THE CHILD ABUSE AMENDMENTS OF 1984:  
THE INFANT DOE AMENDMENT

During the 1960's, a growing public awareness led to state laws regarding child abuse.1 Today all fifty states have statutes, most of which are reporting laws which encourage or mandate the reporting of suspected child abuse.2

In 1974, the federal government felt a need for further action and passed the Child Abuse Prevention and Treatment Act.3 This Act has been amended several times, most recently in 1984.4

This comment focuses upon a new area of child abuse prevention, that of the withholding of medical treatment from disabled newborns. Section one discusses the increased public awareness of the extent of this practice. Section two presents the initial government response to widespread publicity of the practice. Section three examines the Congressional response to this problem via the Child Abuse Amendments of 1984.5 Due to the widespread publicity of one particular case, In re Infant Doe, the portion of the Amendment concerning the withholding of medical treatment from disabled newborns is commonly referred to as the Infant Doe Amendment.6 The intent of Congress was to

3Child Abuse Prevention And Treatment Act, Pub. L. No. 93-247, 88 Stat. 4 (1974) (amended 1978, 1984) (current version at 42 U.S.C. § 5101). This Act established the National Center on Child Abuse and Neglect to conduct studies and award demonstration and research grants to states in an effort to develop new methods of identifying, treating, and preventing child abuse and neglect. State involvement is voluntary; however, as a condition of receiving federal assistance under the Act, states must comply with the requirements of the Act.
5The Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984) (to be codified at 42 U.S.C. §§ 5101-5107). (The 1984 amendment addressed four major issues: (1) In Title I there is an extension of existing child abuse and treatment legislation (codified at 42 U.S.C. §§ 5101-5107); (2) In Title I there is the addition of a new section regarding the withholding of medical treatment from disabled newborns (codified at 42 U.S.C. §§ 5101-5107); (3) In Title II there is an extension and additions to adoption legislation (codified at 42 U.S.C. §§ 5111-5113); (4) In Title III there is the addition of a new section concerning family violence prevention and treatment (codified at 42 U.S.C. §§ 10401-10412). See generally 130 CONG. REC. S12382, 12387-90 (daily ed. Sept. 28, 1984) (for a discussion by Senator Cranston on changes to Title I and Title II); Id. at S12384-85 (for a discussion by Senator Kennedy on the new Title III).
6See In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Ind., Apr. 12, 1982). This case probably more than any other started legislative action on the issue of withholding medical treatment, and for that reason throughout the Congressional debates, this portion of the amendments was referred to as the "Infant Doe" amendment. See generally, 130 CONG. REC. H376 (daily ed. Feb. 2, 1984); 130 CONG. REC. S9307
establish a national policy regarding the ethical standards to be considered, the person(s) to be the primary decisionmaker, and the laws to be applied. In conclusion, the comment examines whether the Infant Doe Amendment accomplishes the intent of Congress.

I. PUBLIC AWARENESS

The Infant Doe Amendment is not the result of a new phenomenon; permitting unwanted and/or seriously ill or disabled newborn infants to die has occurred throughout history. Instead, it is the result of a new public awareness and concern over the very complex moral issues surrounding nontreatment of disabled newborns. This new awareness is the result of publicity regarding the scope and the acceptance within the medical community of the practice of withholding medical treatment and of extensive media coverage of recent court cases concerning nonconsent by parents.

In October of 1973, Doctors Raymond S. Duff and A.G.S. Campbell studied the hospital records at Yale-New Haven Hospital to determine the extent to which death in infants had resulted from withdrawing or withholding treatment. Their findings indicated that of 299 consecutive infant deaths occurring in the special care nursery during the thirty months ending June 30, 1972, forty-three cases (fourteen percent) were related to withholding treatment. Specific incidents across the country have received widespread public attention.

A survey conducted in 1977 examined the attitudes and practices of pediatric surgeons and pediatricians with respect to some of the difficult ethical issues that arise in neonatal practice. This survey revealed the acceptance...
within the profession of withholding treatment. Among the pertinent results of the survey were:

(1) 76.8% of the pediatric surgeons and 49.5% of the pediatricians would acquiesce in the parents' decision to refuse consent for surgery in a newborn with intestinal atresia and Down's syndrome.

(2) 23.6% of the pediatric surgeons and 13.2% of the pediatricians would encourage parents to withhold consent and 51.7% of the former and 38.4% of the latter would respect whatever decision parents made concerning treatment of an infant with duodenal atresia and Down's syndrome.

(3) Of those that accepted withholding lifesaving surgery in the last example, 63.3% of the surgeons and 42.6% of the pediatricians would also stop supportive treatment including intravenous fluids and nasal gastric suction.

(4) 60.7% of the pediatric surgeons and 80% of the pediatricians felt that children with Down's syndrome "are capable of being useful and bringing love and happiness into the home." 62% of the group would nevertheless acquiesce in the parents decision to withhold lifesaving surgery for atresia. Only 7% would seek a court order for surgery.

In addition, recent court cases dealing with the issue of parental nonconsent for corrective treatment have aroused extensive public attention. Probably the best known is In re Infant Doe. On April 19, 1982, a baby known only as "In-

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which 190 were returned). Contra, Strain, The Decision to Forego Life Sustaining Treatment for Seriously Ill Newborns, 72 PEDIATRICS 572 (Oct. 1983).

Intestinal atresia is a congenital obstruction of the intestine at any level due to lack of continuity of the lumen. See DORLAND'S MEDICAL DICTIONARY, 135 (26th ed. 1981).

Down's syndrome is a condition characterized by a small anteposteriorly flattened skull and short flat-bridged nose, associated with a chromosomal abnormality. Results in moderate to severe mental retardation. Also called mongolism. Id. at 1290.

See Shaw, Ethical Issues, supra note 11 at 590.

Duodenal atresia is a congenital absence or occlusion of a portion of the duodenum (first or proximal portion of small intestine) and is associated with Down's syndrome. See DORLAND'S MEDICAL DICTIONARY at 135.

See Shaw, Ethical Issues, supra note 11, at 591-92. It should be noted that only 3.4% of the pediatric surgeons and 15.8% of the pediatricians would seek a court order to overrule parental decisions.

See Shaw, Ethical Issues, supra note 11 at 592-93.

Atresia is a congenital absence or closure of a normal body orifice. See DORLAND'S MEDICAL DICTIONARY at 135.

See Shaw, Ethical Issues, supra note 11, at 595.

fant Doe was born with Down’s syndrome and esophageal atresia with associated tracheoesophageal fistula. The latter condition, which was correctable, is fatal if not surgically repaired. After consulting with the treating physician, the parents refused to consent to corrective surgery or intravenous feeding and Infant Doe died of starvation six days later.

Prior to Infant Doe’s death, the hospital sought legal advice and the issue of withholding corrective treatment went to court. Neither the Monroe County Circuit Court nor the Indiana Supreme Court would overrule the parents’ decision to withhold treatment. Infant Doe died while his guardian ad litem was on the way to appeal the case to the United States Supreme Court.

II. Initial Government Response

Infant Doe’s nontreatment was not the only such incident to reach the courts and/or media. However, the national coverage it received resulted in the federal government’s first reaction to this issue. The initial response came from the White House in the form of a memorandum issued by President Reagan on April 30, 1982, just fifteen days after Infant Doe’s death. The memo instructed the Secretary of the Department of Health and Human Services (HHS) to notify health care providers that section 504 of the Federal

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21 Esophageal atresia with tracheoesophageal fistula is a congenital defect in which the esophagus is connected with the trachea. Repeated aspiration and gastroesophagotracheal reflex cause rapidly progressive respiratory distress and the infant will die if left untreated. See A. Rudolph, Pediatrics 1015-17 (16th ed. 1977).

22Id., corrective surgery is routinely performed with success. See also Pless, Correspondence: The Story of Baby Doe, 309 NEW ENG. J. MED. 664 (Sept. 1983). Dr. Pless performed the autopsy on Infant Doe and reported “an infant with obvious Down’s syndrome and reparable esophageal atresia and tracheoesophageal fistula . . .” (emphasis added).

23In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Ind., April 12, 1983) cert. denied, 104 S. Ct. 394 (1983). See Kuzma, supra note 20, at n.7, reports of the Indiana Supreme Court decision in Bloomington Sunday Herald Times, Apr. 10, 1983, at 1, col. 1. Little is known about this case or the subsequent appeal to the Indiana Supreme Court because the medical records and court proceedings were sealed by the court. Information regarding the case is limited to newspaper reports, correspondence with the attorneys involved, and the Chief Justice of the Indiana Supreme Court. See also Wash. Post, Apr. 16, 1982, at A16, col. 1; Bloomington Herald-Telephone, Apr. 16, 1982, at 1, col. 1; Id., Apr. 20, 1982, at 1, col. 5; Indianapolis Star, Apr. 16, 1982, at 1, col. 4.

24It should be noted that while Infant Doe was allowed to starve to death during the court proceedings, there were people willing to adopt him to save his life. However, apparently this did not matter to the court. See 130 CONG. REC. H376, 394 (daily ed. Feb. 2, 1984) (Rep. Hyde).

25Weber v. Stony Brook Hosp., 95 A.D.2d 587, 467 N.Y.S.2d 685 (N.Y. App. Div. 1983) (rev’d the lower court’s ruling requiring surgery); aff’d, 60 N.Y.2d 208, 456 N.E.2d 1186 (1983) (aff’d for different reasons). This case also received scrutiny by the commentators, e.g., Kerr, Reporting the Case of Baby Jane Doe, 14 HASTINGS CENTER REP. 7 (Aug. 1984); see also Brown & Triuitt, Euthanasia and the Right to Die, 3 OHIO N.U. L. REV. 615, 632-34 (1976) (hereinafter cited as Brown & Triuitt) (Reports on two cases: Maine Medical Center v. Houle, No. 74-145 (Super. Ct. Cumberland Cty., Me., Feb. 14, 1974) (male infant with multiple disabilities, parents refused to consent to corrective surgery overruled by the court); Brown & Triuitt also discuss an unreported case from Detroit in which the court ordered treatment for a child with disabilities similar to Infant Doe’s, Down’s syndrome and duodenal atresia); Note, Birth-Defective Infants: A Standard for Non-Treatment Decisions, 30 STAN. L. REV. 599, 601 n. 13 (1978) (hereinafter cited as Note, Birth-Defective Infants); Stinson & Stinson, On the Death of a Baby, 244 ATL. MONTHLY 64 (1979) (Parents tell their story on the death of their son.)

Rehabilitation Act of 1973\textsuperscript{27} "forbids recipients of federal funds from withholding from handicapped citizens, any benefits or services that would ordinarily be provided to persons without handicaps."\textsuperscript{28} On May 18, 1982, the President’s instructions were carried out when HHS issued a "Notice to Health Care Providers."\textsuperscript{29}

HHS followed this notice with the issuance of regulations on March 7, 1983, which required hospitals receiving federal funds to establish a twenty-four hour "Handicapped Infant Hotline" and to post signs in the delivery rooms, pediatric wards, nurseries, and neonatal intensive-care units which read: "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law."\textsuperscript{30} HHS based its authority to issue the regulations on section 504 of the Rehabilitation Act of 1973.\textsuperscript{31} Reaction to the regulations by the medical profession was quick and negative. The American Academy of Pediatrics brought suit in the district court of the District of Columbia and was successful in preventing implementation of the regulations.\textsuperscript{32}

HHS revised this regulation and on July 5, 1983, issued a new proposed rule which only slightly changed the March 7 version, but did provide for a sixty day comment period.\textsuperscript{33} The proposed regulation resulted in nearly 17,000 comments and based on its analysis of these comments, HHS modified the July 5 proposal and issued a final regulation on January 12, 1984.\textsuperscript{34} This new

\begin{footnotes}
\item[29] 47 Fed. Reg. 26027 (1982) (Notice from Betty Lou Dotson, Director, Office of Civil Rights for HHS to "Health Care Providers" May 18, 1982). The notice in pertinent part stated:
Under section 504 it is unlawful for a recipient of Federal financial assistance to withhold from 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 the treatment or nutritional sustenance medically contraindicated.
\item[31] American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983). Judge Gesell held the regulations were invalid as an arbitrary and capricious agency action because there was no evidence showing the agency considered the possible disruptive effects of the hotline and no attempt was made to address the issue whether termination of treatment might be appropriate in certain cases. Also the regulations were invalid due to the failure to follow procedural requirements in its promulgation as set out in the Administrative Procedure Act, 5 U.S.C. §§ 553b & 553d, 706 (2) (A). HHS usually satisfies this Act by publishing new regulations in the Federal Register, and soliciting comments from interested parties. In dictum, Judge Gesell questioned § 504 as valid authority and raised the constitutional issue of parental autonomy in that the regulations to some extent eliminated the role of the infant’s parents in choosing medical treatment.
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\item[34] American Hosp. Ass’n v. Heckler 585 F. Supp. 541 (1984). (The Jan. 12 rule attempted to deal with some of
regulation was again met with criticism and a successful court challenge by the American Hospital Association and the American Medical Association. HHS has appealed this decision but as it currently stands, there are no HHS regulations governing nontreatment of disabled newborns.

III. CONGRESSIONAL RESPONSE

Handicapped newborns remained in need of legislative protection because, like any other segment of our society, they are entitled to protection from the “deprivation of life.” Each year approximately 30,000 severely disabled infants are born in the United States, and with the continuing advances in neonatology, genetics, and pediatric surgery, this number can only increase. At the same time, because of the complexity of the issue and a lack of legislative guidance, the courts, parents, and physicians were making inconsistent decisions regarding the ethical standards to be considered, the objections found by Judge Gesell. The notice requirement was changed, HHS tried to better identify the infants covered by the rule and justified its authority under § 504 of the Rehabilitation Act of 1973. The new rule included a model for Infant Care Review Committees and also set up HHS investigation guidelines).

For discussions pertaining to the HHS regulations see generally, Kuzma, supra note 20; Weir, supra note 20; Strain, The American Academy of Pediatrics Comments on the “Baby Doe II” Regulations, 309 NEW ENG. J. MED. 443 (Aug. 1983); Annas, Disconnecting the Baby Doe Hotline, 13 HASTINGS CENTER REP. 14 (June, 1983); Berseth, A Neonatologist Looks at the Baby Doe Rule: Ethical Decision by Edict, 72 PEDIATRICS 428 (Sept., 1983); Murray, At Last, Final Rules on Baby Doe, 14 HASTINGS CENTER REP. 17 (1984); Johnson & Thompson, The ‘Baby Doe’ Rule: Is It All Bad?, 73 PEDIATRICS 729 (May, 1984).


What factors should the decision maker be allowed to consider when deciding whether to withhold treatment? Three different views have developed, each with its supporters. One view, the “sanctity of life” ethic, requires maximum treatment in all cases, regardless of the possible outcome. Another view, the “quality of life” ethic, allows consideration of the predicted quality of life of the infant and the resulting burdens on family and society. Lastly, the “medically beneficial” ethic limits the focus to the child’s medical condition and the feasibility of treatment. It allows for those cases where treatment would be futile or inhumane. See text infra, pp. 8-11 and accompanying notes for a discussion of these views.
person(s) to be the primary decisionmaker and the laws to be applied. Thus, the infant’s life depended upon the jurisdiction or hospital in which he is born.

A. The New Requirements

Congress recognized the need for a national policy regarding the nontreatment issue. To satisfy this need, Congress, via the Child Abuse Amendments of 1984, added a new clause (K) to section 4(b) (2) of the Child Abuse Prevention and Treatment Act. Section 4(b) (2) authorizes grants to carry out child abuse prevention and treatment programs and lists the requirements a state must meet to qualify for these grants. Specifically, section 4(b) (2) (K) requires states which receive federal child abuse prevention grants under the Act, to incorporate procedures and/or programs, within the state child protective service system, to respond to reported cases of medical neglect. The term medical neglect, as used in the Act, includes but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition. These procedures and/or programs must be operational by October 9, 1985 and provide for:

4The decision could be made by the parents, the treating physician(s), an infant care review committee, or the court. See Shaw, Ethical Issues, supra note 11, at 594 (half of the surveyed group felt parents should decide, one-third felt either the physician or an infant care review committee should decide). Courts faced with the issue have resulted in conflicting holdings, See e.g., In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Ind., Apr. 12, 1982) (held that parents should decide); contra Maine Medical Center v. Houle, No. 74-145 (Super. Ct. Cumberland County, Me., Feb. 14, 1974) (parents refused consent for corrective surgery, the court intervened and ordered surgery).

4Under existing law, does the right of choice even exist for the parents and physicians? See Robertson, supra note 7 (He argues that parents who withhold ordinary care from a disabled newborn, as well as physicians, nurses and hospital officials who acquiesce to parents’ decisions, risk criminal liability ranging from homicide to neglect and violation of child abuse reporting laws); contra, see Note, Birth-Defective Infants, supra note 25 (argues the choice to withhold treatment in certain situations is legal); see generally Comment, Defective Newborns, supra note 20 (for a discussion of inconsistent application of legal principles by the courts faced with the issue).

4The theme in the Congressional debates was the need for a national policy because of the inconsistency that had developed regarding the Infant Doe issue, see e.g., 130 CONG. REC. H376, 379 (daily ed. Feb. 2, 1984) (Rep. Murphy in explaining to the House the need for the Amendment “...in an attempt to maintain uniformity, we have given legislative authority to the States to address [the issue of withholding treatment]. Courts have no legislative guidance and have thus been handing down different decisions in various sections of the country.”)


4See Joint Statement, supra note 43, at 2970. (States that pertinent existing requirements of 42 U.S.C. § 5103(b) (2) such as reporting mechanisms and provisions for the appointment of a guardian ad litem are applicable to the new clause(K). For a complete list of requirements states must meet in order to qualify for assistance under the Act, see 42 U.S.C. § 5103(b) (2)).


4See, infra n. 69-84 and accompanying text for a discussion of the meaning of medically indicated treatment
(1) Coordination and consultation between the child protective services and designated individuals within the health care facilities;

(2) Prompt notification by designated health care personnel to child protective service systems of cases of suspected medical neglect; and

(3) Authority under state law for the state's child protective services system to pursue any legal remedies, including initiating court proceedings, to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.\(^\text{47}\)

The Infant Doe Amendment was the result of a substantial consensus among Congress, and most medical, professional and advocacy organizations which have an interest in the nontreatment issue.\(^\text{48}\) The Amendment generally followed the guidelines set forth by the *Principles of Treatment of Disabled Infants* issued in 1983 by a broad coalition of medical associations and advocacy organizations, including the American Academy of Pediatrics.\(^\text{49}\)

B. Ethical Standards

A key element of the nontreatment issue is the ethical standard to be followed in each instance. Congress had three alternative standards to consider when writing the legislation: (1) quality of life, (2) sanctity of life, and (3)

\(^{47}\)See, Child Abuse Amendments and Joint Statement *supra* note 45. The new (K) clause is the most important addition of the amendments, however, other changes were made to supplement and help in the enforcement of clause (K): (1) The Secretary of HHS must publish for public comment proposed regulations to implement clause (K) (49 Fed. Reg. 48160 (1984) (to be codified at 45 C.F.R. 1340) (proposed Dec. 10, 1984) and publish final regulations after comments are evaluated. (2) The Secretary must publish interim model guidelines to encourage the establishment within health care facilities of infant care review committees (49 Fed. Reg. 48170 (1984) (to be codified at 45 C.F.R. 1340) (proposed Dec. 10, 1984) and publish final model guidelines after comments are evaluated. (3) The Amendment requires the Secretary to provide directly or through grants or contracts with public or private nonprofit organizations, for training and technical assistance programs to assist states in satisfying the requirements of clause (K), also for establishing and operating national and regional clearinghouses to provide the most current information regarding medical treatment procedures and resources. (4) A new subsection 4(c) is added to authorize the Secretary to make additional grants to states for developing and establishing or implementing (a) the procedures or programs required under clause (K); (b) information and evaluation or training programs for parents, employees of child protective services programs and health care facilities; (c) programs to help coordinate necessary services to assist the families with disabled infants and facilitate adoption placement.

\(^{48}\)The groups who worked with Congress in developing the Infant Doe Amendment are: The American Academy of Pediatrics, American Hospital Association, Catholic Health Association, National Association of Children's Hospitals and Related Institutions, American College of Obstetricians and Gynecologists, American Nurses Association, American College of Physicians, California Association of Children's Hospitals, Nurses Association of the American College of Obstetricians and Gynecologists, American Association on Mental Deficiency, Association for Retarded Citizens (U.S.), Spina-Bifida Association of America, Downs-Syndrome Congress, People First of Nebraska, the Association for Persons with Severe Handicaps (TASH), Disability Rights Center, Operational Real Rights, Christian Action Council, and the National Right to Life Committee. A notable exception from the list is the American Medical Association. The AMA opposed the new legislation because it is against any type of definitive rules and regulations or definitive statutory language on this issue. The AMA wants only the doctors and parents involved in the decision and any type of government intervention is unacceptable. See 130 CONG. REC. S 9307, 9320-1 (daily ed. July 26, 1984) (Senators Hatch & Dodd explaining AMA's position); 48 Fed. Reg. 1622, 1624 (1984) (to be codified at 45 C.F.R. 84) final rules issued Jan. 12, 1984 (declared invalid in American Hosp. Ass'n v. Heckler, 585 F. Supp. 541 (1984)).

medically beneficial. Each standard will be examined.

A quality of life ethic places relative rather than absolute value on human life. This is the standard most often proposed to justify terminating or withholding treatment from disabled newborns. It is based on the theory that certain newborns may not have a "life worth living," and therefore, the type of life the infant will lead if treated should be predicted. The ethic assumes that if the potential quality of life is viewed as extremely poor, then death is preferable, and the infant is better off without treatment.

The essence of the quality of life argument is a proxy's judgment that no reasonable person would prefer life unless he could lead a "normal" life. The proxy is usually a normal adult who has led a life accustomed to his social and intellectual surroundings, who reasons it is better to die than to live a life without these basic human capabilities. However, as pointed out by Professor Robertson, this philosophy may be seriously flawed:

A standard based on healthy, ordinary development may be entirely inappropriate to this situation. One who has never known the pleasures of mental operation, ambulation, and social interaction surely does not suffer from their loss as much as one who has. While one who has known these capacities may prefer death to a life without them, we have no assurance that the handicapped person, with no point of comparison, would agree. Life, and life alone, whatever its limitations, might be of sufficient worth to him.

In addition, one of the more controversial aspects of this ethic is that it includes not only considerations of the infant's future prognosis, but also the impact of the infant's survival on his family and society as a whole. Proponents argue that the minimal benefit of treatment to infants incapable of full social and physical development does not justify the burdens that the care of these infants imposes on parents, family, health professionals and society in general. This argument assumes that because the infant will not lead a "normal" life, the costs or suffering of others is greater than the benefit of life to the child and, as a result, the child is asked to sacrifice his life to benefit others.

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50 See Nolan-Haley, supra note 7, at 9.
51 See Note, Birth-Defective Infants, supra note 25, at 620.
52 Id.
53 Robertson, supra note 7, at 254.
55 Robertson, supra note 7, at 254.
56 Id. at 255; See also Kuzma, supra note 20, at 384.
57 Robertson, supra note 7, at 255-56. Professor Robertson argues that this type of judgment requires a coherent way of measuring and comparing interpersonal utilities which has never been accomplished. "In the absence of principled grounds for such a decision, the social equation involved in mandating direct, involuntary euthanasia becomes a difference of degree, not kind, and we reach the point where protection of life depends solely on social judgments of utility."
Another criticism of this ethic is that the predictive criterion is too unreliable. Because the standard is so flexible, in proxy assessments of the quality of life, there is a great margin for error. Forecasting is not infallible, and since the decision is irreversible, the medical prognosis must be made with a high degree of certainty.

The sanctity of life ethic is at the opposite end of the spectrum. Absolute value is placed on life, and treatment is required in all cases if at all feasible to sustain life regardless of the outcome. Supporters believe that all living creatures contain a spark of the divine and are therefore sacred. The major criticism of this ethic is that requiring treatment in all cases can lead to inhumane consequences.

Congress has opted for a standard between these two extremes by specifying the circumstances under which it is permissible to withhold medically indicated treatment. By definition, treatment is generally considered medically indicated whenever the infant's life-threatening condition can be bettered or corrected. This is a strict standard which places a high regard on the infant's interest in life, but it is also flexible enough to recognize those cases where treatment can be justifiably withheld. This standard received broad backing within the medical community and closely resembles the standards previously proposed by The President's Commission for the Study of Ethical Problems in Medicine and Bio-Medical and Behavioral Research and The Principles of

31Id. at 255.
32See, e.g. Note, Birth-Defective Infants, supra note 25, at 623-24 n. 123 (five children were born with spina bifida, the physicians recommended against treatment. Four have completed several years in normal public school and the fifth is normal except for paralysis from the knees down).
33Criticisms of the quality of life ethic may be best summarized by a passage written by George Will: "The treatment should not be withheld to cause the death of a newborn because parents decide, on the basis of the doctors' guesses, that the child's life would be inconvenient, disappointing, or without acceptable quality." 130 CONG. REC. H376, 382 (daily ed. Feb. 2, 1984) (Rep. Bartlett quoting George Will). Contra see Duff & Campbell, supra note 9; Lorber, Selective Treatment of Myelomeningocele: To Treat or Not to Treat?, 53 PEDIATRICS 307 (March, 1974). See also Shaw, Ethical Issues, supra note 11, at 593 (90% of the surveyed group would base a decision to treat on the potential quality of life).
34See Nolan-Haley, supra note 7, at 9.
35Robertson, supra note 7 at 248. Supporters also point out that identifying which infants are unworthy of care is a difficult task and will eventually take a toll on the decisionmakers. See also Singer, Sanctity of Life or Quality of Life?, 72 PEDIATRICS 128 (July, 1983).
36See Robertson, supra note 7, at 252; See also Brown & Truitt, supra note 25, at 624. (This article points out that even Pope Pius XII in 1976 recognized that when death becomes inevitable a physician can discontinue treatment "in order to permit the patient already virtually dead to pass on in peace.")
37See infra notes 69-84 and accompanying text for a discussion of the definition of medically indicated treatment.
38See supra note 48, for a list of organizations supporting the Infant Doe Amendment.
39Presidents Commission For The Study Of Ethical Problems In Medical & Biomedical & Behavioral Research, Deciding To Forego Life-Sustaining Treatment. Washington D.C.: Government Printing Office, March, 1983. In pertinent part the Commission stated: This [standard for providing medically beneficial treatment] is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too
Treatment of Disabled Infants. The Amendment and these proposals require that the primary focus be upon the infant’s present medical condition and the feasibility of treatment, both of which are arguably less speculative than a prognosis about an infant’s projected quality of life.

To avoid the same potential for abuse that exists in the quality of life standard, the definition of medically indicated treatment must protect the infant’s interests by determinable criteria which provide certainty and consistency in practice. To accomplish this, the exceptions within the definition which permit the withholding of treatment must be narrowly and carefully defined. This will eliminate much of the uncertainty and leave little ambiguity in application.

Interpretive guidance of “medically indicated treatment” is found in three sources. The Amendment itself defines the “withholding of medically indicated treatment” as:

- easy to undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or other older children with similar handicaps would be treated.


  When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual’s medical condition should be the sole focus of the decision. These are very strict standards.

  It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

  In cases where it is uncertain whether medical treatment will be beneficial, a person’s disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

- See generally Note, Birth-Defective Infants, supra note 25, at 625-26.

  First, see Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749, 1752 (1984) (to be codified at 42 U.S.C. § 5102(3)) for the definition of “withholding medically indicated treatment.” Second, see Joint Statement, supra note 43, at 2970, for the definition of “infant” and “reasonable medical judgment.” Third, see 49 Fed. Reg. 48160 (1984) (to be codified at 45 C.F.R. 1340) (proposed Dec. 10, 1984). HHS as required by the Amendment, has issued a proposed regulation which includes definitions of terms and phrases used within the definition of “withholding medically indicated treatment.” HHS states that this was done to help clarify and eliminate possible ambiguities. Final regulations will be issued only after comments have been received and evaluated. Thus the HHS definitions are subject to change. See supra, note 47.

- See Joint Statement, supra note 43, at 2970. “Infant” is defined as less than one year although older infants who have been hospitalized continuously since birth may be included. However, the reference to one year is not to imply treatment is to be changed once the infant reaches one; 49 Fed. Reg. 48160, 48166 (1984) (to be codified at 45 C.F.R. 1340) (proposed Dec. 10, 1984).

- 49 Fed. Reg. 48160, 48166 (1984) (to be codified at 45 C.F.R. 1340) (proposed Dec. 10, 1984). Life-threatening condition “means a condition that threatens the life of the infant or that significantly increases the risk of the onset of complications that may threaten the life of the infant.” HHS gives the example of myelomeningocele which if left untreated increases the risk of infection which may become life-threatening or add to the disability. See 49 Fed. Reg. at 48163.
viding treatment72 (including appropriate nutrition, hydration, and medication) which, in the treating [physician's] reasonable medical judgment,73 will be most likely to be effective in ameliorating or correcting all such conditions[.]. However 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] reasonable medical judgment:

(A) The infant is chronically and irreversibly comatose;
(B) The provision of such treatment would
   (i) merely prolong dying,74
   (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions,75 or
   (iii) otherwise be futile in terms of the survival of the infant; or
(C) The provision of such treatment would be virtually futile76 in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.77

A few general observations can be made about the definitions found in all three sources. In all cases, a disabled infant must receive appropriate nutrition, hydration, and medication.78 Thus, even in cases where treatment is not

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72Fed. Reg. at 48167, "treatment" includes (but is not limited to):
(A) Further evaluation by a physician(s) whose expertise is appropriate to the condition(s) involved or further evaluation at a facility with specialized capabilities regarding the condition(s) involved; and
(B) Multiple medical treatments and/or surgical procedures over a period of time that are designed to ameliorate or correct a life-threatening condition or conditions.


751d. The term 'not be effective in ameliorating or correcting all of the infant's life-threatening conditions' shall not be interpreted to permit the withholding of medically indicated treatment in the following two circumstances:
(A) Treatment for a disabled infant on the grounds that one or more of the infant's nontreatable conditions, although not imminently life-threatening, will become life-threatening in the future. [HHS gave the example of Down's syndrome which is associated with shortening of life span. Id at 48164.]
(B) Ameliorative treatment to make a condition more tolerable, such as providing palliative treatment to relieve severe pain, even if the overall prognosis, taking all conditions into account, is that the infant will survive.

In addition, under the definition, when the infant suffers from more than one life-threatening condition but only one is correctable and no treatment is available to avoid imminent death, then no treatment is necessary for the correctable condition, except with respect to appropriate nutrition, hydration and medication; See Joint Statement, supra note 43, at 2970.


77Id. "The term the treatment itself under such circumstances would be inhumane means that the treatment itself involves significant medical contraindication and/or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive."

medically indicated, medication must be provided to relieve pain and suffering and it is no longer permissible to allow death by starvation or dehydration. All disabled infants must be given medically indicated treatment or the physician may be liable for medical neglect.79

Three circumstances were established in which treatment is not considered medically indicated. The first situation is in the case of certain comatose infants. The second instance pertains to infants who are born dying and treatment would not ameliorate or correct all of the life-threatening conditions, but would just prolong the act of dying. However, treatment which would ameliorate the infant's overall condition is required, such as to relieve severe pain. Congress clearly expects physicians to apply humane treatment whenever necessary to ameliorate the infant's overall condition.80 The third situation allows for those gray areas where there seems to be no clear answer. The physician must make a judgment call in considering whether the treatment itself is inhumane because of the associated pain and suffering as compared to a very slim chance of survival.81

One final observation is that these decisions are to be made based upon the physician's "reasonable medical judgment."82 Only judgments that would be made by a reasonably prudent physician, knowledgeable about the case and treatment possibilities with respect to the medical conditions involved will be deemed reasonable.83 This is not a new standard in the medical community, but it is new in application to the withholding of medically indicated treatment.84


49 Fed. Reg. at 48164. HHS gives an example of an infant with noncorrectable life-threatening congenital heart defect and an imperforate anus. Even though no treatment would correct the heart, a colostomy could be performed to ameliorate the infant's overall condition by relieving the severe pain associated with the imperforate anus. This seems to be a valid interpretation of Congressional intent as Congress specifically stated the consideration of the humaneness of a particular treatment should be considered in selecting among alternatives. See Joint Statement, supra note 43, at 2970.


See supra note 73 for the definition of "reasonable medical judgment." See H.R. Rep. No. 1038, 98th Cong., 2d Sess. 10, reprinted in 1984 U.S. Code Cong. & Ad. News 2918, 2927. (citing Dr. McLone, speaking of infants with spina bifida in testimony submitted to the Subcommittee on Family and Human Services: The single most common reason for the denial of care was lack of recent information of available treatment and the outcome of that treatment. When confronted with recent developments in medical care and documented advances in patient outcome by physicians with substantial experience in the care of these children, most of these parents and physicians were able to resolve their doubts and decide in favor of treating the child. In most cases then, continuing education of the public and professionals provided the solution of the dilemma.

See W. Prosser, Handbook Of The Law Of Torts, § 32, at 161 (1982) (Prosser states that physicians who undertake work requiring special skill are required to possess a standard minimum of special knowledge and ability).
Though inevitably somewhat subjective and imprecise in actual application, by confining or limiting judgment to specific criteria in which treatment can be justifiably withheld and by focusing on the medical condition and treatment possibilities and not abstract concepts such as "quality of life," much of the uncertainty in application should be eliminated.

C. Primary Decisionmaker

By definition, the standard of medically indicated treatment relies upon reasonable medical judgment in the decisionmaking process.65 Once Congress established that the decision must be based upon reasonable medical judgment, it naturally followed that the primary decisionmaker should be a medical professional. Congress realized that the federal government is not in the position to establish medical standards and practices.66 Because of the variety of disabilities and the differing degrees of each, the decision should be left to those most qualified. At the same time, to ensure reliable and informed decisionmaking, it is necessary to hold the decisionmaker to a strict standard of knowledge regarding the medical condition and treatment alternatives. To assist in this decision, the Amendment authorizes HHS to provide grants for the establishment of national and regional clearinghouses. The primary purpose of these clearinghouses is to provide the most current and complete information regarding medical treatment procedures and resources.67 Also, HHS is required to publish interim model guidelines to encourage the establishment within health care facilities of infant care review committees.68 A review committee can serve several important functions. First, it can verify that the most current information is being used. Second, it can confirm the propriety of a decision. Third, it can help solve disputes between decisionmakers. Finally, it can refer cases to the appropriate state child protection service agency when necessary.69

Parental involvement is still necessary due to requirements for parental consent before any medical treatment is initiated.90 However, the Amendment requires that when the infant's life is at stake, the infant's interests must take priority over parental wishes. Once it is decided that treatment is medically indicated, the physician is under a duty to seek parental consent. If he is unable

65See text supra pp. 11-12 for the definition of medically indicated treatment.
to obtain consent he must report the case to the appropriate state agency or face charges of medical neglect. This state agency must then investigate the case and, where appropriate, seek court action. Thus, although parents are involved in the decision-making process, they may no longer be the final decisionmaker.

Since the parents must live with and are the most affected by the decision, is it valid for Congress to take the decision away from them? Arguably this is the very reason parents should not be the final decisionmaker; they are too involved to make a disinterested decision which is necessary to adequately protect the infant's interests. The period following the birth of a disabled child is a very traumatic time for the parents. At the same time, they are confronted with a life or death decision of whether to withhold treatment. Parents are faced with an obvious conflict of interest between their concern over the infant's life and an uncertain future of financial and psychological hardship and the unknown potential stress upon their marriage, family, and personal lives. During the turmoil of the newborn period, can parents, who are often unaware of the facts relevant to the child's future and unable to assimilate these facts until the shock has worn off, make a reasonable decision which places the child's interest first?

Prior to the Infant Doe Amendment, the majority of the treatment decisions were being made by the parents and the treating physician, often in consultation with a social worker and clergyman. Dr. Shaw's survey revealed

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Footnotes:
2. See Duff & Campbell, supra note 9, at 894. But see Robertson, supra note 7, at 262-63. Professor Robertson argues that parents do not necessarily have to live with the choice as there is another option beyond the treatment issue: Termination of parental rights and obligations through adoption or state custody. But the adoption or state custody options raise serious issues of their own which are beyond the scope of this comment. Generally, it is hard to find parents who want to adopt a disabled infant. The Amendment attempts to remedy some of the negative factors associated with adoption of a disabled infant with additional funding to help in his or her adoption. See The Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749, 1755 (1984) (to be codified at 42 U.S.C. §§ 5111-5113). Institutionalization is another alternative which under the existing state of the art may be more inhumane than allowing the infant to die. Thus, it is argued if the government is going to require treatment of a disabled infant, it must supply the resources necessary to ensure proper development of the child. See generally, Glick, Pediatric Nursing Homes: Implications of the Massachusetts Experience for Residential Care of Multiply Handicapped Children, 309 NEW ENG. J. MED. 640 (Sept., 1983); Goldstein, Medical Care for the Child at Risk: On State Supervision of Parental Autonomy, 86 YALE L. J. 645, 657-58 (1977) (hereinafter cited as Goldstein); Angell, Handicapped Children: Baby Doe and Uncle Sam, 309 NEW ENG. J. MED. 659, 660 (1983); Duff & Campbell, supra note 9, at 892.
4. Fost, Counseling Families Who Have a Child with a Severe Congenital Anomaly 67 PEDIATRICS 321 (March, 1981). (Dr. Fost suggests that those who believe the parent should make an informed decision risk adding more anguish and anxiety to a family already under great stress. Also, because of the mass of data and ethical analysis involved, to expose parents to such complexity may seem inhumane.)
5. Id.
6. See, e.g. In re Infant Doe, No. GU8204-004A (Monroe County Cir. Ct., Ind., Apr. 12, 1982). See also, Duff & Campbell, infra note 9; Shaw, Dilemmas of "Informed Consent" in Children, 289 NEW ENG. J. MED. 885.
most practitioners felt the decision should be made by parents. However, commentators have been in sharp disagreement whether parents can make an informed life or death decision within hours or days after the birth of a disabled infant.  

There was extensive debate in the House of Representatives on the parents' role in the decisionmaking process. Some members argued that the Amendment would be too intrusive into a decision which should be left to the family. They proposed that the final decision should be made by the parents after an informed consultation with the treating physician and a hospital review committee. However, a majority of the House felt that this was inadequate assurance that the interest of the infant would be properly protected.

Since most decisions were being made by the parents, the Amendment as passed does represent a reduction of parental autonomy. An examination of the possibility of a constitutional challenge to the lessening of parental autonomy is warranted. Judicial recognition of parental autonomy in recent years has restricted government intervention into family matters. Yet, governmental involvement in such areas as custody disputes, abortion, foster care, and child abuse and neglect, demonstrates an often necessary and permissible role in regulating areas of parental decisionmaking concerning the welfare of children.

The Supreme Court has never directly addressed the broad issue of whether there is a fundamental right of parental autonomy that is applicable to the full range of parental decisions. Nor has the Court addressed the specific issue of the extent of parental autonomy in the context of medical decision-making. 

(1973) [hereinafter cited as Shaw, Dilemmas].

"See Shaw, Ethical Issues, supra note 11, at 594 (In Dr. Shaw's survey 50% of the group felt the parents should make the decision while 33% felt either the physician or a hospital committee should decide.) (When asked whether the courts or the legislature should decide there was uniform opposition) Id. at 598.

"See, e.g. Duff & Campbell, supra note 9 (They believe parents if properly informed are able to understand and make reasonable decisions); Shaw, Ethical Issues, supra note 11, at 592-93 (The survey revealed that 71% of the pediatric surgeons and 62% of the pediatricians felt parents could make an informed decision within hours of birth. Contra Robertson, supra note 7, at 263 (He discusses a potential need for an impartial decisionmaker beyond the parents and physicians.) See generally Shaw, Dilemmas, supra note 96.


See supra nn. 11-19, 96-98 and accompanying text for a discussion on how decisions were being made.


"See J. NOWAK, R. ROTUNDA, J. YOUNG, CONSTITUTIONAL LAW 590-91 (2d ed. 1983). If a fundamental right is involved the Court reviewing the constitutionality of the law, will employ strict scrutiny and will uphold the law only if it is the least restrictive means necessary to promote a compelling state interest. In practice it is virtually impossible to satisfy this standard. If a fundamental right is not found then the Court will review the law based on minimal scrutiny and will uphold the law so long as it is rationally related to a legitimate governmental interest.
making. However, an examination of the relevant decisions of the Court reveals a limited constitutional protection of parental decisionmaking with regard to certain aspects of family life.

Three cases suggest the existence of a parental fundamental right against undue interference by the state in child rearing. In *Myer v. Nebraska*, the Supreme Court invalidated a state statute which prohibited the teaching of foreign languages in elementary schools. This was found to be an unconstitutional infringement of "liberty" guaranteed by the fourteenth amendment. In *Pierce v. Society of Sisters*, the Court upheld the parents' free exercise claim by striking down a state law requiring children to attend public schools and thus preventing a choice of either private or parochial schools. More recently in *Wisconsin v. Yoder*, the Court upheld the right of Amish parents to remove their children from school after the eighth grade and to provide any further education at home as required by their religious belief.

Parental autonomy arguably may be protected by the fundamental right of privacy. Although the Constitution does not explicitly mention the right of privacy, the Court in *Griswold v. Connecticut* formally recognized as a fundamental constitutional right, the right of personal privacy which guarantees the individual freedom to make certain personal choices and decisions without governmental intervention. *Griswold* did not attempt to define the scope of the right of privacy and left its boundaries to be decided on a case by case basis. The Court, however, in dictum has incorporated *Myer* and *Pierce* under the protection of privacy through the concept of liberty guaranteed by the fourteenth amendment. Nevertheless, in establishing the boundaries of

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105 U.S. CONST. amend. XIV, § 1. (states in pertinent part; "No state shall deprive any person of life, liberty, or property without due process of the law.").
106 *Myer v. Nebraska*, 262 U.S. 390, 399 (1923) (The Court acknowledged that it had never attempted to define "liberty," but in broad language went on to state it included the right to marry, establish a home, and bring up children).
108 *Id.* at 534-35 (The Court stated "we think it entirely plain that [the law] unreasonably interferes with the liberty of parents and guardians to direct the upbringing and education of children under their control.").
110 *Id.*
112 *Id.* Based on the opinions in this decision and in *Roe v. Wade*, 410 U.S. 113 (1973) the zone of privacy has been found in the penumbra of the Bill of Rights, the first, fourth, fifth, and ninth amendments, and in the concept of liberty guaranteed by the first section of the fourteenth amendment.
113 The decisions in which the Court has directly found the fundamental right of privacy at issue have dealt mainly with the areas of contraception and abortion. See *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Roe v. Wade*, 410 U.S. 113 (1973).
114 *See Roe v. Wade*, 410 U.S. 113 (1973) (In *Roe* the issue before the Court was whether an individual right of privacy exists to decide whether to have an abortion. Justice Blackmun citing *Myer* and *Pierce* stated that the right of personal privacy has some extension to activities relating to child rearing and education. Note that the phrase "some extension" implies that not all decisions relating to child rearing are covered.) *Id.* at 153. *Carey v. Population Services Int'l*, 431 U.S. 678 (1977) (In *Carey* the issue concerned distribution of
privacy the Court has never been directly faced with the issue of parental autonomy pertaining to health care choices for children.

Myer, Pierce, and Yoder did establish certain fundamental rights in parental decisionmaking which were later incorporated by dictum into the fundamental right of privacy. However, since the issues in these cases were limited to education, religion, and morality, it does not necessarily follow that parental autonomy would extend to medical decisionmaking. In fact the Court has specifically recognized that there are limits to parental authority, particularly where such decisions place the child's health or welfare in serious jeopardy. The Court in Prince v. Massachusetts clearly recognized these limitations on parental autonomy and noted that when the state is acting to guard the general interest in a child's well being, the state can use its role as parens patriae to restrict the parents' control over the child. Wisconsin v. Yoder reaffirmed this principle when the Court stated "the power of the parent . . . may be subject to limitation . . . if it appears that parental decisions will jeopardize the health or safety of the child.

Another limitation on parental autonomy may be found in the infant's own constitutional rights. "Constitutional rights do not mature and come into being magically only when one obtains the state-defined age of majority. Minors as well as adults are protected by the Constitution and possess constitutional rights." In addition, the Court in Prince suggested strongly in dicta that if, in the exercise of parental authority, a conflict develops between parents' rights and children's constitutionally protected interests, the latter will prevail.

The manner in which treatment decisions were being made prior to the Infant Doe Amendment arguably raises equal protection and due process challenges on behalf of the infant under the fourteenth amendment. An
equal protection challenge could be brought by a disabled infant because it is the fact that he is disabled that presents the issue of nontreatment. In cases involving a "normal" child where treatment is required to save a life, treatment is provided even against parental wishes.\textsuperscript{124}

A due process challenge would be based on deprivation of life without due process of law. The Court recently faced a similar due process challenge in \textit{Parham v. J.R.}\textsuperscript{125} Minor children brought the action alleging that they had been deprived of their liberty without due process of law by virtue of a state statute which permitted parents to voluntarily admit minors to a mental hospital. The Court held that although a minor's due process rights were not equivalent to an adult's, the risk inherent in parental decisions to have a child institutionalized is sufficiently great as to require an inquiry by a "neutral factfinder."\textsuperscript{126} This requirement was found to be satisfied by a physician's independent examination and medical judgment. In addition, the Court required that the "neutral factfinder" have the authority to disagree with the parents if the child does not satisfy the medical standards for admission.\textsuperscript{127} Basically, the Infant Doe Amendment embodies these same requirements. Based on the rationale of \textit{Parham} and the dicta in \textit{Prince} it appears valid to limit parental autonomy in medical decisions in order to protect the infant's due process rights. The finality of a decision not to treat a disabled infant only increases the need for protection recognized in \textit{Parham}.

In summary, the Amendment should survive review by the Court on the issue of parental autonomy. No fundamental right has been established con-

\textsuperscript{124}See 130 CONG. REC. H 376, 381 (dailey ed. Feb. 2, 1984). (Rep. Erlenborn's example during the debates puts the equal protection challenge in perspective:
If a robust 10-year old youngster became a victim of a serious automobile accident and sustained a series of injuries that were both life-threatening and likely to result in severe and permanent handicaps, there would be no question . . . this 10-year old should receive immediately the best medically indicated treatment, nutrition, appropriate general care and social services.
Why, therefore, should a day old infant who, at birth, is at risk with life-threatening congenital impairments be denied the right to equal treatment and care?
The intent of the new [Infant Doe Amendment] affirms simply and unequivocally that such infants are to be afforded the same rights to live that is guaranteed to an individual of any age with or without a handicapping condition.)

\textit{See also} Shaw, Ethical Issues, supra note 11, at 596-97 (The responses in the survey show a much higher regard for non handicapped children in need of surgery or treatment); Lower court decisions, outside the Infant Doe context, have consistently upheld a child's need for treatment over the parents objections whenever the child's health is in serious jeopardy, for pertinent cases see Note, Judicial Limitations on Parental Autonomy in the Medical Treatment of Minors, 59 NEB. L. REV. 1093, at 1115 n. 125; Note, Choosing for Children, supra note 102, at 161-62. See also, Goldstein, supra note 92, at 652; R. HOROWITZ \\& H. DAVIDSON, LEGAL RIGHTS OF CHILDREN § 7.08, at 278-83 (1984).

\textsuperscript{125}442 U.S. 584 (1979).

\textsuperscript{126}Id. at 606. \textit{See also} Bellotti v. Baird 443 U.S. 622, 634 (1979) (Justice Powell, with Chief Justice Burger and two Justices concurring, and four Justices concurring in the judgment). Justice Powell listed three reasons why the constitutional rights of children cannot be equated with those of adult's: (1) their particular vulnerability; (2) their inability to make critical decisions in an informed and mature manner; (3) the importance of the parental role in child rearing.

cerning parental authority to make medical decisions for a child. The decisions of Prince and Yoder recognize a limitation on parental decisionmaking where it appears the decision will jeopardize the health or safety of the child. Furthermore, based on Parham the Amendment protects the infant's own due process rights by requiring a neutral factfinder, using reasonable medical judgment to determine if treatment is medically indicated.

D. Applicable Law

The Infant Doe Amendment places responsibility for the protection of disabled infants in existing state child protection service systems. Protection of children from abuse and neglect has always been a state and local responsibility; the Amendment represents an expansion of these existing responsibilities. The Amendment requires states which receive financial assistance under the Child Abuse Prevention And Treatment Act to provide its designated child protective service agencies with the authority to seek legal redress for cases of medical neglect, including the withholding of medically indicated treatment from disabled infants with life-threatening conditions. Basically the Amendment requires states to include medical neglect as defined in the Amendment in their definition of child abuse and neglect.

While previous attempts at governmental protection of disabled newborns required federal governmental enforcement, the Amendment leaves enforcement to the state. This is one reason that groups which were adamantly opposed to the previous HHS attempts now support the Amendment.

While many groups supported the idea of enforcement on a state level, others have argued that child protective service systems are not capable of handling this new responsibility. In testimony before the Senate Committee on Labor and Human Resources, Wayne M. Holder, Director of the children's division of the American Humane Association, questioned the capability of child protection personnel in preventing child abuse: "The current state of the art in child protective services is marginal to poor... The field has moved forward,... But serious problems in service delivery exist due to overload, worker incompetence, inadequate supervision, inadequate leadership, lack of resources, and inadequate community support."
Congress recognized this as an expansion of existing responsibilities and in an effort to alleviate inadequacies in child protective service systems, has appropriated additional funds to carry out the requirements of the Amendment. In addition, child protective service agencies will be able to draw upon the new resources developed to assist the families and physicians concerning availability of professional and private services within the community.

IV. CONCLUSION

On April 9, 1982, Infant Doe died of starvation because his parents, the medical community, and the courts refused to provide routine corrective surgery. This case aroused national interest and the ensuing attention revealed that the various jurisdictions were arriving at different decisions regarding medical treatment of disabled newborns. Because of this lack of uniformity, an infant's life depended upon the jurisdiction in which he or she was born.

Congress passed the Infant Doe Amendment in order to develop a national policy on treatment decisions. The Amendment sets forth specific circumstances under which treatment can be justifiably withheld and requires the decision to be based upon reasonable medical judgment.

As with all legislation, some will argue government involvement of any sort is unwarranted, while others will seek stricter laws to ensure compliance. The Amendment was a compromise of ideas set forth by a variety of groups ranging from medical organizations to civil rights groups. Since the Amendment limits parental authority in treatment decisions, a constitutional challenge is likely. However, a review of applicable Supreme Court cases suggests that the Court will weigh the parents' right to decide against the infant's own constitutional rights. Cases such as Prince v. Massachusetts, Wisconsin v. Yoder, and Parham v. J.R. indicate that the Court will uphold the Amendment.

Other groups may question whether the Amendment will accomplish its objective. Although the treatment decisions must be based on specific criteria, a physician's own personal biases and relationship with the parents may inadvertently sway the decision. Perhaps the suggested infant care review committees should be mandatory.

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139 See Robertson, supra note 7, at 262-65.
It has been pointed out that a decision to save the life of a disabled newborn may require considerable financial support. This need is also a factor that may not be fully addressed by the Amendment.

In summary, while the Amendment may not address all of these issues it has taken a large step toward protecting disabled newborns with minimal government intervention. If the Amendment had been in effect on April 9, 1982, Infant Doe would be celebrating his third birthday this year.

Daniel J. Mumaw

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The editors of the Akron Law Review respectfully dedicate this issue to Albert S. Rakas, Professor Emeritus of Law.