1987

Treatment Decision-making in the Neonatal Intensive Care Unit—Governmental Regulation Compromises Parental Autonomy

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NOTE

TREATMENT DECISION-MAKING IN THE NEONATAL INTENSIVE CARE UNIT—GOVERNMENTAL REGULATION COMPROMISES PARENTAL AUTONOMY

Technological advances have provided the medical community with methods to prolong the lives of critically ill and disabled infants. These advances have drawn the attention of members of Congress, resulting in governmental attempts to regulate parental decisions concerning the extent of medical treatment to be rendered in these cases. After examining the brief history of the resulting regulations, the author recommends that, absent providing for comfort care to the ill infant, governmental regulation is inappropriate.

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INTRODUCTION

Advances in neonatology and perinatology have allowed infants born with significant defects or deformities to be kept alive. Since

1. Neonatology is the branch of medical practice involved in the care of a newborn child. AMERICAN HERITAGE DICTIONARY 837 (2d ed. 1982).
2. Perinatology is the branch of medical practice involved in the care of a pregnant woman near the time of birth. Id. at 923.
3. Defective children who, in the past, would have died naturally, can now be
1940, the infant mortality rate in the United States has been more than halved. Some of these infants go home to bring great joy to their parents. Some of these infants may lead productive, independent lives in society. However, for others, the result may be institutionalization, repeated, highly invasive surgeries, or an inability to care for themselves. In the most severe cases, these children may be incapable of any human interaction and put a great social and economic stress on the rest of the family. These are tragic situations which underscore the importance of considering the potential benefit to be derived from intensive treatment.

Traditionally, parents, with physicians' guidance and support, have made medical treatment decisions for their critically ill and disabled infants. The development of biomedical ethics committees has provided additional support and consultation. Recently, special interest groups have pressured government at all levels into implementing regulations aimed at monitoring medical treatment decisions concerning critically ill and disabled infants. Parental autonomy in this decision-making process is being challenged. As a result, parents are faced with expensive, traumatic, and annoying legal battles to defend their treatment decisions.

This Note begins by delineating the considerations in today's culture that necessitate medical decision-making about critically ill and disabled infants in the neonatal intensive care unit (NICU). The history and implications of governmental involvement in this decision-making process are then discussed. This Note then analyzes the constitutional right to parental autonomy in medical decision-making and outlines the appropriate functions of the various levels and branches of government. Finally, this Note concludes that beyond

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4. Between 1940 and 1980, neonatal deaths dropped from 28.8 per thousand to 8.5 per thousand live births. U.S. DEPARTMENT OF CENSUS, STATISTICAL ABSTRACT OF THE UNITED STATES 77 (104th ed. 1984); see also Duff & Campbell, supra note 3, at 890.

5. See Longino, supra note 3, at 386-87.


7. See generally Gibson, Kushner, Will the "Conscience of an Institution" Become Society's Servant? HASTINGS CENT. REP., at 9, 10 (June, 1986).

8. See infra note 194 and accompanying text.


10. See infra note 157 and accompanying text.
providing non-burdensome, symbolic comfort care, governmental intrusion into the medical decision-making process is unwarranted.

I. TREATMENT DECISION-MAKING REQUIRED IN THE NEONATAL INTENSIVE CARE UNIT

The "vitalist" approach to treatment decisions creates a significant risk that the life of a critically ill and disabled infant will be unjustifiably prolonged. This approach assumes that noncomatose, nonterminal life is always preferable to nonexistence. Undeniably, there are conditions, other than irreversible coma or imminent death, in which some people would choose a shorter life over a longer life of very poor quality. Treatment policies in adult patient care areas are addressing this possibility. Physicians are required to obtain the informed consent of an adult patient for life-saving or life-prolonging treatment.

An infant's inability to express a preference regarding the continuation of life should not require a longer life of significant suffering. The doctrine of "substituted judgment" has long been used to ensure that the best interests of an incompetent or a minor child are observed in medical decision-making.

The ever-increasing capability to support life may often produce treatment with significant harm, as well as benefit. At some point, the burden of painful and disabling treatment outweighs the benefit of a chance of survival with a diminished quality of life. The physician violates the ancient and honored Hippocratic principle of pro-

11. Vitalism refers to the principle that "life is the ultimate value, and something that is to be preserved regardless of prognosis, regardless of cost, and regardless of social considerations." Moskop & Saldanha, The Baby Doe Rule: Still a Threat, Hastings Cent. Rep., at 9 (Apr., 1986).
12. Id.
13. Id.
14. Id.
15. Id.
19. See Moskop & Saldanha, supra note 11, at 11.
fessional ethics, "[f]irst, do no harm," when aggressive treatment significantly harms an infant without the prospect of greater compensating benefits. 20

Infants whose conditions are severe enough to raise questions about the wisdom of aggressive treatment are fairly common in NICUs. 21 Sophisticated life-support systems make it possible to sustain the lives of critically ill and disabled infants. Technology, however, cannot ameliorate severe underlying handicaps or prevent life-threatening complications. 22 Adopting a "save now, cure later" policy is impractical and will surely produce an undesirable effect on the distribution of health care. 23

Aggressive treatment often results in great financial expense. 24 Today, at least ten percent of the gross national product is expended on health care. 25 Additional funds spent on health care may not yield as much benefit today as they did previously. 26 Even if additional funds are expended for medical care, they may yield a greater benefit if directed to other areas, such as basic research or preventive health care, rather than aggressive life-support. 27

Treatment decisions are required in light of advances in technology which prolong the life of critically ill and disabled infants without providing compensatory benefits for the parents, child, or society. Dollars spent in the NICU represent dollars not spent and lives lost

20. Id.

21. Among such conditions are extreme prematurity, severe intracranial hemorrhage, severe asphyxia, trisomy 13 (patay syndrome) and 18 (Edward's syndrome), and multiple severe congenital anomalies (such as spina bifida cystica, which is characterized by a high lesion meningomyelocele with hydrocephalus, quadriplegia, scoliosis and incontinence). Moskop & Saldanha, supra note 11, at 9-10. See generally Rhoden, Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts, 58 S. Cal. L. Rev. 1283, 1285-94 (1985) (describing the nature and variety of neonatal medical problems by diagnosis category).

22. Moskop & Saldanha, supra note 11, at 10.

23. Id. at 11-13.

24. Neonatal intensive care is very expensive. According to one study, the average cost per patient is over $20,000. 50 Fed. Reg. 14,886 (1985). "A Canadian study calculated the cost in 1978 dollars to be $52,182 per survivor weighing 1000 to 1499 gms and $89,892 per survivor for newborns weighing 500 to 999 gms." Moskop & Saldanha, supra note 11, at 11; See also Zook & Moore, High-Cost Users of Medical Care, 302 New Eng. J. Med. 996 (1980).


26. Id. at 239.

27. Id. For example, the artificial heart can be considered aggressive life-support. The question becomes "do we... want to provide an artificial heart for all of the 140,000 potential candidates for this procedure at a cost of $3 to $5 billion annually?" Moskop & Saldanha, supra note 11, at 14 (cit ing Rowlands, Bionic Bill's Heart: Critics Say Deficient, Medical News and Int'l Rpt., at 9 (Feb. 4, 1985)).
in another segment of the health services delivery system.\textsuperscript{28} In addition, the physician must be allowed to practice medicine without being called on to violate the obligation to do no harm.\textsuperscript{29} Even though treatment decisions are necessary, the question of who makes the decisions remains.

II. GOVERNMENTAL INTRUSION IN THE PROCESS OF TREATMENT DECISION-MAKING

All three branches of government at both the federal and the state level have intervened in the process of treatment decision-making.\textsuperscript{30} The absence of clear guidelines concerning the non-treatment of critically ill and disabled infants continues today despite a barrage of judicial,\textsuperscript{31} regulatory,\textsuperscript{32} and legislative\textsuperscript{33} activity in the last five years. Three federal lawsuits have been filed,\textsuperscript{34} two administrative rules have been promulgated and struck down,\textsuperscript{35} and legislation on the subject has been enacted by Congress.\textsuperscript{36} State legislation and administrative regulations were developed to incorporate the federal mandates.\textsuperscript{37} The result of this activity is law with ambiguous language which has already caused confusion in the courts of Minnesota.\textsuperscript{38}

A. Executive Comment Resulting in Administrative Regulation

Widespread public debate on the care and treatment of critically ill and disabled infants began with \textit{In re Infant Doe} in Bloomington, Indiana, in the spring of 1982.\textsuperscript{39} Baby Doe was born with Downs Syn-


\textsuperscript{29} Moskop & Saldanha, \textit{supra} note 11, at 14.

\textsuperscript{30} See infra notes 39-157 and accompanying text.


\textsuperscript{32} Id.

\textsuperscript{33} Id.


\textsuperscript{36} See infra notes 100-12 and accompanying text.

\textsuperscript{37} See infra notes 132-42 and accompanying text (discussing Minnesota's legislation in this area).

\textsuperscript{38} See infra notes 147-55 and accompanying text.

drome\textsuperscript{40} and a tracheo-esophageal fistula\textsuperscript{41} that precluded normal feeding. His parents refused to consent to corrective surgery and asked that food and water be withheld. The hospital sought court intervention but the Indiana Supreme Court refused on the grounds that the parents had made a reasonable treatment decision.\textsuperscript{42} The county attorney and the guardian ad litem then sought emergency action in the United States Supreme Court.\textsuperscript{43} The case, however, was mooted by the baby's death after six days without food or water.

Responding primarily to public concern over the death of Baby Doe, President Reagan directed a memorandum to the Attorney General and the Secretary of the Department of Health and Human Services (DHHS) on April 30, 1982. The directive concerned the enforcement of federal laws designed to prohibit discrimination against handicapped persons.\textsuperscript{44} The president's memorandum elicited prompt action by the DHHS.

On May 18, 1982, the DHHS issued a “Notice to Health Care Providers” who receive federal funding. The letter reminded approximately 7,000 hospitals of the provisions of section 504 of the Rehabilitation Act of 1973,\textsuperscript{45} and set forth DHHS's position that section 504 makes it unlawful to withhold nutritional sustenance or necessary medical treatment from handicapped infants.\textsuperscript{46}

\textsuperscript{40} Down's Syndrome or Trisomy 21 is a common chromosomal disorder resulting in mental retardation. Congenital heart defects and intestinal obstructions commonly occur at birth. Rhoden, \textit{supra} note 21, at 1287-88.

\textsuperscript{41} A tracheo-esophageal fistula is an abnormal connection between the esophagus and the trachea which allows food (milk in the newborn) to be aspirated into the lungs. Surgical correction is required immediately in the newborn period to avoid asphyxia and pneumonia from aspiration. G. Sciapen, M. Barnard, M. Chard, J. Howe, P. Phillips, \textit{Comprehensive Pediatric Nursing} 650-53 (1975).

\textsuperscript{42} Following the hearing, the court accepted the contention of the parents and their attending physician that a “minimally acceptable quality of life” was never present in a child with Down's Syndrome. \textit{In re} Infant Doe, No. GU8204-004A (Cir. Ct. Monroe County, Ind. Apr. 12, 1982). The court determined that the parents, “having been fully informed of the opinions of two sets of physicians, have a right to choose a medically recommended course of treatment for their child in the present circumstances” and ordered Bloomington Hospital “to allow the treatment prescribed” by the mother's obstetrician “as directed by the natural parents.” \textit{Id}.

\textsuperscript{43} For a procedural review of \textit{In re} Infant Doe, see Longino, \textit{supra} note 3, at 381 n.30.

\textsuperscript{44} The directive stated that “[r]egulations under federal law specifically prohibit hospitals and other providers of health services receiving federal assistance from discriminating against the handicapped.” Wash. Post, May 1, 1982, at A11, col. 3.

\textsuperscript{45} 29 U.S.C. § 794 (1982). Section 504 states in part: “[n]o otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance.” \textit{Id}.

\textsuperscript{46} Discrimination Against the Handicapped by Withholding Treatment or Nourishment, Notice of Health Care Providers, 47 Fed. Reg. 26,027 (June 16, 1982) (notice issued May 18, 1982, applying 45 C.F.R. § 84 to health services for handi-
On March 7, 1983, the DHHS promulgated an “interim final rule,” to become effective on March 22, concerning nondiscrimination on the basis of handicap under section 504. The regulation required health care facilities receiving federal financial assistance to conspicuously post a notice stating: “Discriminatory Failure to Feed and Care for Handicapped Infants in this Facility is Prohibited by Federal Law.” This interim regulation also established a 24-hour “hotline” to report suspected cases of handicapped infants who were being discriminatorily denied nutrition or medical care. The regulation also required access to business records after normal hours when necessary to protect the life and health of handicapped children. The notice stated it was “unlawful for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if: 1) the withholding is based on the fact that the infant is handicapped; and 2) the handicap does not render treatment or nutritional sustenance contraindicated.”

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48. The rule provided:

Pursuant to 45 C.F.R. 80.6(d), each recipient that provides covered health care services to infants shall post and keep posted in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery, the following notice:

**DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW**

Section 504 of the Rehabilitation Act of 1973 states that:

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Heath and Human Services
Washington, D.C. 20201
Phone 800-

OR

Your State Child Protection Agency

Federal law prohibits retaliation against any person who provides information about possible violations of the Rehabilitation Act of 1973. Identity of callers will be held confidential. Failure to feed and care for infants may also violate the criminal and civil laws of your State.

49. Id. at 9631. The notice further advised that persons having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should contact a “Handicapped Infant Hotline” by means of a 24-hour toll-free telephone number listed on the sign. Id. No definition of “customary medical care” appeared in the rule. In Heckler, 561 F. Supp. 395, the court found that, “as even the most cursory investigation by the Secretary would have revealed, there is no customary standard of care for the treatment of severely defective infants.” (Emphasis in original). Id. at 400.

This “customary care” language proved to be very embarrassing to the DHHS. In documenting the claims that treatment of infants with certain anomalies was a widespread practice requiring immediate governmental action, Surgeon General Koop has relied on various surveys showing that pediatricians would withhold treatment from certain infants. These surveys, therefore, demonstrated that it was the
individuals.50

On March 21, 1983, the day before the effective date of the interim final rule, a report was issued by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.51 A chapter of the report discussed the treatment of seriously ill infants and newborns. The Commission’s report examined the actual medical practices involving critically ill and disabled infants and found instances of seriously erroneous treatment decisions to be “very rare.”52 The report criticized the approach taken by the new rule, hereinafter referred to as “Baby Doe” Rule I.53

Despite this criticism, the DHHS proceeded to implement the rule. Nonmedical teams, designated by the DHHS as “Baby Doe Squads,” responded to anonymous calls to the DHHS under the rule.54 The withholding of treatment that was customary, making the requirement that hospitals provide “customary care” thoroughly ambiguous.

The health care profession strongly opposed the rule. Public posting of notices with the hotline number resulted in calls from disgruntled hospital employees, ill-informed bystanders, such as parents of other infants, and cranks. During the first four weeks the first hotline was in operation, almost 400 calls were received, many of which were “hang-ups” and “cranks.” Culliton, “Baby Doe” Regs Thrown Out By Court, 220 Sci. 479, 479 (1983).

When the calls were genuine, “Baby Doe squads” were immediately dispatched to the hospital in question to investigate the matter. Each geographical region was to identify a specialist and an alternate for medical consultation. These specialists would comprise the “special assignment Baby Doe squad team.” Team members were to investigate immediately if they received a report. Id. No violations of the rule were found, but the appearance of the Baby Doe squads upset parents of defective children as well as parents of other infants. In at least one instance, parents who had read in the local newspaper of a DHHS investigation removed their critically ill child against medical advice before treatment could be completed, because they feared that the hospital being investigated was somehow harming children. Id. at 480. In addition to upsetting parents, the Heckler decision noted the potential and consequences for interfering with hospital personnel:

In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of “Baby Doe” squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

561 F. Supp. at 399.

50. Hospitals were required to provide access to their premises and medical records to agency investigators. 48 Fed. Reg. 9632 (1983).


52. Id. at 208-09.

53. Id.

DHHS investigated forty-nine reports and found no violation of section 504. The validity of "Baby Doe" Rule I did not go unchallenged in the federal courts.

B. Judicial Response to Administrative Regulation

The first judicial challenge of the administrative regulations took place in American Academy of Pediatrics v. Heckler. Soon after the "Baby Doe" Rule I was proposed, the American Academy of Pediatrics filed a lawsuit in federal court challenging the rule. On April 14, 1983, a few weeks after the rule took effect, it was struck down by Judge Gesell of the United States District Court for the District of Columbia. The court invalidated the regulations for being hasty, arbitrary and capricious, and for failing to follow the Administrative Procedures Act.

After the "Baby Doe" Rule I was invalidated by Judge Gesell, the DHHS published a new proposed rule in July, 1983, and solicited public comment. The proposed rule was virtually identical to the

57. Id.
58. Judge Gesell cited numerous shortcomings in the rule, including the impossibility of hospitals and physicians meeting the nonexistent standard of "customary medical care," and the unlikelihood that the DHHS investigations, which were based on questionable information from anonymous tipsters, would produce a higher quality of care for infants. Id. at 399-403; see supra note 49 and accompanying text.
59. The court found the DHHS lacked a rational, factual basis for the rule. 561 F. Supp. at 403. It did not rule on the plaintiff's claims that the Secretary lacked statutory authority to act. Id. at 401. Nor did the court address whether the regulation intruded without justification into family-physician relationships protected by the Constitution. Id. at 402-03.
60. The DHHS failed to follow mandatory procedure for advance notice of and public comment on the rule. It was not issued in accordance with the public notice or 30-day delay-of-effective date requirements of the Administrative Procedures Act, 5 U.S.C. §§ 553(b), (d) (1982). Heckler, 561 F. Supp. at 400-01. Judge Gesell concluded that "[o]nly by preserving the democratic process [of widespread notice and public comment] can good intentions be tempered by wisdom and experience." Id. at 403.
62. The DHHS received 16,739 comments, of which 16,331 (97.5%) supported the proposed rule and 408 (2.5%) opposed it. Other aggregate descriptions are:
—Of 322 nurses, 314 (97.5%) supported and 8 (2.5%) opposed it.
—Of 100 handicapped persons, 95 (95%) supported and 5 (5%) opposed it.
—Of 141 pediatricians or newborn care specialists, 39 (37.7%) favored and 102 (72.3%) opposed it.
—Of 255 physicians, not including pediatricians or newborn care specialists, 140 (55.3%) favored and 113 (44.7%) opposed it.
one stricken by Judge Gesell. The American Academy of Pediatrics submitted extensive comments on the proposed rule. The Academy stressed its opposition to the federal intervention contemplated by the rule and proposed, instead, the establishment of Infant Bioethical Review Committees as a condition of receiving federal funds. The committees, consisting of both physicians and nonphysicians, would assist parents and physicians in making difficult treatment decisions concerning critically ill and disabled newborns. The committees would also recommend institutional policies concerning the withholding or withdrawal of medical or surgical treatment from infants and would serve as educational resources for hospital personnel and families of seriously ill infants.

The comment process produced a rule that differed from earlier versions. Some consideration of the comments presented by the Academy and others was apparent. The new rule, "Baby Doe" Rule II, took effect on February 13, 1984. Although refined, "Baby Doe" Rule II retained many of the provisions of the first rule.

Of 137 comments from hospital officials and medical, hospital, nursing, and other health related associations, 31 (22.6%) favored and 106 (77.4%) opposed it.

Of 77 comments from associations representing the handicapped, all supported the proposed rules.

Of 100 parents of handicapped persons, 95 (95%) supported and 5 (5%) opposed it.

Letter-writing campaigns by right-to-life groups skewed the result but it was clear pediatricians and health-related organizations were not satisfied with the proposed rule. 49 Fed. Reg. 1622 (1984).


"A Proposal for an Ethics Committee," (July 5, 1983) (submitted by the American Academy of Pediatrics in its comments to the DHHS).

Id.


While the "Baby Doe" Rule II still employed the use of signs, they were reduced in size and needed only to be posted so as to be visible by those directly affected (i.e., the medical and nursing staff). Id. § 84.55(b)(2).

The signs were entitled "Principles of Treatment of Disabled Infants." The substance of the required notice was changed to "nourishment and medically beneficial treatment (as defined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental and physical impairments." Id. § 84.55(b)(3). The phrasing of the notice no longer gave rise to the presumption that the hospital had engaged in the past wrongdoing. In addition, the signs did not refer to the previously undefined "customary medical care" standard. Id.

The original regulations failed to provide guidance to physicians concerning their legal obligations. Instead, the rules mandated that physicians follow "custom." In the neonatal setting, where treatment methods are new, no medical "custom" has been defined. Instead of offering useful guidance to physicians, the original regulations frightened the physician into treating all infants in all cases. The result was
While the DHHS was in the process of preparing the final "Baby Doe" Rule II, an infant referred to as "Baby Jane Doe" became the focus of a controversy in the New York state, federal courts. The scope of the DHHS's regulatory authority in specific circumstances was the issue considered in this second judicial challenge of the now revised administrative regulations.

The facts of the challenge revolved around the birth of Baby Jane Doe on October 11, 1983, in a New York hospital. She suffered from multiple birth defects, including spina bifida, microcephaly and hydrocephalus. While surgery was likely to prolong her life, it would not improve many of her disabling conditions, including severe mental retardation. After consulting with physicians, nurses, often "over-treating" at the expense of increased suffering on the part of incurable and dying infants.

Surgeon General Koop claimed that it was not the Administration's intent to prolong the dying process. The "medically beneficial" amendment was an attempt to clarify their position. However, what constitutes "medically beneficial" treatment begs the question of the criteria used to judge such treatment, including the extent to which quality of life judgments can be used by parents and physicians in determining "medical benefit." 68 § 84.55(e)(1)(c).

This regulation goes on to encourage hospitals to set up Infant Care Review Committees (ICRC) to aid DHHS policy enforcers and investigators. While not mandating such committees, the new rule encouraged their formation and set forth guidelines for their operations. The model sees this group developing treatment guidelines for the management of specific cases or diagnoses and reviewing specific cases brought by those involved in treatment decisions. In reviewing treatment termination cases, the committee must appoint one member to act as an advocate for the infant to ensure that all consideration in favor of the provision of life-sustaining treatment are fully evaluated and considered. 69 § 84.55(f).

The model is heavily weighted in favor of continued treatment. If the family refuses consent, but the ICRC disagrees with the family (whether or not the family is supported by the physician), the ICRC is expected to recommend to the hospital that a court or child protection agency be notified. 70 § 84.55(f)(3)(F).

The DHHS makes it clear that it sees the ICRC as its local investigatory arm. DHHS investigators will make immediate contact with the ICRC when a complaint is made. After examining the ICRC's point of view, the DHHS may require a written report of its findings, accompanied by pertinent records and documentation. 71 § 84.55 (c)(d)(e). One wonders if this responsibility of an ICRC is really any different than allowing "Baby Doe Squads" access to medical records under the first rule.

The second set of regulations retained the substance and thus, the problems of the original proposal. The ICRC was an encouraging sign but the guidelines focus on medical rather than ethical considerations, making them little more than in-hospital "Baby Doe" squads. A number of legal cases have addressed the challenges raised by the revised regulations.


70. See id.

71. Spina bifida refers to the exposure of the spinal cord and membranes. Microcephaly refers to an abnormally small head. Hydrocephalus refers to the accumulation of fluid in the cranial fault. University Hosp., 729 F.2d at 146.
religious advisors and others, the parents decided to forego the corrective surgery. Instead, the parents chose "conservative" medical treatment consisting of good nutrition, the administration of antibiotics, and the dressing of the baby's exposed spinal sac.\footnote{Weber, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.}

Court proceedings surrounding Baby Jane Doe began on October 16, 1983, when an attorney, who was unrelated to the baby and her family, commenced a proceeding in New York State Supreme Court.\footnote{University Hosp., 729 F.2d at 146. See also Weber, 60 N.Y.2d at 211, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.} The attorney petitioned for the appointment of a guardian ad litem and an order directing the hospital to perform surgery. The court appointed a guardian ad litem. After an evidentiary hearing, the court concluded that surgery was necessary and ordered that it be performed.\footnote{University Hosp., 729 F.2d at 147.}

The next day, the Appellate Division of the New York Supreme Court reversed the decision and dismissed the proceeding.\footnote{Weber, 95 A.D.2d at 589, 467 N.Y.S.2d at 687.} The court found that the parents' decision was based on responsible medical authority and was in the best interests of the infant.\footnote{Id.} The court's decision was affirmed by the New York Court of Appeals.\footnote{Weber, 60 N.Y.2d at 213, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.}

While the action involving the guardian appointment and order to perform surgery was still in progress at the state level, the federal government became involved in the controversy. The DHHS received a complaint from an unidentified "private citizen" that Baby Jane Doe was being discriminatorily denied medical treatment on the basis of her handicaps in violation of section 504 of the Rehabilitation Act.\footnote{University Hosp., 729 F.2d at 147.} The DHHS repeatedly requested that the hospital produce all of Baby Jane Doe's medical records since October 19, 1983, citing as legal authority its investigatory powers under section 504.

\begin{itemize}
\item \footnote{Weber, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.}
\item \footnote{University Hosp., 729 F.2d at 146. See also Weber, 60 N.Y.2d at 211, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.}
\item \footnote{University Hosp., 729 F.2d at 147.}
\item \footnote{Weber, 95 A.D.2d at 589, 467 N.Y.S.2d at 687.}
\item \footnote{Id.}
\item \footnote{Weber, 60 N.Y.2d at 213, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.}
\item \footnote{Id. New York's highest court found that the trial court had abused its discretion by permitting the procedure to go forward. First, the petitioner had no direct interest in or relationship to any party and had failed to contact the State Department of Social Services. Second, the trial court had failed to seek the Department's investigatory assistance. \textit{Id.}}
\item \footnote{University Hosp., 729 F.2d at 147. The DHHS obtained a copy of the state court record and forwarded it to the Surgeon General of the United States, who determined that immediate access to the baby's current medical records was necessary before a judgment could be made about whether Baby Jane Doe's care was "within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment . . . ." \textit{Id.}}
\end{itemize}
The hospital refused to honor the DHHS request.\textsuperscript{80}

The Department of Health and Human Services then brought a lawsuit in the United States District Court for the Eastern District of New York.\textsuperscript{81} The suit challenged the hospital’s refusal to allow the DHHS access to the medical records.\textsuperscript{82} The government alleged that the hospital violated section 504 and section 80.6(c) of title 45 of the Code of Federal Regulations.\textsuperscript{83} The federal district court held that the hospital did not have to disclose the medical records because it had not discriminated against Baby Jane Doe by failing to perform surgery.\textsuperscript{84}

The government appealed this decision to the United States Court of Appeals for the Second Circuit.\textsuperscript{85} This court held that section 504 does not apply to treatment decisions involving seriously ill newborns.\textsuperscript{86} The legislative history,\textsuperscript{87} the case law interpreting section 504,\textsuperscript{88} and the purposes of the Rehabilitation Act of 1973\textsuperscript{89} did

\textsuperscript{80} \textit{Id.} at 148.

\textsuperscript{81} \textit{See University Hosp.}, 575 F. Supp. 607 (E.D.N.Y. 1983), aff’d, 729 F.2d 144 (2d Cir. 1984).

\textsuperscript{82} \textit{Id.} at 609.

\textsuperscript{83} \textit{Id.}; 45 C.F.R. § 80.6(c) (1983). Section 80.6(c) requires recipients of federal assistance to permit the responsible department official or his designee access to information pertinent to ascertain compliance with the nondiscrimination provisions of 45 C.F.R. § 80.3 (1983).

\textsuperscript{84} 575 F. Supp. at 614. The trial court ruled in favor of the parents and the hospital. First, the court found that the hospital had not discriminated against Baby Jane Doe because the hospital could not institute surgical procedures without parental consent. The hospital was willing to perform the surgery but did not do so because the parents had refused consent. Second, the parents’ decisions were reasonable and based on a genuine concern for the best interests of the child. \textit{Id.} at 614-15.

\textsuperscript{85} 729 F.2d at 144.

\textsuperscript{86} \textit{Id.} at 156-57. The court concluded that an infant suffering from multiple birth defects would not ordinarily be considered “otherwise qualified” under section 504. \textit{See supra} note 25 and accompanying text. Neither the language or the history of the Rehabilitation Act bring the medical treatment decision involving infants with numerous birth defects into its ambit. The court went so far as to say that “[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was ‘discriminatory.’” 729 F.2d at 157.

\textsuperscript{87} The court reasoned that the legislative history of the statute indicated that Congress never intended section 504 to apply to treatment decisions involving critically ill and disabled infants. \textit{Id.} It concluded that the articulated purpose of section 504 concerned access and admission to federally funded programs and activities for otherwise qualified handicapped individuals and not the “far-reaching position advanced by the government in this case.” \textit{Id.} at 161 (citing Montana Power Co. v. Federal Power Comm’n, 445 F.2d 739 (D.C. Cir. 1970)).

\textsuperscript{88} \textit{University Hosp.}, 729 F.2d at 160. \textit{See, e.g.,} Southeastern Community College v. Davis, 442 U.S. 397 (1979); American Pub. Transit Ass’n v. Lewis, 655 F.2d 1272 (D.C. Cir. 1981) (while not directly on point, both cases indicate that the government’s interpretation of section 504 exceeds the authority conferred by Congress).
not sustain the DHHS's authority to obtain the infant's medical records. The court concluded that absent a clear congressional directive allowing federal intervention in the medical decision-making process, "it would be an unwarranted exercise of judicial power to approve of the type of investigation that has precipitated this lawsuit."90 The Second Circuit's decision in the Baby Jane Doe case put the legal status of the "Baby Doe" Rule II at issue. This decision led to the third federal judicial challenge.

Several medical groups brought a lawsuit91 challenging the "Baby Doe" Rule II on the theory that the Second Circuit's decision in the Baby Jane Doe case rendered the rule invalid.92 On June 11, 1984, the medical group plaintiffs obtained a nationwide injunction prohibiting the DHHS from implementing the "Baby Doe" Rule II and from undertaking any other actions to regulate treatment decisions involving critically ill and disabled infants.93 The district court held that the Baby Jane Doe decision established that the DHHS had no authority under section 504 to investigate or otherwise regulate treatment decisions involving these infants.94

Appeals to the United States Court of Appeals and the Supreme Court followed. On December 27, 1984, the United States Court of Appeals for the Second Circuit affirmed the district court's decision in American Hospital Association v. Heckler.95 The case was renamed American Hospital Association v. Bowen96 at the Supreme Court level when the DHHS secretary changed. On June 9, 1986, the Supreme Court held no evidence existed to show that hospitals had discriminated against handicapped infants or had refused treatment sought by parents.97 The Court went on to say that federal intervention in a

Cf. Dopico v. Goldschmidt, 687 F.2d 644, 647 (2d Cir. 1982) (commenting that recipients of federal funds must make a "special effort" with those funds to satisfy the national policy that Congress embodied in section 504).

89. See, e.g., Paralyzed Veterans of America v. Civil Aeronautics Bd., 752 F.2d 694 (D.C. Cir. 1985) (stating Congress intended the Rehabilitation Act to offer handicapped individuals an opportunity to pursue employment, education and recreational goals free of the additional handicap of discrimination against them); Connolly v. United States Postal Service, 579 F. Supp. 305 (D. Mass. 1984) (holding that Congress intended the Rehabilitation Act to be the exclusive remedy for employment discrimination by a federal employer on the basis of handicap).

90. University Hosp., 729 F.2d at 161.
92. Id. This lawsuit was filed on March 12, 1984, in the United States District Court for the Southern District of New York.
93. Id.
94. 585 F. Supp. at 542.
95. 794 F.2d at 676 (no published opinion).
96. 106 S. Ct. 2101 (1986).
97. Id. at 2113-17.
sensitive area usually left to state agencies is not needed. It is be-
lieved by some that the Court's decision will reinforce the primacy of
the family and the doctor in medical decision-making.99

C. Congressional Response to Judicial Mandates: More Administrative Regulation

Federal child abuse legislation was originally enacted in 1974 as
the Child Abuse Prevention and Treatment Act.100 The Act estab-
lished a federal funding program to assist states and other entities in
preventing and treating child abuse and neglect.101 Under regula-
tions implementing the Act, the terms "child abuse and neglect" are
defined to include, among other things, the failure to provide "ade-
quate medical care" for a child.102

Late in the summer of 1984, a coalition of medical, disability, and
right-to-life groups met with six United States senators.103 They
drafted compromise legislation which was enacted by Congress and
signed by the President.104 While American Hospital Association v. Heckler (Bowen)105 was being heard in the lower courts, the legisla-
tion was enacted as part of the 1984 amendments to the Child Abuse
Prevention and Treatment Act.106

The Child Abuse Amendments (CAA)107 provided the clear con-
gressional directive called for by the court in United States v. University
Hospital.108 A legislative intent to allow governmental intervention
in the medical decision-making process was established. The legisla-

98. Id. at 2121-23.
99. See Malcolm, "Baby Doe" Truly a Case of the '80s, St. Paul Pioneer Press and
Dispatch, June 15, 1986, G1, col. 4; see also The "Baby Doe" Ruling, L.A. Daily J.,
June 12, at 4, col. 1.
101. See infra note 111 and accompanying text.
103. The senators represented an unlikely mix of conservatives and liberals:
Christopher Dodd, D-Conn.; Orrin Hatch, R-Utah; Jeremiah Denton, R-Ala.; Alan
Cranston, D-Cal.; Don Nickles, R-Okla.; and Nancy Kassebaum, R-Kansas.
25 (1982)).
105. 106 S. Ct. 2101.
National Center on Child Abuse and Neglect. The Center's primary responsibilities
are to make state grants to implement child abuse and neglect treatment programs,
fund private research organizations attempting to prevent, identify and treat child
abuse and neglect and to coordinate federal child abuse and neglect programs. Id. See
14,878, 14,878 (1985) (to be codified at 45 C.F.R. § 1340) (a background summary of
the NCCA, its purpose and goals).
108. 729 F.2d at 161. See supra note 90 and accompanying text.
tion is described as "a careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities."109 Under this legislation, the states, rather than the federal government, implement programs and procedures addressing the problems of child abuse and neglect, including instances of medical neglect.

The CAA, like the original legislation, focus on state child abuse agencies, rather than on the federal government, as the authorities capable of investigating "Baby Doe" complaints. In order to receive federal grants for state child abuse and neglect programs under the CAA after October 9, 1985, states must have in place within their child protective systems, procedures or programs designed to respond to reports of medical neglect.110 The CAA included "withholding of medically indicated treatment" from disabled infants with life-threatening conditions as a form of medical neglect.111 Under


110. Child Abuse Amendments of 1984, Pub. L. No. 98-457, §§ 121-23, 122, 98 Stat. 1749, 1752 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-03 (1986)). Every state has a Child Protective Service (CPS) system regardless of whether the state obtains federal grant money under the Act. These agencies are designated by the states to respond to child abuse and neglect. Id. The focal point of their efforts is "on the family—to protect the child, preserve the home, prevent separation of the child from the family if at all possible, prevent further abuse or neglect and alleviate or correct the factors leading to the report." Id. Further, the "agency generally regards its contact with the family as a demonstration of community concern and evidence of a desire to be of help to both parents and children." Id.

Under the Child Abuse Prevention and Treatment Act, Minnesota receives Child Neglect & Abuse Basic State Grant No. 05 CA 5388/09-2 in the amount of $158,521 for the eighteen months beginning September 30, 1985.

111. Id. § 121, 98 Stat. at 1751. The phrase is defined as:

[T]he failure to respond to the infant's life threatening conditions by providing treatment (including appropriate nutrition, hydrations, and medication) which, in the treating physician's or physicians' best judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that 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 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. The Senate sponsors of the measure noted in a joint explanatory statement that "reasonable medical judgment" refers to a medical judgment that would be made by a reasonably prudent physician who is knowledgeable about the case and treatment.
the new amendments, the DHHS is required to publish regulations implementing the new requirements, including guidelines for hospital ethics committees, and to provide technical assistance to the states. The DHHS is not, however, authorized to investigate or take other action on individual "Baby Doe" cases such as was contemplated by the earlier "Baby Doe" rules.

On December 10, 1984, the DHHS issued preliminary guidelines for implementation of the CAA. These preliminary guidelines expanded the definition "withholding of medically indicated treatment" beyond that in the legislation. Interim model guidelines were established for the composition, functions, and procedures of Infant Care Review Committees (ICRC). The DHHS received thousands of comments on the proposed rule, including critical comments stating that the proposed rule went beyond the balancing intent of the legislation.

possibilities with respect to the medical conditions involved. The term "infant" is defined as an infant less than one year of age, although it may include older infants who have been continuously hospitalized since birth, who were born extremely prematurely or who have long-term disabilities. In addition, the joint statement explains that the use of the term "inhumane" in exception (c) is not intended to suggest that the consideration of the humaneness of a particular treatment is not legitimate in any other context; rather, the sponsors recognize that the issue of humaneness is an appropriate consideration in selecting among alternative treatments. See Joint Explanatory Statement by Principal Sponsors of Compromise Amendment Regarding Services and Treatment for Disabled Infants, 130 Cong. Rec. 9,319 (daily ed. July 26, 1984).


114. Child Abuse and Neglect Prevention and Treatment Program, 45 C.F.R § 1340.

115. As originally proposed, the rules set forth extensive clarifying definitions of many of the statutory terms in the rule itself. These terms include: "treatment," "medical neglect," "infant," "merely prolong dying," "not be effective in ameliorating or correcting all the infant's life-threatening conditions," "virtually futile," and "the treatment itself under such circumstances would be inhumane." The definitions provided examples of each of the different types of circumstances which would be encompassed by each term. 50 Fed. Reg. 14,878-901 (1985). By including these clarifying definitions in the rule, any discretion that may have existed is significantly eliminated. See Letter from McDermott, Will & Emery to health care clients and selected interested parties (April 17, 1985) [hereinafter McDermott letter] (comparing the proposed Baby Doe regulations with the DHHS' final rules); E. Van Allen, Summary of Federal and State "Baby Doe" Legislation (1985) (published by the Minnesota Network of Institutional Ethics Committees, a service supported by the Minnesota Hospital Association).

116. See E. Van Allen, supra note 115, at 1. The DHHS received 116,000 comments on its proposed rule, the majority expressed general support for the regulation. See Kerr, Negotiating the Compromises, HASTINGS CENT. REP., June, 1985, at 6. Evidently, another letter-writing campaign was conducted by the right-to-life organi-
The final rules, hereinafter referred to as "Baby Doe" Rule III, published on April 15, 1985, do not have the detailed definitions of the preliminary guidelines. However, these definitions are in-

zations as many letters strongly endorsed supplying hydration and nutrition to all disabled infants no matter what their condition and refusing to acknowledge any role for "quality of life" considerations in the process of medical decision-making. Id.

Among the disapproving comments, the DHHS received input objecting to any governmental action that interfered with an individual's right to make a personal treatment decision. Id. These letters urged that the extensive definitions and examples be eliminated as they led to restraint in treatment decision-making and a presumption of federally-prescribed and approved medical standards in specific cases. Id.

Another criticism of the proposed rule centered on the absence of any reference to ethical considerations in treatment decisions. See Letter from Dana Johnson to Margeret Heckler (Jan. 23, 1985) (commenting on the proposed rules); Letter from Daniel Rode to Margaret Heckler (Feb. 8, 1985) [hereinafter Rode Letter] (suggesting substantial changes in the proposed ICRC guidelines). The definitions and some of the ICRC guidelines neglect the fact that treatment decisions for handicapped or critically ill children involve ethical considerations and are rarely made on the basis of medical judgments alone. In failing to address this issue, the proposed rules oversimplify the complicated dilemmas faced in treatment decision-making rather than providing a methodology for approaching these dilemmas in a well-rea-

soned fashion. Id.

Well-reasoned, ethical decisions are part of good medical care. The process of making a treatment decision for a critically ill or handicapped newborn infant has been facilitated in some facilities by a step-wise approach. The process centers on six ethical propositions on which to base a decision, five decision-making principles and, finally, review by the infant bio-ethics committee. In reviewing the decision, the committee need not agree or disagree with the parents, who are the primary decision-makers, but, rather, only ensure that a decision has been made through the principles of decision-making consistent with the six ethical propositions. Without such a step-wise process, the ethics committee has no framework in which to operate and it appropriately becomes the decision-making body rather than a committee whose role is to facilitate a well-reasoned decision by the patients' primary caregivers. See Johnson, Life Death and the Dollar Sign, 252(2) J. AM. MED. Ass'n 235 (1984) (discussing financial aspect of ethical decision-making); Johnson, Thompson, "Baby Doe" Rules: There are Alternatives, 138 AM. J. DISEASES OF CHILD. 523 (1984) (describing the ethical propositions and decision-making principles in the process of ethical decision-making).

The guidelines in the proposed rule provide that CPS and ICRC have distinct functions. The ICRC is intended to counsel physicians, hospital personnel and families of patients, while the CPS is charged with determining when the power of the state must be invoked. However, when a situation arises where the family or physician believe life-sustaining treatment should be withheld and the ICRC disagrees, the ICRC is charged with immediately notifying the court or local CPS agency. 50 Fed. Reg. 14,893 (Apr. 15, 1985).

The model guidelines do not allow the ICRC to serve in the manner mentioned in the preamble to the guidelines. The guidelines establish committees whose role is punitive, reactive, and investigative. The ICRC becomes an extension of the state enforcement agency and takes the physician, and to some extent the family, out of the decision-making process surrounding the treatment and care of the critically ill infant. Rode Letter, supra note 116.

117. See supra note 38 and accompanying text. DHHS removed all but two of the proposed rules clarifying definitions from the text of the final rule.
cluded as an appendix. Child protection agencies are encouraged to refer to them.

Implementation of the final regulations was delegated to the states. By October 9, 1985, each state was required to have in place programs and/or procedures within the state child protection service system to respond to reports of withholding medically indicated treatment from disabled infants with life-threatening conditions. These programs and procedures are included in the state grant application for federal child abuse and neglect funds, which must be approved by DHHS. Enforcement of the law itself will be done under state child abuse and neglect laws.

The final model guidelines for ICRCs were more permissive than were the interim guidelines. Although the ICRCs were optional in both, the interim guidelines contained mandatory requirements for composition, functions, basic and specific policies, and procedures for prospective and retrospective review of cases. They also mandated resolution of cases in which there is disagreement among the parents, the physician, and/or the ICRC. These requirements appear in the final guidelines as recommendations, drafted in language which is more conciliatory than the interim guidelines. However, most of the provisions of the interim guidelines are contained in the appendix.

Despite changes in the rule, the DHHS has apparently not abandoned its position of absolute "vitalism." Surgeon General C. Everett Koop emphasized that the ICRCs were not intended to be infant bioethics committees, indicating "ethical" criteria could not justify nontreatment. The rules articulate a "best interest of the infant"

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119. See 45 C.F.R. § 1340.15(e)(2) (1986). While the DHHS states that the guidelines will not serve as binding rules of law, the guidelines would likely be given at least some weight by the court. See also McDermott Letter, supra note 115, at 2.

120. Id. § 1340.15 (c)(1)(5). The rule describes the minimum requirements that a state CPS must fulfill in order to qualify for federal grants under the Child Abuse Prevention and Treatment Act. State CPS agencies must have a procedure to (1) identify contact persons in health care facilities for initiating and pursuing suspected cases of medical neglect and (2) assure that state law authorizes the CPS agency to go to court to intervene in such cases if necessary. The rule also requires that the state agencies devise ways to get medical records or other information pertinent to an investigation of medical neglect and to obtain an independent medical examination as part of such an investigation. Id. § 1340.15 (c)(2).

121. Id. § 1340.15 (c)(2)(iii).


123. Id.


125. See E. Van Allen, supra note 115 (quoting the comments of Surgeon General Koop).
standard in making treatment decisions and explicitly denounce consideration of the infant's future "quality of life" as inconsistent with the statute.\textsuperscript{126} While allowing "reasonable medical judgment," the rules repeatedly restrict a physician's discretion to "medical" considerations.\textsuperscript{127} While the discretion of physicians and parents in treatment decisions is less constrained than under previous rules, the primacy of the family in decision-making remains in check with this most recent rule.

"Baby Doe" Rule III still requires treatment in all but a very few extreme circumstances. This "vitalistic" federal policy has not changed significantly from the "Baby Doe" Rule I.\textsuperscript{128} While the rules encourage what may be a supportive measure in the form of the ICRC,\textsuperscript{129} the guidelines fail to achieve the stated purpose by ignoring ethical considerations and constraining physicians. Both ICRCs and child protection service agencies must abide by the substantive federal policy regarding treatment of disabled infants stated in "Baby Doe" Rule III.\textsuperscript{130} This is of special concern in Minnesota where the state legislation implementing the rule is more intrusive than the rule requires.\textsuperscript{131}

\textbf{D. Minnesota Incorporates Federal Regulations}

\textit{1. Minnesota Legislation}

In 1985, the federal definition of "withholding of medically indicated treatment" was included in the definition of medical neglect in Minnesota Statutes section 260.015.\textsuperscript{132} The state law was also changed to include the exceptions to the withholding of medically indicated treatment as initially charted by the CAA and implemented by "Baby Doe" Rule III.\textsuperscript{133} The resulting state implementation of

\begin{itemize}
  \item \textsuperscript{126} 45 C.F.R. § 1340, App. 9 (1986).
  \item \textsuperscript{127} Id.
  \item \textsuperscript{128} Moskop & Saldanha, supra note 11, at 9.
  \item \textsuperscript{129} Id.
  \item \textsuperscript{130} Id.
  \item \textsuperscript{131} Under the state Baby Doe law, CPS workers are required to verify that "appropriate nutrition, hydration, and medication" are being provided for a disabled infant and to conclude whether or not medical neglect has occurred. To do so, the CPS agency must consult with designated hospital staff and the parents and arrange an independent review of the infant's medical records. If the review is inconclusive, the CPS agency must seek a court order for an independent medical examination of the infant. If the review of examination leads to a conclusion of medical neglect, CPS must intervene by getting a court order for protective custody of the child and file an expedited motion (with juvenile court) to prevent the withholding of medically indicated treatment. Minn. Stat. § 626.556, subd. 10(c) (1986).
  \item \textsuperscript{132} Minn. Stat. § 260.015, subd. 10(e) (1986). \textit{See supra note 111 (citing text of federal act).}
  \item \textsuperscript{133} Compare Minn. Stat. § 260.015, subd. 10(e) with Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121, 98 Stat. at 1751.
\end{itemize}
the procedural requirements was more intrusive than required by the federal regulation. The state law went beyond putting in place a program or procedure for responding to reports of medical neglect. Minnesota law mandated steps that local child protection services must take upon receipt of a report alleging withholding of medically indicated treatment. At the time these requirements were being incorporated, local problems involving child abuse litigation in Scott County contributed to distrust of hospitals and physicians and resulted in a more strict state child abuse and neglect reporting law.

A responsible parent or guardian's failure to supply a child with the necessary food, clothing, shelter, and medical care is neglect if the parent is reasonably able to provide these needs. Minnesota's policy is to protect children whose health and welfare might be endangered by abuse or neglect. Child neglect laws provide for the termination of all parental rights by a petition to a juvenile court if the parents have failed to provide their child with the care necessary for the child's welfare.

In situations where parental rights are terminated by the state, pa-

134. See Minn. Stat. § 626.556, subd. 10(c) (1986) (outlining procedures to be followed in case of medical neglect as defined by Minnesota Statutes section 260.015, subdivision 10(e)).
135. E. Van Allen, supra note 115.
136. Minn. Stat. § 626.556, subd. 2(c). That section provides:

"Neglect" means failure by a person responsible for a child's care to supply a child with necessary food, clothing, shelter or medical care when reasonably able to do so or failure to protect a child from conditions or actions which imminently and seriously endanger the child's physical or mental health when reasonably able to do so . . . . Neglect also means "medical neglect" as defined in section 260.015, subdivision 10, clause (e).

Id.
137. Minn. Stat. § 626.556, subd. 1. That section provides:
The legislature hereby declares that the public policy of this state is to protect children whose health or welfare may be jeopardized through physical abuse, neglect or sexual abuse; to strengthen the family and make the home, school, and community safe for children by promoting responsible child care in all settings; and to provide, when necessary, a safe temporary or permanent home environment for physically or sexually abused children.

Id.
138. Minn. Stat. § 260.221. That section provides:
The juvenile court may, upon petition, terminate all rights of a parent to a child in the following cases: (a) With the written consent of a parent who for good cause desires to terminate parental rights; or (b) If it finds that one or more of the following conditions exist: (1) The parent has abandoned the child; or (2) That the parent has substantially, continuously, or repeatedly refused or neglected to comply with the duties imposed upon that parent by the parent and child relationship, including but not limited to providing the child with necessary food, clothing, shelter, education, and other care and control necessary for the child's physical, mental or emotional health and development, if the parent is physically and financially able . . . .

Id.
rental financial responsibility may continue.\textsuperscript{139} Although the child receives financial assistance from the state,\textsuperscript{140} a parent can be ordered to reimburse the county or state agency for the child’s care.\textsuperscript{141}

The details of this legislative action send conflicting messages. State claims that preserving sanctity of life is a compelling state interest are inconsistent with state actions requiring parental contributions. If the state’s interest in protecting the health and welfare of children is compelling enough to overcome the presumption of parental autonomy in deciding a child’s welfare, then the state should be financially responsible for that interest. Statutory ambiguities and vague statutory language have resulted in limited holdings and confusion in Minnesota courts.\textsuperscript{142}

2. Minnesota Case Law

Minnesota cases have failed to provide guidance concerning the courts’ involvement in the decision-making process and the circumstances in which termination of life support systems is appropriate without court involvement. The Minnesota Supreme Court limited its decision \textit{In the Matter of the Conservatorship of Rudolfo Torres} \textsuperscript{143} to its specific fact situation.\textsuperscript{144} In a case involving an incompetent individual with a court-appointed conservator, a court order was required to discontinue Mr. Torres’ life support systems.\textsuperscript{145} In those situations where no conservator is involved, no court involvement is required.\textsuperscript{146}

The first suit invoking protection of “Baby Doe” Rule III for a handicapped infant was brought in Redwood County Family Court in
southwestern Minnesota. Under the auspices of "Baby Doe" Rule III, *In re Steinhaus* was brought to prevent the withholding of medically indicated treatment from a seven-month-old child-abuse victim in an irreversible coma. Confusion over the definition of "chronically and irreversibly comatose" prompted the court to require medical treatment. Upon re-opening the case, the court declared that an infant in a persistent vegetative state falls within the statutory definition of "chronically and irreversibly comatose." This exception


148. Id.

149. *Steinhaus* Order at 2. The facts of the case were not disputed. Lance was born on March 20, 1986. As a result of a severe beating by his father in April of 1986, Lance was rendered comatose and was found by his treating physician to be in a persistent vegetative state. Lance was admitted to the University of Minnesota Hospitals for intensive care. Lance became a ward of the Redwood County Department of Welfare shortly after admission to the University of Minnesota Hospitals. After consulting with Lance's physicians, the child's mother, Amy Steinhaus, requested that he not receive antibiotics and that a Do Not Resuscitate (DNR) order be placed on his medical chart. *Id.* On the motion of the Redwood County Department of Welfare for such an order, Judge G. Harrelson of the Redwood County Court issued a temporary restraining order requiring that Lance receive both antibiotics and resuscitation as needed. *Id.* at 16.

150. The court was faced with motions from Amy Steinhaus and Dr. D. Steinhorn requesting that the court dissolve the temporary injunction requiring treatment and order, instead, that personal hygiene, nutrition, hydration and suctioning of oral secretions be continued, but aggressive medical treatment including antibiotic treatment, resuscitation efforts, surgical interventions, and the use of respiratory devices be proscribed. *Steinhaus* Order at 2. The court held that Lance was entitled to antibiotic treatment as part of the appropriate nutrition, hydration, and medication. *Id.* at 10. The court went on to hold that Minnesota Statutes section 260.015, subdivision 10(e) required treatment of Lance because he did not clearly fit into one of the three exceptions. *Id.* at 12, 15.

Because Dr. Steinhorn gave undisputed testimony that Lance might survive for "decades" with treatment, the court held that the language of the futility exceptions did not apply to Lance. *Id.* at 11-15. See also 42 U.S.C. § 5102 (3)(b)&(c) (Supp. III 1985); MINN. STAT. § 260.015, subd. 10(e)(2)&(3) (1986). Judge Harrelson's judgment relied on the Interpretative Guidelines accompanying 45 C.F.R.§ 1340 App. (1985). *Steinhaus* Order at 12-15.

The court went on to hold that it was not clear whether the child met the "chronically and irreversibly comatose" exception. *Id.* at 11. The court's recollection of the testimony did not support the finding, but the court went on to state further testimony and a review of the transcript may be in order. *Id.* at 11-12. See also 42 U.S.C. § 5102 (3)(a) (Supp. III 1985); MINN. STAT. § 260.015, subd. 10(e)(1) (1986).

The court relied on definitions of "coma" and "persistent vegetative state." A person in a coma is unresponsive and appears asleep. *Steinhaus* Order at 11-12. A person in a vegetative state is unresponsive but appears awake. *Id.* Although the level of consciousness is identical, the court held there is a difference. *Id.*

151. On a motion by Dr. D. Steinhorn and Amy Steinhaus for an order amending the Findings of Fact and Conclusions of Law and Order, the court found Lance to be "chronically and irreversibly comatose." *Steinhaus* Amended Order at 3. As such,
to the medical neglect statute permitted the legal custodian to withhold treatment, other than appropriate nutrition, hydration or medication, without running afoul of the law.152

The court held that the Steinhaus fact situation satisfied one of the statutory exceptions, namely, exempting the child from aggressive treatment.153 In actuality, the statute should never have been applied to this fact situation. The requirement of non-consent to treatment, constituting neglect, was absent.154 Since neither the mother nor the father had custody of the baby, neither was in a position to deny medical treatment, thereby medically neglecting their son. In fact, the state agency charged with protecting medically neglected children brought the petition to provide only comfort care.155 Absent medical neglect, the statute does not operate to require all medical treatment available. Procedurally, this was not a “Baby Doe” case.

From the confusion in the Steinhaus case,156 it is apparent that substantive ambiguity and procedural laws which plagued the initial “Baby Doe” Rule I are unresolved after almost five years of governmental modification. Governmental intervention has failed to clarify issues, and promulgated procedures do not reflect the stated legislative purpose. As a result, parents, already traumatized by the birth of

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152. Steinhaus Amended Order at 3.
153. Id.
154. A child must be “neglected” under Minnesota Statute section 260.15, subdivision 10 to warrant intervention by the Welfare Department or the Commissioner. Lance was not denied any medical care until the court allowed his guardian ad litem to make the decision. Investigation by the local welfare department is required before legal proceedings can be instituted. See Minn. Stat. § 626.556, subd. 10(c) (1986). In this case, it was the local welfare agency who petitioned the court to provide only appropriate nutrition, hydration, and medication in a situation where any appreciation or expression of life was impossible. Obviously, the welfare agency felt it was a valid request or they would not have filed the motion. Special interest group intervention mushroomed the significance of the case and brought it to the attention of the media. As a result, the family court judge in rural Minnesota was forced to adjudicate on an ambiguous, controversial and emotional issue of first impression. Interview with Dana Johnson, M.D., Director of the University of Minnesota Hospitals and Clinics NICU, in Minneapolis, Minnesota (Oct. 1, 1986).
155. Supra note 154.
156. See supra notes 150-55.
a critically ill and disabled child, have been subjected to legal harass-
ment.\textsuperscript{157} Given other state and societal protections for handicapped
children, a withdrawal by the government from all but minimal par-
ticipation in treatment decision-making will prevent the further wast-
ing of resources and time.

III. THE PARENTAL UNIT AS THE PRIMARY LOCUS FOR MEDICAL
DECISION-MAKING

The primacy of the parents in the medical decision-making process
involving critically ill and disabled infants should be maintained for
several reasons. First, a balancing process is used to determine the
most compelling constitutional interest. A parent's right to make
family decisions is a fundamental right to be protected provided the
child is given basic comfort care. Second, the very nature of the fed-
eral government is ill-suited to involvement in medical decision-

making in complex situations. The rules promulgated by the federal
government are too general to deal with particular situations and are

subject to influence by special interest groups. Third, involvement
at the state level has not eliminated all the problems specific to state
attempts to regulate. State regulation should be limited to providing
for parental informed consent in medical decisions and warmth, nu-
trition, hydration, and appropriate medication for all infants. Fi-

nally, intra-hospital mechanisms presently exist to maintain a
standard of care acceptable to the public at large.

A. Balancing the Constitutional Interests

Parents have a fundamental right to make medical decisions con-

cerning their incompetent, critically-ill, and disabled infants. In re-
cent years, the United States Supreme Court has recognized that
persons possess fundamental rights in certain areas of life under the
constitution. In \textit{Griswold v. Connecticut,}\textsuperscript{158} the Court established the
fundamental right to make family planning decisions without state
interference.\textsuperscript{159} The Court found this freedom present in the pen-
umbral right to privacy emanating from the first, third, fourth, fifth,
and ninth amendments.\textsuperscript{160} Society has long enforced parents' right
to make family decisions to protect family strength, unity, and paren-

\textsuperscript{157} Although four out of five courts found their decision reasonable, parents of
Baby Jane Doe were forced to defend that decision in three state courts and two
federal courts. In addition to the emotional distress, Baby Jane Doe's parents had to
suffer the financial consequences of extensive litigation at a time when they were
already facing large medical bills. \textit{University Hosp.}, 729 F.2d at 144.
\textsuperscript{158} 381 U.S. 479 (1965).
\textsuperscript{159} \textit{Id.} at 485-86. The court held state interference in a married couple's use of
birth control was unconstitutional. \textit{Id.}
\textsuperscript{160} \textit{Id.} at 483-84.
Interference with any of an individual’s fundamental rights under the Constitution is allowed only when a strict standard of review has been satisfied. Under this strict standard of review, state interference is tolerated only when it stems from a compelling state interest accomplished through a legislative enactment that is narrowly drawn to express only the legitimate state interests at stake. Because of this strict standard of review, family decisions on child rearing have been upheld even when they conflicted with the state’s interest.

The Supreme Court’s decision in Roe v. Wade indicates that parents’ rights to make decisions are not absolute. Roe recognized the competing interest of a child’s right to life had to be balanced against the mother’s right of choice, the mother’s right to life, the impact on the family of an unwanted child and even the impact upon the child if it were born as an unwanted child. The constitutional right to an abortion was limited to the first trimester of pregnancy when neither the state nor the medical profession had an interest in the decision to carry a fetus to term. During the second and third trimesters, the health of the mother and the state’s interest in the life of the fetus became compelling, allowing state regulation of abortion.

The Roe case has important implications for medical decision-making in the NICU. Concluding that the life of the fetus was distinct from the life of the mother and the family, Roe pointed out the necessity for a balancing approach. Parental rights should be balanced against the interests of the child and the responsibilities of the state. In the NICU setting, parents, as compared to the state or physicians, are most intimately and permanently affected by the life or death of a child. Protection of a parental decision concerning the medical treatment of a child is a personal right fundamental to the concept of ordered liberty. Over the years, the United States

163. See Griswold, 381 U.S. at 485.
164. See Wisconsin v. Roder, 406 U.S. 205, 234-36 (1972) (Amish parents permitted to take children out of school before they reached the state’s permissible age of removal).
166. Id. at 153.
167. Id. at 164.
168. Id. at 164-65.
169. See id. at 153.
Supreme Court has continued to hold sacred privacy issues that involve family decisions.\(^{172}\)

The Court recently affirmed the *Roe* decision in *Thornburgh v. American College of Obstetricians and Gynecologists*.\(^{173}\) The Supreme Court continues to protect parental decision-making in instances where a potentially viable fetus with chances for an excellent quality of life is terminated to preserve the family integrity. A parental decision aimed at maintaining the family structure and preventing the prolonged suffering of a child with little chance for any appreciation of life is likewise a privacy interest deserving of protection.

Rights obtained as a result of a privacy interest are not absolute.\(^{174}\) They are qualified and must be considered against important state interests in regulation.\(^{175}\) State interests in the protection of health and medical standards at some point become dominant.\(^{176}\) However, like privacy interests, the state’s interest in the preservation of life is not absolute.\(^{177}\) The welfare of the child must also be considered. “Children are not property whose disposition is left to parental discretion without hindrance.”\(^{178}\) Parental decisions that amount to abuse or neglect are outside the sphere of constitutionally protected parental rights.\(^{179}\) Governmental attempts to define these terms in the context of treatment decisions for critically ill and disabled infants, however, have been unsuccessful.

Judicial action has consistently affirmed the primacy of the family in conjunction with the physician in medical decision-making.\(^{180}\) The Supreme Court’s opinion in *Bowen v. American Hospital Association*\(^{181}\) once again invalidated federal regulations which encroached upon the autonomy of family decision-making in life prolonging medical treatment.\(^{182}\) Despite this, the current regulations do not allow for non-treatment decisions in all the situations where they


\(^{174}\). Griswold, 410 U.S. at 155.

\(^{175}\). *Id.*

\(^{176}\). *Id.*

\(^{177}\). *See American Academy of Pediatrics*, 561 F. Supp. at 403.


\(^{180}\). *See supra* notes 71-99 and accompanying text.

\(^{181}\). 106 S. Ct. 2101 (1986).

\(^{182}\). *Id.* at 2101. *See also supra* notes 92-100 and accompanying text.
may be justifiable.\textsuperscript{183} Judicial action may be required to mandate further revisions, probably as further cases present themselves.\textsuperscript{184}

B. Ineffectiveness of the Federal Government

The legislative and executive branches at both the state and the federal levels have been unsuccessful at drafting workable standards in the area of medical decision-making for critically ill and disabled infants. Their functions within the governmental scheme as well as their very natures make them ineffective in promulgating regulations concerning the treatment of critically ill and disabled infants. The lawmaking powers of the country are delegated to the legislative branch,\textsuperscript{185} while the executive branch is charged with carrying the laws into effect and securing their observance.\textsuperscript{186} Both branches are required to make decisions on a myriad of topics daily. Individual members are not experts on all subjects and must rely, on outside sources for guidance.

Federal agencies acknowledge that they are inexperienced in the area of medical decision-making.\textsuperscript{187} Medical complexities in these cases are highly technical and best left to evaluation by the medical professionals who encounter these cases on a regular basis as opposed to the majority who encounter these cases only on an emergency or personal basis.\textsuperscript{188}

In order to ensure adequate representation of the people in the operation of government, legislative and administrative bodies are large in size. Because of this large size, compromise is required in order to incorporate all opinions and concerns. Goals may be lost in conciliatory or vague language. Complicated procedures involving multiple agencies are developed to satisfy all factions participating in the decision. The Lance Steinhaus situation\textsuperscript{189} resulted from vague language and complicated procedures emanating from state and federal legislative and administrative bodies.\textsuperscript{190}

Executive and legislative branches, and the administrative agencies carrying out their mandates, are ill-equipped for treatment decision-making because they are subject to political and special interest group pressure. Interest group pressure was evident in the com-

\begin{itemize}
\item \textsuperscript{183} See Weir, *When Is It Justifiable Not to Treat?*, SECOND OPINION—HEALTH, FAITH AND ETHICS 42, 42-44 (1986).
\item \textsuperscript{184} See id. at 60.
\item \textsuperscript{185} BLACK'S LAW DICTIONARY 810 (5th ed. 1979).
\item \textsuperscript{186} Id. at 510.
\item \textsuperscript{187} See Malcolm, "Baby Doe" Truly a Case of the '80s, St. Paul Pioneer Press & Dispatch, June 15, 1986, G1, col. 4.
\item \textsuperscript{188} S. JORDAN, supra note 6, at xiii.
\item \textsuperscript{189} See supra notes 147-55 and accompanying text.
\item \textsuperscript{190} See supra note 131.
\end{itemize}
ment process surrounding both "Baby Doe" Rules II and III. Elected officials clearly felt pressure from pro-life voters in promulgating laws upholding a "vitalistic" view.

The stated goals of federal regulations and other federal actions are inconsistent. Recent and proposed cuts in federal health care and social welfare programs jeopardize continuing care for those infants who finally leave intensive care units with severe disabilities. Whether a handicapped child maximizes his or her potential depends on what resources are available. A strong network of services providing custodial, medical, rehabilitative and educational support for handicapped infants bolsters claims that such infants will benefit from neonatal intensive care. Mandating care for most ill infants is inconsistent with the policy seeking to dismantle many of the services on which handicapped individuals will later depend.

This inconsistency supports the contention that presidential directives, congressional action, and federal regulations are in response to political strategies to pacify right-to-life and disability groups. If the goal was truly to eliminate discriminatory treatment of handicapped individuals, increased funds for welfare programs would have been provided.

C. Problematic State Involvement

State child protection service agencies enforcing medical treatment of handicapped infants are an improvement over federal "Baby Doe squads." However, attempts to control medical decision-making through child abuse and neglect laws are not ideal. Numerous procedural and systematic problems have been documented de-

191. See supra notes 62 and 116 and accompanying text.
192. Moskop and Saldanha, supra note 11, at 13.
193. Id.
194. See L.A. Daily J., June 16, 1986, at 2, col. 5 ("[a]lled with the administration are the increasingly assertive 'pro-life' groups that have struggled to circumvent or overturn the court's 1973 abortion rights decision and more recently have championed a movement to prevent what they believe to be the common practice of withholding life-prolonging treatment of handicapped newborns"). See also Vitiello, The Baby Jane Doe Litigation and Section 504: An Exercise in Raw Executive Power, 17 CONN. L. REV. 95, 95-97 (1984) (discussing the Reagan Administration and its political allies in the right-to-life movement).
195. See supra notes 192-93 and accompanying text.
196. Numerous questions were raised by the Minnesota Regional Committee for Neonatal Life Support Policy concerning procedures:
(1) What is the rule of the juvenile court?
(2) What are the implications if the mother is a minor?
(3) What constitutes a valid report? Current state procedures require certain information from the reporter to weed out "crank" reports; are these applicable to medical neglect reports?
(4) How best to provide feedback to the reporters? The reporting law authorizes the CPS agency to provide a summary of the disposition of the re-
spite the release of individualized state guidelines.197

Like federal actions, state responses are also inconsistent with stated goals. If the rights of disabled infants and the sanctity of life are compelling state interests, the state should be willing to pay for those interests.198 In Minnesota, the parents of critically ill and disabled children can be made to bear the costs, even in the absence of any parental right.199

The state's interest in this area should be restricted to providing for informed consent for parents and non-burdensome, symbolic care for infants which upholds public policy. Ambiguous language supposedly defining when treatment is not required should be eliminated.200 Language providing for warmth, nutrition, hydration, and appropriate medication for all infants should be maintained.201 Such an enactment is narrowly drawn to uphold medical standards and protect the child from neglect. In addition, the language suggested upholds the public policy against starving children to death.202 Parental autonomy in medical decision-making is maintained while the state's interest in protection of the child is maintained.

Advisory committees may provide the most discrete enforcement of stated federal regulation goals. Bioethics committees have been shown to maintain the primacy of the parents in the decision-making process.203 In addition, they are also already in place and functioning in many institutions, thereby decreasing the time delay in achiev-

198. See supra notes 139-42 and accompanying text.
199. See MINN. STAT. § 256.87, subd. 1 (1986).
200. See MINN. STAT. § 144.651, subds. 9, 10, 12 (1986).
201. These terms can be concertedly defined. While "appropriate medication" has been a source of confusion in the past, the definition either includes antibiotics or it does not. This is a much easier determination to make than whether treatment is "futile." Medications to control seizures and secretions and pain are well accepted already. Lecture by Dana Johnson to the Neonatal and Pediatric Special Interest Group (Feb. 18, 1987).
202. Id. Dr. Johnson suggested avoiding the legislation of both medical and ethical practice.
ing productive operation. Twenty-two percent of Minnesota hospitals have ethics committees; 33 are established committees and six more are in various stages of formation. Ethics committees are most likely to be found in large hospitals; 89% of hospitals with 200 or more beds have ethics committees; 50% of the ethics committees are in hospitals with religious affiliation. Minn. Network for Institutional Ethics Committees, 6 ETHICS NEWS 1, Jan., 1986.

205. See Annas, Refusal of Lifesaving Treatment for Minors, 23 J. FAM. L. 217 (1985). This author feels that committee decision-making, at least in areas of life and death is the worst kind available. Two outcomes are possible. First, a pattern may develop, as more and more decisions are made, whereby one can begin to articulate the principles that the committee is applying to make its decision. If principles can be articulated, then a committee is not needed to apply them. Alternatively, no pattern will develop and the committee will be making decisions arbitrarily. Id. at 229.


207. See E. Van Allen, supra note 115, at 1.

208. BLACK’S LAW DICTIONARY 318 (5th ed. 1979).

209. See, e.g., Bowen, 106 S. Ct. at 2114; University Hosp., 729 F.2d at 144; Weber, 60 N.Y.2d at 208, 456 N.E.2d at 1186, 469 N.Y.S.2d at 63, aff’d, 95 A.D.2d at 587, 467 N.Y.S.2d at 685.

210. S. JORDAN, supra note 6, at xiii.

211. Moskop & Saldanha, supra note 11, at 11.

NICUs are the locus for the great majority of treatment decision-making concerning critically ill and disabled infants. Smaller hospitals routinely transfer their critically ill patients to larger tertiary care centers which are better able to supply the technology and skilled personnel to care for these patients. Likewise, critically ill and disabled patients are transferred to NICUs which exist almost exclusively in tertiary care centers.

A network of medical professionals and support staff are involved in the care of any patient in a tertiary care center. Ethics committees are in place in eighty-nine percent of tertiary care centers in Minnesota. The very nature of the tertiary care center provides a set of checks and balances to ensure protection of critically ill and disabled newborns from medical neglect.

Reports of alleged medical neglect of critically ill and disabled infants have been few in number. Of those reported, all have been unfounded. Given the very rare occurrence of even a suspected problem, the state's interest does not rise to the compelling level, justifying the vague and ambiguous statutory exceptions. Unfortunately, parents of critically ill and disabled infants continue to face legal harassment as a result of the administrative regulations prompted by executive and legislative mandate addressing a problem that does not exist.

**CONCLUSION**

Parents are in the best position to make decisions concerning the

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213. Tertiary care centers are equipped to provide advanced life support and highly complex treatments and surgery. In addition to possessing highly technical capabilities, teaching and researching are part of the program. Tertiary care centers are generally large by necessity to accomplish these goals.

214. The large size and capability of caring for the most complex patients requires a large medical support staff. A survey of the medical staffing of the NICUs in the Twin Cities revealed a minimum of two and a maximum of eight neonatalists plus two to seven residents and interns. The residents and interns manage the care of NICU patients under the direction of the staff neonatalists. Nursing staffs of sixty to one hundred provide direct patient care. All hospitals have social work and patient relation departments as well to serve patients and their families.


216. Two cases have been reported since the rules went into effect on Oct. 9, 1985, but none in the last year. Lecture by Dana Johnson to Neonatal and Pediatric Special Interest Group (Feb. 18, 1987) (discussing the legal and ethical issues of Baby Doe legislation).

217. One case involved a child more than one year old and, therefore, by definition, did not invoke Baby Doe regulation. A second case was parent neglect rather than medical neglect. Id.

218. See supra note 157 and accompanying text.
medical treatment of their critically ill and/or disabled infant. The parents are most intimately and permanently affected by the treatment decision whether it results in the life or death of a child. Emotional, physical and financial effects will be felt by the family no matter what decision is made. This parental right is constitutionally protected as a privacy interest.219 "[S]o long as the child is part of a viable family, his own interests are merged with those of the other members."220

Judicial fiat has affirmed the strict protection of privacy interests as well as the primacy of the family in medical decision-making.221 The executive and legislative branches of the government continue to promulgate regulations undermining this position, apparently believing their judgment superior to the parents and the medical professionals directly involved.222 The infrequent incidence of withholding treatment nationwide emphasizes societal constraints. These constraints maintain a standard of care for these critically ill and disabled newborns that we can all live with.223

Despite attempts at clarification, the regulations remain ambiguous in structure. In attempts to eliminate the ambiguity, parents, already suffering the anguish of having a severely handicapped child, are forced to defend themselves in court.224 In addition to the emotional distress, parents are suffering legal harassment and the financial consequences of extensive litigation when they were already facing large medical bills.225

As mandated by the Supreme Court, state legislation and federal regulation should be amended so that parents regain their primacy in the decision-making process.226 The state’s legitimate interest in a child’s welfare can be unambiguously expressed and narrowly drawn, thereby upholding public policy without disrupting the parental decision-making process.

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219. See supra notes 158-68 and accompanying text.
221. See supra notes 96-104 and 161-82 and accompanying text.
223. See E. Van Allen, supra note 115, at 1.
224. See supra note 160 and accompanying text.
225. Id.
226. Bowen, 106 S. Ct. at 2123.