medical neglect, which is at the heart of the federal effort to protect newborns, would be used at the state level where these nontreatment decisions are actually made. Further, the definition of medical neglect, particularly withholding lifesaving treatment, should be included unambiguously in the definition of abuse and neglect in the federal statute. This change would help ensure that states would be required to treat the refusal of lifesaving like other forms of child abuse and neglect, with respect to state reporting requirements, immunity for persons who report instances of child abuse and neglect, and adequate procedures for dealing with reports of abuse and neglect.[270]

The exceptions to the treatment requirements also should be more carefully defined. The confusion over when treatment is "futile," "otherwise futile," or "merely prolongs dying" threatens to frustrate the purpose of the federal law by expanding the exceptions well beyond those intended, thus allowing inappropriate refusal of treatment.[271] In addition, the meaning of "appropriate" nutrition, hydration, and medication should be clarified. The current definition invites the consideration of social and "quality of life" factors in deciding what is appropriate, although that was apparently not the intent of Congress. Thus, the ambiguity about the meaning of "appropriate" may result in the inappropriate denial of food, water, and medicine.[272]

Last, the definition of infant, as applying only to those less than a year old and those in other uncertain, vaguely defined groups is also unnecessarily restrictive. As a result, the current federal law runs the risk of permitting the refusal of lifesaving treatment to older children that it would not sanction if the children were younger. For example, the refusal of an appendectomy to a Down's syndrome child of one year would not necessarily violate the definition of medical neglect, although it would if the child were six months old.[273] These simple changes could enhance significantly the federal law's impact on decisions to provide or withhold treatment.

In implementing these changes, the following factors must be considered. First, decision-makers must be aware of the laws and their ramifications. Ideally, all parents would know about and understand the law concerning the withholding of treatment, but this seems unrealistic.

270. *See supra* notes 230-47 & accompanying text.
271. *See supra* notes 210-204 & accompanying text.
272. *See supra* notes 208-10 & accompanying text.
273. *See supra* note 212 & accompanying text.

Physicians treating newborns, however, should be fully aware of legal standards requiring treatment. Given the experience in other areas of law in which medical professionals seriously misinterpret even simple legal principles, however, this is also probably impractical.[274] Perhaps the next best option to facilitate awareness by decision-makers is to provide for a review by a person or group with particular expertise in the legal requirements and medical issues involved in deciding to withhold lifesaving treatment.[275] ICRCs or other ethics committees may serve this function in part, although they are hampered by their size and may lack clear understanding of the legal principles. The decision to withdraw lifesaving treatment is of such importance that it should be reviewed by some neutral person or group with an understanding of the legal and medical issues. The review should occur before it is too late to provide the treatment. In addition, there should be some mechanism for resolving clearly and consistently the continuing disagreements over lifesaving treatments. The second factor that must be considered is that the standards for requiring lifesaving treatment should be as clearly stated as possible. Significant ambiguity encourages the use of improper factors and inconsistency in some of the most important decisions that the legal system is called upon to consider.

The federal statute and regulations should be revised to reflect these principles more fully. Even in the absence of changes in the federal law, however, states and individual hospitals can do much to implement these principles.[276] Because the federal law is meant to provide only minimum standards to states, the states should adopt clear and effective rules concerning lifesaving treatment.

274. For example, a review of mental health professionals' understanding of fairly elementary legal concepts indicates considerable confusion, such as confusing competency to stand trial with the insanity defense or psychosis. *See* R. ROESCH & S. GOLDING, COMPETENCY TO STAND TRIAL 18-19, 50, 55, 69 (1980) (Mental health experts evaluating competency to stand trial routinely confuse psychosis, the insanity defense (responsibility), and competency.); Pfeiffer, Eisenstein, & Dabbs, *Mental Competency Evaluation for the Federal Courts: I. Methods and Results*, 144 J. NERVOUS & MENTAL DISEASE 320 (1967).

275. *See generally* Ellis, *supra* note 7 (The legislature should at least set guidelines so that the decisions, which should be made by parents and physicians, will be informed and consistent.); Longino, *supra* note 13, at 399-405 (advocating the judicial model as the best impartial decision maker); Note, *supra* note 3 (advocating a judicial model of decision-making in medical care cases); Note, *Withholding Treatment from Birth-Defective Newborns: The Search for an Elusive Standard*, 31 WAYNE L. REV. 187 (1984) (Parents, when fully informed, should decide. Otherwise, a hospital ethics committee should be established.).

276. *See* Note, *The Child Abuse Amendments of 1984: Congress is Calling North Carolina to Respond to the Baby Doe Dilemma*, WAKE FOREST L. REV. 975 (1984).

Alternative for States and Hospitals: Interdisciplinary Review Teams

It is generally appropriate for states to require lifesaving treatment for infants unless: the treatment would not significantly extend the life of the infant or is too risky; the treatment itself would be so painful that it is not warranted to extend life a relatively short time; or the proposed treatment is experimental.[277] The state should provide for some review of all decisions to withhold treatment when the withholding is likely to cause the death of the infant, but this review must be as simple and expeditious as possible. Potential reviewers, at a minimum, must be able to understand the legal requirements concerning treatment and the medical prognosis and options.

A large ethics committee may not be the optimal way of conducting such a review. Instead, a two-person interdisciplinary team composed of an attorney and a physician, both of whom are familiar with the issues involved in withholding treatment, could be a more effective method of reviewing these cases and should be called whenever withholding of lifesaving treatment is proposed.

Similar interdisciplinary teams have been proposed for reviewing other complex medico-legal issues.[278] The size of the team would permit an expeditious, yet full, consideration of the legal and medical issues. The attorney member would be responsible for ensuring that existing legal standards for refusing lifesaving treatment had been met before treatment could be withdrawn. The physician would ensure that reasonable medical judgments concerning the outcome of treatment and the medical prognosis had been made by the treating physicians. Working together to review nontreatment cases, the team could provide for immediate intervention if legal standards were not met or if reasonable medical judgments had not been made. The team could be appointed by the ICRC, but the team members should have no other formal connection with the hospital. The members of the team necessarily would have to be available on very short notice. Institutions might find it desirable to have more than one team so that expeditious review would be available at all times.

If there is any question concerning the propriety of the refusal of treatment, the interdisciplinary team should immediately forward it to the appropriate state agency or body, such as a child protective services agency. The team also should refer such treatment questions to an ethics

277. *See supra* notes 66-86 & accompanying text.

278. *See* R. ROESCH & S. GOLDING, *supra* note 274, at 205-07 (proposing a two or three person interdisciplinary team consisting of an attorney and one or two mental health professionals to conduct evaluations of competency to stand trial).

committee, which could aid in recommending treatment, counseling, and informing parents of other services available. As a check to ensure that treatment is not being withheld improperly, the team routinely should file with the child protective services agency and with any institutional ethics committee a confidential report of every case reviewed. This procedure would infringe to some degree upon the right of parents to make decisions for their children. Because the review would occur only when the refusal of treatment was a serious threat to the life of the child, however, the infringement would be justified by the very strong interest of the child and of the state in protecting the child.[279]

Support For Families

No matter which standards or procedures are used to review decisions to refuse treatment to infants, there is a crying need for better social and economic support for disabled infants and their families. Ironically, as concern for saving disabled newborns has grown, programs that could help them and their families have not kept pace with the increasing number of infants who can now be saved. Ethics committees can help make families aware of existing resources,[280] but the fact remains that considerable additional support is necessary.[281] Realistically, this calls for additional funds in a time of tight governmental budgets. If society is going to demand treatment for these infants, however, it has some responsibility for helping to ensure that they are adequately cared for and that the strains placed on the family are reduced as much as possible. For some families, this will mean giving up custody of the infant. For many other families, it will mean finding other ways of coping with difficult problems. The 1984 amendments promote easy adoption of children, but much remains to be done to support families facing the social and economic problems associated with many disabled newborns.

Scarce Resources

Current procedures are insufficient to protect disabled newborns even now and must be altered to improve review of these critical treatment decisions. As the congressional and public debate about the new federal legislation indicates, setting standards for withdrawal of treatment from impaired infants is extremely sensitive and highly emotional. The future may hold even more difficult questions concerning lifesaving

279. *See supra* notes 52-65.

280. *See* 50 Fed. Reg. 14,894 (1985).

281. For excellent examples of the kinds of support that should be available to families, see Gostin, *supra* note 39, at 77.

treatment for infants. This Article has assumed essentially unlimited medical resources for caring for the critically ill. It is, of course, possible that in the near future medical resources will become more limited and will be rationed in some way.[282] If the current issues are difficult, in the face of scarce resources decision-makers will require even greater wisdom and compassion.

Conclusion

Child abuse and neglect laws are intended to protect children from physical, emotional, and sexual abuse at the hands of their parents. This interference with parental child-rearing rights is justified by the strong social interest in protecting the weakest in our society from serious harm. Recent amendments to federal law have extended state abuse and neglect laws to prevent the improper withholding of lifesaving treatment from infants. State review or interference with parental decision-making in this area is appropriate because of the importance and irreversibility of such decisions. Indeed, abuse and neglect laws permit interference with child-rearing decisions that are much less harmful than withholding lifesaving treatment.

The intent of the federal law is to provide broad protection to impaired infants in order to ensure that parental decisions to withhold treatment are properly made. States may require lifesaving treatment unless it would be of no value because it would not significantly extend the life of the infant or because it is too risky, the treatment itself would be so painful that it is not warranted to extend life a relatively short time, or the proposed treatment is experimental.

Sadly, the new federal statute is not likely to be very effective in ensuring that lifesaving treatment is provided to newborns. Several of its key terms are open to interpretations that could limit protection severely. Even more disturbing, it does not appear that the federal law requires states to provide for the mandatory reporting of decisions to withhold lifesaving treatment that the states must provide for other, less serious, forms of abuse. Nor does the federal law provide that state legislatures must ensure that their courts follow federal guidelines in deciding whether to order treatment for infants. Thus, the protection for disabled newborns promised by the federal statute is tenuous indeed.

States and hospitals wishing to ensure that lifesaving treatment is

282. *See, e.g.*, G. CALABRESI & P. BOBBITT, TRAGIC CHOICES (1978); Childress, *Who Shall Live When Not All Can Live?*, in VALUING LIFE, PUBLIC POLICY DILEMMAS 203 (S. Rhoads ed. 1980); Mehlman, *Rationing Expensive Lifesaving Medical Treatments*, 1985 WIS. L. REV. 239.

not improperly withheld could provide for review by an interdisciplinary team composed of an attorney and a physician. The team would review all decisions to withhold treatment. If any decision did not meet legal standards or was based on an inadequate medical evaluation, the team could refer the case for further action by the state (acting through a child protective services agency, or, ultimately, a court).

Congress will review the federal child abuse law again in the next few years.[283] When it does so, it should remove the current weaknesses in the statute that impede adequate protection for newborns. In addition, Congress should consider providing a procedure for a more effective review of decisions to withhold lifesaving treatment before it is too late to benefit the child. The interdisciplinary team could perform such a service. With these changes, the federal child abuse law could become an important mechanism for ensuring lifesaving treatment for disabled newborns.

283. The federal child abuse laws are effective through fiscal year 1987. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified at 42 U.S.C.A. §§ 5102-5106, 5111-5113, 5115 (West Supp. 1985)). Therefore, following fiscal year 1987 Congress will again have an opportunity to consider the federal act carefully.