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## PROTECTING THE HANDICAPPED NEWBORN: WHERE THE COURTS FAILED AND THE LEGISLATURE SUCCEEDED—THE CHILD ABUSE AMENDMENTS OF 1984

*The offspring of the good, I suppose, they will take to the pen or creche, to certain nurses who live apart in a quarter of the city, but the offspring of the inferior, and any of those of the other sort who are born defective, they will properly dispose of in secret, so that no one will know what has become of them.—Socrates<sup>1</sup>*

Unlike Socrates' position, our society still prohibits infanticide.<sup>2</sup> This is true even though approximately five percent of babies born today suffer from some type of major congenital anomaly or defect.<sup>3</sup>

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1. PLATO, *The Republic*, in *THE COLLECTED DIALOGUES OF PLATO* 699 (E. Hamilton & M. Cairns eds. 1978). Interestingly, Socrates was not the only person that espoused the practice of infanticide. It has been practiced as far back as the Roman period and recently in the Republic of China. For an indepth history of the practice of infanticide, see J. LYONS, *PLAYING GOD IN THE NURSERY* 61-64 (1985). Interestingly, during the 1860's approximately 150 newborn infants were found drowned in the Thames River in London apparently the result of infanticide. *Id.* at 63. Likewise, during the same period Paris was encountering numerous sewers full of dead newborn babies. *Id.*

2. *But see* Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, 49 Fed. Reg. 1622, 1646 (1984) (to be codified at 45 C.F.R. § 84), invalidated in *American Hosp. Ass'n v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984), *cert. denied*, 55 U.S.L.W. 3877 (U.S. June 18, 1985), where one nurse wrote:

I am a registered nurse and have worked in the labor and delivery area, newborn nursery and intensive care nursery. I think the average American would be shocked at the decisions that are made regarding 'non-perfect' infants. I have personally heard physicians and nurses talk to new parents about their child and persuade the parents to 'let the child die and therefore end its suffering'—which really meant 'let us starve your child to death'—that is certainly not a humane way to 'let a child die.'

*Id.* See also Weir, *The Government and Selective Nontreatment of Handicapped Infants*, 309 NEW ENG. J. MED. 661, 663 (1982) ("Fatal discrimination against [handicapped] infants has been increasing for years . . . . The ethic which promotes infanticide is related to the elitist 'quality of life' argument used to justify abortions on demand.")

3. See R. BEHRMAN & V. VAUGHAN, *NELSON TEXTBOOK OF PEDIATRICS* 311 (12th ed. 1983). Some of these anomalies include DiGeorge's syndrome, Encephalomeningocele, Trisomy 21 (Down's Syndrome), and defects associated with severe perinatal trauma.

DiGeorge's syndrome is a rare but usually fatal disease characterized by the absence of thymic and parathyroid glands. *Id.* at 507. The lack of parathyroid glands causes tetany, a condition that is easily treated by widely practiced therapeutics. *Id.* However, the absence of thymic glands creates a severe immunodeficiency similar to Acquired Immune Deficiency Syndrome (AIDS). Early death is frequent due to the chronic infections associated with infancy. *Id.* at 507-08. See also R. HOEKELMAN & S.

While recent medical advances in the treatment of these conditions have substantially decreased neonatal<sup>4</sup> mortality rates,<sup>5</sup> they have in turn created a serious decision-making dilemma. Today, many handicapped infants that would have died from natural causes are given the chance to survive for long periods of time, although many with serious handicaps and physical impairments.<sup>6</sup> Because the chance to lead normal lives is slim for most handicapped newborns, it is now common for parents to withhold medical treatment knowing fully that the consequence of such a decision usually results in the infant's death.<sup>7</sup>

The decision to withhold life sustaining treatment from defective infants is not an infrequent or recent phenomenon. Doctors Raymond S. Duff and A. G. Campbell, in 1973, broke what they termed a "public and professional silence on a major taboo" in their

BLATMAN, *PRINCIPLES OF PEDIATRIC HEALTH CARE OF THE YOUNG* 1067 (1978).

Encephalomeningocele is a condition where the newborn's brain protrudes from the skull. Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 397 (1984). Surgery often requires removing a large portion of the brain in order to close the cranial vault. With surgery, the infant may have a normal life span but experience motor and mental dysfunction. *Id.* Without surgery, the infant usually dies. *Id.*

Trisomy 21 (Down's Syndrome) is chromosomal anomaly causing mental retardation of various degrees. *Id.* at 396. With proper care and stimulation an infant with this condition can at best attain an I.Q. of 60. *Id.* Usually, Trisomy 21 by itself poses no questions regarding whether to withhold treatment. But frequently, the condition is accompanied with serious heart and bowel defects that require surgery in order to avoid death. *Id.* Life expectancies for those infants that have undergone surgical treatment to correct the additional anomalies is slightly shorter than normal (i.e. 40-60 years). *Id.* Even with surgical treatment the infants often experience lives that are severely impaired. Failure to render surgical treatment generally results in the death of the baby. *Id.* at 396-97.

Severe perinatal trauma occurs most frequently during labor resulting in lack of oxygen or blood flow to the neonate's brain. *Id.* at 397. Immediate medical measures must be taken to save these infants but, even if timely, the risk is for the infant to suffer severe mental and motor dysfunction. *Id.* at 397-98.

4. The term "neonate" is medical jargon referring to a newborn infant. C. THOMAS, *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* N-11 (13th ed. 1977). Any general references throughout this comment to infants or babies will be used synonymously with this definition of neonate.

5. Between 1940 and 1980 neonatal deaths decreased from 28.8 per thousand live births to 8.5 per thousand live births. Note, *Life or Death in the Intensive Care Nursery: Who Should Decide?*, 11 WM. MITCHELL L. REV. 127 (1985) (citing U.S. DEPT. OF CENSUS, *STATISTICAL ABSTRACT OF THE UNITED STATES* 77 (104th ed. 1984)). Correspondingly, during the years 1970 through 1980 neonatal deaths declined from 15 to 8 per 1000 live births. Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14886 (1985) (to be codified at 45 C.F.R. § 1340).

6. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 214 (1975).

7. *Id.* See also *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588, 589 (1977) which lists the results of a statistical survey of pediatric surgeons and pediatricians questioned concerning their attitudes about recommending to parents the alternative of withholding treatment from their handicapped newborns. For a discussion of the frequency of the problem, see *infra* note 9.

article entitled *Moral and Ethical Dilemmas in the Special Care Nursery*.<sup>8</sup> They openly acknowledged the magnitude and frequency of the practice of withholding treatment from newborn babies. Their research focused on the Yale-New Haven Hospital where between January, 1970, and June, 1972, 43 of the 299 infant deaths (14%) in the intensive care nursery resulted from an affirmative decision to withhold treatment.<sup>9</sup>

Several commentators believe that the practice of withholding ordinary treatment from handicapped newborns is the only wide scale instance of passive euthanasia<sup>10</sup> that both the medical profession<sup>11</sup> and the courts condone.<sup>12</sup> This is not to imply, however, that the decision to withhold treatment is one that parents or physicians easily make. One author has poignantly characterized this emotional decision-making dilemma by noting that "[t]he experience of learning that your child is defective immediately after birth can still be categorized among the most painful and stigmatizing experiences of modern people. It is as if the parents' *raison d'être* were called into question before an imagined parental bar of justice."<sup>13</sup> Indeed, it is

8. Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890, 894 (1973).

9. *Id.* at 890. While the argument can be made that their findings were unique to that one particular hospital, a variety of other sources assert that the practice of withholding treatment is widely regarded in many circumstances as acceptable medical practice. For instance, one article told of a newborn infant who died fifteen days after birth from an intestinal blockage that could have been repaired with a simple operation. *Doctors Ponder Ethics of Letting Mongoloid Die*, Washington Post, Oct. 15, 1971, at A1., col. 1. Reportedly, the parents withheld treatment since the child was born a mongoloid. *Id.* The attending physician was quoted as stating that "[s]imilar life and death decisions are made at least twice a week at [John Hopkins University Hospital]." *Id.* See generally F. INGRAHAM & D. MATSON, *NEUROSURGERY OF INFANCY CHILDHOOD* 35-39 (1954) (medical textbook listing clinical indicators for withholding treatment); Fost, *Passive Euthanasia of Patients With Down's Syndrome*, 142 ARCHIVES INTERNAL MED. 2295, 2295 (1982) ("It is common in the United States to withhold routine surgery and medical care from an infant with Down's Syndrome for the explicit purpose of hastening death."); Gimbel, *Infanticide: Who Makes the Decision?*, 73 WIS. MED. J., no. 5, at 10 (1974) (listing medical journal articles advocating the practice); N.Y. Times, June 12, 1974, at 18, col. 4 (noting the number of physicians at a senate hearing attempting to justify the practice).

10. Passive euthanasia refers to the decision to withhold life sustaining procedures whereas active euthanasia refers to the affirmative act, rather than the omission to act, of causing death by aborting life sustaining procedures. Robertson, *supra* note 6, at 214-15 n.16. The reader should note that this comment focuses solely on the withholding of "ordinary treatment" (e.g. nutrition, water, medication) not on the withholding of "extraordinary treatment" (e.g. respirators or renal dialysis) from defective newborns. To attempt to distinguish the legal ramifications and underlying similarities and differences between the two concepts is beyond the limits of this comment.

11. See Robertson, *supra* note 6, at 214-15. See also *supra* note 9 for a listing of numerous sources indicating the breadth of the medical profession's support of the practice.

12. See cases cited *infra* note 20. For an analysis of three particular cases, see notes 53-100 and accompanying text.

13. Fletcher, *Attitudes Towards Defective Newborns*, 2 HASTINGS CENTER

hard not to sympathize with parents forced with making the difficult decision of whether to withhold life sustaining medical treatment from their newborn. Nevertheless, one must remember that the innocent newborn, albeit defective, is a human being with a constitutional right to life<sup>14</sup>—a right deserving of the most rigid protections our society can offer.

Historically, parents held an almost exclusive responsibility to protect and rear their children. The parents' right to make decisions regarding their children has traditionally been protected at common law<sup>15</sup> and guaranteed by the Constitution of the United States.<sup>16</sup> However, this right is not absolute.<sup>17</sup> When it appears that the interests of the infant are being unjustly compromised, the common law doctrine of *parens patriae*,<sup>18</sup> as well as state child abuse and neglect laws,<sup>19</sup> give the state the right to intervene in order to protect the infant. Recently, following several cases where newborns were denied medical treatment because of their birth defects,<sup>20</sup> the federal government intervened with legislation aimed at ensuring that handicapped infants receive appropriate medical treatment.<sup>21</sup>

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STUD., no. 1, at 24 (1974), cited in Robertson, *supra* note 6, at 256 n.228.

14. The newborn infant attains citizenship at birth and is, therefore, protected by the due process clause of the fourteenth amendment. See U.S. CONST. amend. XIV and amend. V.

15. *E.g.*, State v. Stehr, 92 Neb. 755, 139 N.W. 676, *aff'd on rehearing*, 94 Neb. 151, 142 N.W. 670 (1912).

16. See *infra* text accompanying notes 32-38.

17. See *infra* text accompanying notes 39-41.

18. For a discussion and definition of the *parens patriae* doctrine, see *infra* note 40 and accompanying text.

19. See *infra* note 42. See generally Wilcox, *Child Abuse Laws: Past, Present, and Future*, 21 J. FORENSIC SCI. 71, 71-72 (1976).

20. The most publicized case was that of the Indiana baby referred to by the press as "Infant Doe." *In re Infant Doe*, No. GU 8204-004A (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), writ of mandamus dismissed sub nom. State ex rel. Infant Doe v. Baker, No. 482 S 140 (Ind. May 27, 1982) (case mooted by Infant Doe's death), cert. denied, 104 S. Ct. 394 (1983), reprinted in Margret M. Heckler, *To Be Secretary, Department of Health and Human Services—Additional Consideration: Hearing Before the Senate Committee on Labor and Human Resources*, 98th Cong., 1st Sess. 73-76 (1983) [hereinafter cited as *In re Infant Doe*]. For a discussion of the Infant Doe case, see *infra* notes 88-99 and accompanying text. *Accord* United States v. University Hospital, 729 F.2d 144 (2d Cir. 1984) (decision to use "conservative treatment" to treat neonate with multiple defects); Maine Medical Center v. Houle, No. 74-145 (Super. Ct. Cumberland County, Me. Feb. 14, 1974) (decision to forego surgery for neonate with multiple defects); *In re Teague*, 140-212-81886 (Cir. Ct. Balt., Md. filed Dec. 4, 1974) (decision to forego surgery to repair spinal column defect); *In re McNulty*, No. 1960 (P. Ct. Essex County, Mass. Feb. 15, 1978) (decision to forego heart surgery); *In re Obenauer* (Juv. & Dom. Rel. Ct. Mon., N.J. Dec. 22, 1970) (decision to forego surgery to correct Down's Syndrome infant's duodenal atresia). For a discussion of these cases, with the exception of *In re Infant Doe* and *University Hospital*, see generally Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 Mo. L. REV. 337, 361-68 (1981).

21. For a brief background of this legislation, see *infra* notes 122-76 and accompanying text.

Numerous individuals and organizations have argued that such government intervention is unwarranted, and intrudes into an area of privacy usually entrusted to parents.<sup>22</sup> This comment will refute these arguments. In addition, this comment will show that the Child Abuse Amendments of 1984<sup>23</sup> represent a much needed, yet careful balance between the parental right to make medical decisions regarding their children and the states' right to intervene where a handicapped infant's life is threatened. This comment will first analyze the basis for these competing interests.<sup>24</sup> The comment will then discuss the judicial system's futile attempt at balancing these interests.<sup>25</sup> Although the case law on point is limited, several cases indicate that the apparent trend of the courts has been to subtly abandon their inherent commitment to defend human life by allowing parents unbridled discretion in determining their handicapped infants' fates. The comment will then analyze the federal government's response to the dilemma of withholding medical treatment from newborns.<sup>26</sup> Particular emphasis will be given to the Child Abuse Amendments of 1984<sup>27</sup> and the resulting Department of Health and Human Service's Final Rules of April 15, 1985.<sup>28</sup> The comment will demonstrate that the federal legislation, unlike the courts' response, establishes guidelines that are both considerate of the parental right to make decisions regarding their children, and laudable in that they create workable protections for handicapped infants.<sup>29</sup>

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22. The American Hospital Association, for example, declared in a formal statement that "[the government intervention] is *not* in the best interest of the handicapped person. . . . Withholding medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients." Weir, *supra* note 2, at 663 (emphasis in original). Likewise, the Chief Justice of the Indiana Supreme Court stated that "[t]here's no need for any legislation. . . . We can't legislate miracles. We can't pass a law saying doctors have to save every child that is born." *Id.* See generally J. LYONS, *supra* note 1, at 39-40 (discussing the diverse group of individuals and organizations opposing the federal intervention).

23. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984) (amending 42 U.S.C. §§ 5101-5115 (1982)).

24. See *infra* notes 30-52 and accompanying text.

25. See *infra* notes 53-120 and accompanying text.

26. See *infra* notes 121-75 and accompanying text.

27. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984) (amending 42 U.S.C. §§ 5101-5115 (1982)). See *infra* notes 151-63 and accompanying text.

28. Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14886 (1985) (to be codified at 45 C.F.R. § 1340). See *infra* notes 164-76 and accompanying text.

29. See *infra* text accompanying notes 176-94.

## THE RIGHT OF PARENTAL AUTONOMY

*The Parents' Right to Decide*

Traditionally, the difficult decision of when to withhold medical treatment from a defective newborn has been made within the privacy of the parent-physician relationship.<sup>30</sup> This tradition is premised on the notion that a natural bond of affection exists between parents and their newborn, which leads the parents, after consulting with the pediatrician, to act in the best interests of the child.<sup>31</sup> Reflecting this historical presumption, the Constitution has been interpreted to specifically protect the parents' right to decide the appropriate care and upbringing for their children so long as the decision is truly in the child's best interests.

In *Griswold v. Connecticut*,<sup>32</sup> the United States Supreme Court established the constitutional right of parents to make decisions regarding their families.<sup>33</sup> Even though this right is not explicit in the Constitution, the Court has repeatedly affirmed that parents have a constitutionally protected interest in raising their children free from unwarranted government interference.<sup>34</sup> More recently, the Court has expanded the notion of a parental right to decide family matters to include situations ranging from decisions concerning conception to decisions regarding childbearing and education.<sup>35</sup> A necessary co-

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30. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 396 (D.D.C. 1983).

31. See generally 1 W. BLACKSTONE, COMMENTARIES \*447-48 ("natural right obliges [parents] to give necessary maintenance to their children") (emphasis in original); 2 J. KENT, COMMENTARIES ON AMERICAN LAW \*189-90 ("wants and weaknesses of children renders it necessary that some person maintains them, and the voice of nature has pointed out the parents as the most fit and proper persons . . . this is a plain precept of universal law").

32. 381 U.S. 479 (1965).

33. *Id.* at 484-85. The Court found this protection present in the penumbral right to privacy inherent in the first, third, fourth, fifth, and ninth amendments. *Id.* Even though these amendments are substantively dissimilar, the Court held that they protect the common interest of privacy and that this interest constitutes a fundamental right. *Id.*

34. In *Wisconsin v. Yoder*, 406 U.S. 205 (1972) the Court held that the first and fourteenth amendments protect the parental right to decide matters affecting religious upbringing. *Id.* at 213-14. The focal point of the Court's analysis was on the recognition that parents bear primary responsibility for decisions regarding childrearing. *Id.* at 232. See also *Quilloin v. Walcott*, 434 U.S. 246, 255 (1978) ("[I]t is now firmly established that 'freedom of personal choice in matters of . . . family life is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment'"); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (responsibility for childrearing resides first with parents); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925) (compulsory education statute held unconstitutional since it was an unreasonable interference with the rights of parents to control the upbringing and education of their children); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (criminal statute invalidated as being an interference with the parental rights recognized by the liberty clause of the fourteenth amendment).

35. See, e.g., *United States v. Orito*, 413 U.S. 139, 142 (1973) (right of privacy

rollary to this parental right, however, is the equally strong parental duty to care for and safeguard minor children.<sup>36</sup> While the Supreme Court has never explicitly stated whether the authority to make medical decisions is within the scope of these parental rights, it has implied<sup>37</sup> that such a conclusion is warranted.<sup>38</sup>

### *The State's Right to Intervene*

Even though parents undoubtedly possess the constitutionally protected right to make decisions regarding the care and upbringing of their children, this right is limited.<sup>39</sup> In those instances where it appears the parental decision threatens the health, educational development, emotional well-being, or general safety of the infant, the common-law doctrine of *parens patriae*<sup>40</sup> authorizes the state to in-

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includes right of marriage, procreation, motherhood, childrearing, and education); *Paris Adult Theater I v. Slaton*, 413 U.S. 49, 65 (1973) (right to privacy "encompasses and protects the personal intimacies of the home, the family, marriage, motherhood, procreation, and childrearing"); *Roe v. Wade*, 410 U.S. 113, 153-54 (1973) (right to privacy protects the female's decision to undergo an abortion within certain parameters); *Eisenstadt v. Baird*, 405 U.S. 438, 453-54 (1972) (right of privacy protects the freedom of a person to use contraceptives); *Griswold v. Connecticut*, 381 U.S. 479, 484-85 (1965) (right of privacy guaranteed by the Bill of Rights protects married couples' freedom to use contraceptives).

36. See cases cited *infra* note 39.

37. In *Parham v. J.R.*, 442 U.S. 584, 602 (1978) the Court acknowledged that "parents generally 'have the right, coupled with the high duty, to recognize and prepare their children for additional obligations,'" (quoting *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925)), and this right "includes a 'high duty' to recognize symptoms of illness and to seek and follow medical advice." *Parham*, 442 U.S. at 602.

38. See Comment, *Withholding Treatment from Seriously Ill and Handicapped Infants: Who Should Make the Decision and How—An Analysis of the Government's Response*, 33 DEPAUL L. REV. 494, 509 n.88 (1984) (citing *Parham*, 442 U.S. at 602-03).

39. See *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944) ("Parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children . . ."); *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925) (recognizing parental rights as well as duties to protect the well being of their children); *In Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), *aff'd*, 379 Mass. 732, 744, 393 N.E.2d 836, 843 (1979) (although the court recognized a parental autonomy interest, it cautioned that "parental rights . . . do not clothe parents with life and death authority over their children").

40. *Parens patriae* translates to "parent of the country." BLACK'S LAW DICTIONARY 1003 (5th ed. 1979). The term dates back to English common law where the King had a royal privilege to "act as guardian to persons with legal disabilities such as infants, idiots, and lunatics." *Id.* See *Schall v. Martin*, 104 S. Ct. 2403, 2410 (1984) ("[Children] are assumed to be subject to the control of their parents, and if parental control falters, the state must play its part as *parens patriae*."); *Santosky v. Kramer*, 433 U.S. 745, 766 (1982) (the state has "a *parens patriae* interest in preserving and promoting the welfare of the child"); *Ginsberg v. New York*, 390 U.S. 629, 641 (1968) ("The state also has an independent interest in the well being of its youth."). Historically, the *parens patriae* doctrine was even applied to situations where the sovereign sought to protect children from "objectionable" parents. *E.g.*, *Wellesley v. Wellesley*, 4 Eng. Rep. 1078, 1082 (H.L. 1829). See generally Kleinfeld, *The Balance of Power Among Infants, Their Parents, and the State*, 5 FAM. L.Q. 64, 66-71 (1971) (discussing the *parens patriae* doctrine).



tervene in order to protect the infant. One commentator analogized the parental role to that of a trustee holding the children in trust.<sup>41</sup> When the trust is breached, it becomes the duty of the state to intervene and safeguard the infant from the parents' actions, just as a trustee would intervene to protect property for which he is responsible.

In addition to the common law doctrine of *parens patriae*, child abuse and neglect statutes provide the state with the statutory authority to intervene when necessary to protect the infant.<sup>42</sup> Generally, these statutes define certain "minimal parental duties" and authorize the state to intervene when parents neglect to fulfill those duties.<sup>43</sup> Included in these minimal parental duties is the obligation for parents to provide necessary medical care and attention to their children.<sup>44</sup>

A serious problem arises, however, when parents decide to withhold medical treatment from their newborn infant which another perceives as necessary. Most often these parental decisions are based on religious grounds,<sup>45</sup> apprehension that the risks of treatment will

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41. Brant, *supra* note 20, at 362-63.

42. For a thorough review of all fifty states' child abuse and neglect statutes, see S. KATZ, M. McGRATH & R. HOWE, *CHILD NEGLECT LAWS IN AMERICA* (1976). See also *Child Abuse and Neglect*, 2 CHILD. LEGAL RTS. J., no. 5, at 13 (Mar./Apr. 1981) (discussing the basis and application of child abuse and neglect statutes). The use of statutes enabling state intervention into traditional familial concerns can be traced as far back as 1899. In the case of *Regina v. Senior*, 1 Q.B. 283 (1899), a father failed to provide medical treatment to his eight month old infant suffering from diarrhea and pneumonia. The court, relying on the English statute entitled *Prevention to Cruelty to Children Act* which made it a misdemeanor for any person to "willfully . . . neglect . . . [a] child . . . in a manner likely to cause such child unnecessary suffering, or injury to his health," 57 & 58 Vict., ch. 41, § 1 (1884), found the man guilty of manslaughter. See Robertson, *supra* note 6, at 220 nn.41-43.

43. See *Child Abuse and Neglect*, *supra* note 42, at 15.

44. For example, the Illinois Abused and Neglected Reporting Act, ILL. REV. STAT. ch. 23, § 2053(e) (1981 & Supp. 1984), defines "neglected child" as "any child whose parent or other person responsible for the child's welfare withholds or denies nourishment or medically indicated treatment including food or care . . . ." *Id.*

45. Much of the case-law in this area involves parents who are Jehovah's Witnesses who believe blood transfusions violate the divine law and, therefore, attempt to withhold such treatment from their children. See *Jehovah's Witnesses in Washington v. King County Hosp.*, 278 F. Supp. 489, 491 (W.D. Wash. 1967) (parents refused to allow surgery on religious grounds since it was likely blood transfusions would be needed), *aff'd*, 390 U.S. 598 (1968); *People ex rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, 772 (parents refused blood transfusions to dying daughter stating "we believe it would be breaking God's commandment to . . . take of the blood into our systems.") *cert. denied*, 344 U.S. 824 (1952); *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670, 671 (1971) (court appointed guardian when parents refused to approve daughter's blood transfusions). See also *In re Karwarth*, 199 N.W.2d 147, 150 (Iowa 1972) (court ordered removal of tonsils and adenoids of three minor children over father's resistance); *Craig v. State*, 220 Md. 590, 155 A.2d 684, 690 (1959) (parents' belief in divine healing used to support decision to withhold treatment from child); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, 753 (1962) (Jehovah's Witnesses allowed surgery for their child but requested no blood transfusion).

outweigh the benefits to the infant,<sup>46</sup> or fears that the infant's handicap will impair the quality of the child's life.<sup>47</sup> Where necessary, the state will intervene and challenge the parents' decision to withhold treatment as a breach of parental duty or statutory neglect.<sup>48</sup> In deciding who should determine the appropriate course of treatment, the courts must balance the parents' right to decide the best treat-

sions), *cert. denied*, 371 U.S. 890 (1968); *In re Sampson*, 65 Misc. 2d 641 (N.Y. Fam. Ct. 1970) (Jehovah's Witness denied blood transfusions necessary for surgery on her fifteen year old son), *aff'd*, 37 A.D.2d 688, 323 N.Y.S.2d 253 (1971), *aff'd*, 29 N.Y.2d 900, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972); *In re Clark*, 21 Ohio Op. 2d 86, 185 N.E.2d 128, 129 (Ct. of Common Pleas 1962) (Jehovah's Witnesses refused life saving blood transfusions for their severely burned son); *In re Green*, 448 Pa. 338, 292 A.2d 387, 388 (1972) (Jehovah's Witnesses refuse surgery for their son since it would require blood transfusions).

46. See, e.g., *Bothman v. Warren*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48, 50 (1979) (parents refused surgery on their handicapped son due to alleged uncertainty of diagnosis and risks of surgery), *cert. denied*, 445 U.S. 949 (1980); *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053, 1055 (1978) (parents refused chemotherapy and radiation treatment for their son asserting laetrile treatment would be more appropriate), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979); *Dickson v. Lascaris*, 53 N.Y.2d 204, 423 N.E.2d 361, 440 N.Y.S.2d 884 (1981) (father refused brain surgery for daughter stating there was "nothing we can do about it, let her die"); *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 939 (1979) (parents refused chemotherapy and radiation treatment for their son requesting nutritional therapy instead); *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (father instilled fear of surgery in his fourteen year old son and both refused surgery to correct son's cleft lip and palate); *In re Vasko*, 238 A.D.2d 128, 263 N.Y.S. 552 (1933) (parents refused surgery on son's malignant eye); *In re Green*, 12 CRIME AND DELINQUENCY 377 (Child Div., Milwaukee County Ct. Wisc. 1966) (mother refused to submit child with sickle cell anemia to complex and controversial treatment).

47. E.g., *Bothman v. Warren*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979) (parents openly acknowledged the reason for withholding treatment from their son was due to his potential quality of life as a mongoloid), *cert. denied*, 445 U.S. 949 (1980). The quality of life argument is premised on the belief that whenever the defective infant's potential quality of life is low, death should be preferred over continued existence. Logino, *Withholding Treatment from Defective Newborns: Who Decides, and on What Criteria?*, 31 KAN. L. REV. 377, 395 (1983). In the situation of a defective neonate, the position advanced by some commentators is that the infant's life will be so below normal and void of meaningful human experiences that, if the infant were competent to choose, it would prefer death. See *Death by Default—May a Parent Deny Life-Sustaining Surgery to His Retarded Child?*, 1 CHILD. LEGAL RTS. J., no.6, 23, 24 (May/June 1980) [hereinafter cited as *Death by Default*]. A more extreme argument for withholding treatment from defective handicapped infants is that, due to the severity of their mental retardation or physical handicap, they are essentially "non-persons" or less than human. *Id.* But cf. Bok, *Ethical Problems of Abortion*, 2 HASTINGS CENTER STUD., no. 1, at 33 (1974), where the author severely criticizes such reasoning by arguing:

Slavery, witchhunts and wars have all been justified by their perpetrators on the grounds that they held their victims to be less than fully human. The insane and the criminal have for long periods been deprived of the most basic necessities for similar reasons, and been excluded from society. . . . Even when entered upon with the best of intentions, and in the most guarded manner, the enterprise of basing the protection of human life on such criteria and definitions is dangerous. To question someone's humanity or personhood is a first step to mistreatment and killing.

*Id.* at 44.

48. See cases cited *supra* notes 45-47.

ment for their handicapped infant with the state's right to protect the infant's life from parents who may be acting contrary to its best interests.<sup>49</sup>

A court presented with the issue of whether to override a parental decision must first determine whether the state should be allowed to intervene. Because the presumption exists that parents act in their children's best interests, states have the burden of proving that the child is being denied appropriate care.<sup>50</sup> Historically, courts have given deference to the parents' decision to withhold treatment.<sup>51</sup> Recently, however, several cases dealing with the issue of withholding medical treatment from handicapped children have indicated that too much deference is being paid to the parental choice.<sup>52</sup> Such a trend foreshadows a serious and dangerous departure from the courts' inherent duty to protect and preserve human life.

### THE JUDICIARY'S RESPONSE

#### *When Parents Decide: Three Unfortunate Examples*

##### *The Story of Phillip B.*<sup>53</sup>

Phillip B. is a Down's Syndrome child who was placed in a private care institution at birth.<sup>54</sup> Although his case did not involve a

49. In *Parham v. J.R.*, 442 U.S. 584 (1978), the Court noted that parents "may at times [act] against the interests of their children" which creates a reason for caution, but hardly enough of a reason to completely eradicate the presumption that parents generally do act in the children's best interests. *Id.* at 602 (citing *Bartley v. Kremens*, 402 F. Supp. 1039, 1047-48 (E.D. Pa. 1975), *vacated and remanded*, 431 U.S. 119 (1977)).

50. See, e.g., *Bothman v. Warren*, 92 Cal. App. 3d 796, 800, 156 Cal. Rptr. 48, 51 (1979) ("since the state should usually defer to the wishes of the parents, it has a serious burden of justification before abridging that parental autonomy"), *cert. denied*, 445 U.S. 949 (1980); *Custody of a Minor*, 375 Mass. 733, 794, 379 N.E.2d 1053, 1063 (1978) (court held in order to take a child from the custody of the parents a showing that the child is deprived of physical care or the required care is necessary), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979).

51. See, e.g., *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978) (parental decision given significant deference), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979); *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979) (parents' choice of appropriate treatment must be afforded great deference).

52. See *United States v. University Hospital*, 729 F.2d 144 (2d Cir. 1984) (parents demand to render only conservative treatment instead of the recommended surgery to their newborn child upheld by court); *Bothman v. Warren*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979) (parents' decision upheld even though surgery could have corrected all of their son's physical impairment), *cert. denied*, 445 U.S. 949 (1980); *In re Infant Doe*, *supra* note 20, at 73 (parents allowed to withhold surgery from their newborn child).

53. *Bothman v. Warren*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980).

54. Besides having Down's Syndrome, Phillip was classified as mildly retarded having an I.Q. of slightly below sixty. *In re Guardianship of Phillip B.*, 139 Cal. App.

newborn infant, the issues the case presented are analogous to those raised in instances where handicapped newborns are denied treatment.

When Phillip was six years old, he was diagnosed as having a cardiac defect.<sup>55</sup> A pediatric cardiologist recommended that Phillip undergo a relatively simple and safe diagnostic procedure to determine the condition's severity.<sup>56</sup> Without stating a reason, Phillip's parents refused to authorize the procedure.<sup>57</sup> Four years later Phillip was in need of extensive dental surgery. The oral surgeon, however, refused to administer anesthesia without knowing the extent of Phillip's heart condition.<sup>58</sup> After repeated attempts to persuade Phillip's parents to allow diagnostic procedures to be performed on his heart, they finally acquiesced. Test results showed a serious cardiac defect, and surgery was recommended.<sup>59</sup> Absent surgery, Phillip had little hope of living past the age of thirty.<sup>60</sup> Even though his physician felt the operation would significantly expand Phillip's lifespan, Phillip's parents refused consent.<sup>61</sup>

The California juvenile probation department filed suit requesting it be allowed to intervene. The department alleged that Phillip's parents were depriving him the necessities of life.<sup>62</sup> At trial, the parents openly admitted that Phillip's mental retardation was the primary reason for refusing to consent to surgery.<sup>63</sup> The parents also

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3d 407, 420, 188 Cal. Rptr. 781, 789 (1983). He was institutionalized because his parents believed he would receive better care and because "they were worried about how his presence in the home would effect their other children." Note, *Domestic Relations—Custody—Refusal to Award Custody of Retarded Child to State Where Parents would not Permit Heart Surgery*, 63 MARQ. L. REV. 511, 522 n.56 (1980). At the institution, Phillip slowly learned to dress himself and to do certain chores assigned to him, such as making his bed, helping clear the table, folding laundry, stacking groceries, and feeding his cat. *Id.* Phillip was tested periodically and the results showed that he had good motor and visual skills. *Id.* at 512.

55. *Bothman*, 92 Cal. App. 3d at 799, 156 Cal. Rptr. at 50. It was discovered that he suffered from a ventricular septal defect, a condition evidenced by a hole between the two main chambers of the heart. *Id.*

56. *Id.*

57. *Id.*

58. See Note, *supra* note 54, at 512.

59. *Bothman*, 92 Cal. App. 3d at 800, 156 Cal. Rptr. at 50. The surgery recommended for Phillips usually has less than a ten percent mortality rate. However, the risk to a Down's Syndrome child is greater due to post-operative difficulties. *Id.* Likewise, a condition that is allowed to persist as long as Phillip's is correspondingly riskier to undergo than if it had been corrected earlier in life. *Id.*

60. *Id.* The prognosis that Phillip's physician indicated was that without surgery his lungs would degenerate and gradually be unable to carry or oxygenate blood. Slowly, he would suffer "a progressive loss of energy and vitality until he [was] forced to lead a bed-to-chair existence." *Id.*

61. *Id.* at 801, 156 Cal. Rptr. at 50.

62. *Id.* at 799, 156 Cal. Rptr. at 49-50. The juvenile probation department requested the court to declare Phillip a dependent child of the court in order to insure that he receives the cardiac surgery. *Id.*

63. Baines, *Unequal Protection for the Retarded?* 4 AMICUS, no. 3, 128, 128-29

asserted that they refused consent because of the unacceptably high risk of death.<sup>64</sup> Moreover, Phillip's father testified that he questioned the quality of life that Phillip was experiencing.<sup>65</sup> He expressed fears that "if Phillip outlived him and his wife, he would become a burden on his brothers."<sup>66</sup> Further, he testified that Phillip was better off dead than alive<sup>67</sup> and that the refusal of surgery was "what he thought best for Phillip and for the rest of the family."<sup>68</sup>

The juvenile court judge dismissed the state's petition.<sup>69</sup> He concluded, first, that there was no clear and convincing evidence to support the petition requesting corrective surgery and, second, that the parents had made a decision believed to be in Phillip's best interests.<sup>70</sup> Several commentators have suggested that the judge simply ignored the uncontradicted evidence that without surgery Phillip's heart condition would kill him.<sup>71</sup> In fact, the judge surprisingly decided that the surgery was not necessarily lifesaving because "medical experts have made mistakes before."<sup>72</sup> The California Court of Appeals affirmed the decision, relying on the experts' testimony that the risks of surgery for Phillip would be slightly higher than average.<sup>73</sup> Thereafter, the Attorney General unsuccessfully sought review for Phillip in both the California and United States Supreme Court.<sup>74</sup> Unfortunately, the high courts' refusals to review the case established a precedent that places the plight of the handicapped infant in serious jeopardy.

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(May/June 1979).

64. *Bothman*, 92 Cal. App. 3d at 799, 156 Cal. Rptr. at 50.

65. *Id.*

66. *Note, supra* note 54, at 522 n.56. To add credence to their arguments, the parents received testimony from several doctors that Phillip's life was "devoid of those qualities which give it human dignity." *See Death by Default, supra* note 47. Therefore, they believed Phillip would be a helpless victim to anyone wishing to take advantage of him and that it would be difficult for him to conform to society because of the rejected and isolated ways retarded persons are frequently treated. *Id.*

67. *See Note, supra* note 54, at 518 (citing Trial Transcript at 134, *In Re, Phillip B.*, No. 66103 (Super. Ct. Santa Clara County, Ind. Apr. 27, 1978)).

68. *Note, supra* note 54, at 522 n.56.

69. *Id.*

70. *Bothman*, 92 Cal. App. 3d at 802, 156 Cal. Rptr. at 52. *See also Death by Default, supra* note 47, at 24 (commencing on juvenile court decision); *Note, supra* note 54, at 516 (criticizing parents decision).

71. *See Longino, supra* note 47, at 389; *Death by Default, supra* note 47, at 26; *Note, supra* note 54, at 516.

72. *See Note, supra* note 54, at 516 (citing Trial Transcript at 136, *In re Phillip B.*, No. 66103 (Super Ct. Santa Clara County, Ind. Apr. 27, 1978)).

73. *Bothman*, 92 Cal. App. 3d at 803, 156 Cal. Rptr. at 52. Even though the court held that it could not say "as a matter of law there was no substantial evidence to support the decision of the trial court," *id.* at 803, 156 Cal. Rptr. at 51, neither it nor the juvenile court made any attempt to quantify the increased risk. *See Longino, supra* note 47, at 389 n.81.

74. *Bothman*, 445 U.S. 949 (1979) (denial of certiorari).

### *The Baltimore Tragedy*<sup>75</sup>

In 1972, a mongoloid infant<sup>76</sup> with duodenal atresia,<sup>77</sup> a blockage of the small intestine, was born at John Hopkins Hospital in Baltimore.<sup>78</sup> Doctors involved in the birth, and several consulted afterwards, recommended corrective surgery.<sup>79</sup> The parents, however, refused consent. They argued that it would be unfair to their two normal children to bring a mongoloid infant home.<sup>80</sup>

Pursuant to a state statute,<sup>81</sup> doctors from the hospital immediately petitioned a Maryland court to appoint a guardian for the infant who could authorize the necessary lifesaving surgery.<sup>82</sup> The court, however, refused to intervene in the parents' decision and denied the state's request.<sup>83</sup> The court declared that it would not force

75. Case opinion not published. Although the opinion of this case is unpublished, references to the juvenile hearing appear in several sources. Four of these sources will be cited to aid the reader in locating further information. See Brown & Truitt, *Euthanasia and the Right to Die*, 3 OHIO N.U. L. REV. 615, 634 (discussion of case); *Death by Default*, *supra* note 47, at 23 (discussion of case); Ellis, *supra* note 3, at 400-01 (discussion of case); Freeman, *The God Committee*, N.Y. Times, May 21, 1972, § 6 (Magazine), at 84 (a doctor's perspective of the case). The incident received significant press coverage and a documentary entitled "The Baltimore Tragedy" was made concerning it. See Freeman, *supra*, at 84.

76. Mongolism, or Down's Syndrome named after John Langdon Haydon Down the geneticist who first described the condition, is the presence of one extra chromosome in the human nucleus. See Shaw, *Doctor, Do We Have A Choice?*, N.Y. Times, Jan. 30, 1972, § 6 (Magazine), at 44. Instead of having the normal forty-six chromosomes, a mongoloid infant has forty-seven. It has been noted that:

Virtually all individuals with Down's Syndrome have some degree of developmental retardation. The range of I.Q. scores has been wide, but most individuals are trainable by adulthood. Social skills usually are closer to the normal range than performance abilities. . . . The degree of mental retardation is quite variable, but most children learn to walk and develop some communication skills; there is a steady progress of development, at a lower pace than usual . . . [and c]hildren reared at home have higher I.Q.'s than those reared in institutions.

A. RUDOLPH, PEDIATRICS 244 (17th ed. 1983).

77. Duodenal atresia frequently accompanies mongolism. See Shaw, *supra* note 76, at 44.

78. See Brown & Truitt, *supra* note 75, at 634; *Death by Default*, *supra* note 47, at 23; Ellis, *supra* note 3, at 400; Freeman, *supra* note 75, at 84; Shaw, *supra* note 76, at 44-45.

79. See Brown & Truitt, *supra* note 75, at 634; *Death by Default*, *supra* note 47, at 23; Ellis, *supra* note 3, at 400; Freeman, *supra* note 75, at 84; Shaw, *supra* note 76, at 44-45. Such a surgery is relatively simple and risk free to the infant and, once performed, relieves the infant of pain and other complications associated with the defects. Freeman, *supra* note 75, at 84.

80. *Death by Default*, *supra* note 47, at 24. It should be noted that mongoloid infants usually grow into happy family members and, albeit retarded, beneficial and useful citizens. See Freeman, *supra* note 75, at 84. For a discussion of Down's Syndrome childrens' lifestyles, see *supra* note 76.

81. See MD. FAM. LAW. CODE ANN. § 5-317 (1984).

82. See Brown & Truitt, *supra* note 75, at 634; *Death by Default*, *supra* note 47, at 24; Ellis, *supra* note 3, at 400; Freeman, *supra* note 75, at 84.

83. See Brown & Truitt, *supra* note 75, at 635; *Death by Default*, *supra* note 47, at 24; Ellis, *supra* note 3, at 400; Freeman, *supra* note 75, at 85.

the parents—or society—to bear the burden of rearing such a child.<sup>84</sup> Subsequent to the ruling, all supportive therapy including intravenous feedings were discontinued.<sup>85</sup> Fifteen days later the infant succumbed to dehydration and died.<sup>86</sup>

Unlike Phillip B.'s surgery, this case presented no unacceptably high risks associated with the recommended surgery.<sup>87</sup> Nevertheless, the court refused to intervene. The direct result of the holding was to save the parents the burden of rearing a handicapped infant while allowing the termination of a human life.

### *The Story of Infant Doe*<sup>88</sup>

Infant Doe was born in Bloomington, Indiana, on April 9, 1982<sup>89</sup> with two congenital anomalies, Down's Syndrome<sup>90</sup> and a repairable condition where the esophagus is attached to the trachea which, if not surgically corrected, causes death by suffocation.<sup>92</sup> The Doe's obstetrician consulted with two other obstetricians and three pediatricians regarding the appropriate course of treatment. The three pediatricians recommended that Infant Doe receive corrective surgery and the three obstetricians recommended that the infant not receive the surgery but instead be allowed to die.<sup>93</sup> Similar to the former cases, the three obstetricians based their decision on a quality of life argument claiming that "even if the surgery were successful, the possibility of a minimally adequate quality of life was non-existent due to the child's severe and irreversible mental retardation."<sup>94</sup>

84. See Brown & Truitt, *supra* note 75, at 635; *Death by Default*, *supra* note 47, at 25; Ellis, *supra* note 3, at 401-02; Freeman, *supra* note 75, at 85.

85. See Brown & Truitt, *supra* note 75, at 635-56; *Death by Default*, *supra* note 47, at 25; Ellis, *supra* note 3, at 402; Freeman, *supra* note 75, at 86.

86. See Brown & Truitt, *supra* note 75, at 635-56; *Death by Default*, *supra* note 47, at 26; Ellis, *supra* note 3, at 402; Freeman, *supra* note 75, at 86.

87. See *supra* note 59.

88. For the official cite to the Infant Doe case, see *supra* note 20.

89. *In re Infant Doe*, *supra* note 20, at 73.

90. For a discussion of Down's Syndrome, see *supra* note 76.

91. See Pless, *The Story of Baby Doe*, 309 NEW ENG. J. MED. 664 (1983). The media reported that the defect could not be required. See, e.g., Indianapolis Star, Apr. 16, 1982, at 1, col. 4. However, an autopsy performed on Infant Doe revealed that the defect was not as severe as originally believed. See Kuzma, *The Legislative Response to Infant Doe*, 59 IND. L.J. 377, 377 n.2 (1984).

92. More specifically, this is a condition where the esophagus ends in a pouch, with an abnormal connection between the trachea and the esophagus which causes substances taken orally to pass to the lungs instead of the stomach. See generally, G. AVERY, NEONATOLOGY PATHO-PHYSIOLOGY AND MANAGEMENT OF THE NEWBORN 798-99 (2d ed. 1981); R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 893-94.

93. See *In re Infant Doe*, *supra* note 20, at 73-74.

94. One pediatrician, however, did testify to the contrary arguing that Down's Syndrome children often lead lives of reasonable quality. *Id.* See also A. RUDOLPH, *supra* note 76, at 244 (referring to the acceptable quality of life experienced by most

Within twenty-four hours the case was brought before an Indiana court.<sup>95</sup> The issue presented was "[w]hether Mr. and Mrs. Doe, as natural parents of Infant Doe, have a right, after having been fully informed of the consequences, to determine the appropriate course of treatment for their minor child?"<sup>96</sup> The court answered affirmatively and allowed the parents to decide the fate of their newborn baby.<sup>97</sup> Six days later on April 15, 1982, infant Doe died from multiple congenital abnormalities<sup>98</sup>—abnormalities that, aside from the retardation, could have been corrected. Nevertheless, like in the former cases, the court decided that the parents' had made a fully informed decision.<sup>99</sup> Additionally, the court reasoned that it lacked the authority to intervene in a decision that was in the best interests of the infant.<sup>100</sup>

### *The Judiciary's Response—A Critique of Failure*

Each of these three cases exemplify the unwillingness of various state courts to provide adequate protections to handicapped infants. In reality, the courts have subtly abandoned their premier responsibility to preserve life while keeping up the facade of carefully balancing the parental and state interests involved. An analysis of these cases indicates at least three reasons why the judiciary's trend unjustifiably threatens the future of these helpless individuals.

First, the courts' unyielding deference towards parental autonomy in cases where a handicapped infant's life is in question is contrary to the United States Supreme Court ruling in *Roe v. Wade*.<sup>101</sup> In *Roe*, the Court faced the issue of whether a state could interfere in a woman's decision to have an abortion.<sup>102</sup> While the decision to abort a fetus does not initially seem to parallel the decision to affirmatively withhold lifesaving treatment from a severely handicapped newborn, some commentators argue that any distinctions are insubstantial.<sup>103</sup> Arguably, they assert that the right to abortion im-

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Down's Syndrome children).

95. See *In re Infant Doe*, *supra* note 20, at 74.

96. *Id.* at 75.

97. *Id.*

98. Kuzma, *supra* note 91, at 378 (quoting Bloomington Herald-Telephone, Apr. 20, 1982, at 1, col. 5).

99. *In re Infant Doe*, *supra* note 20, at 75-76.

100. *Id.* at 76.

101. 410 U.S. 113 (1973).

102. *Id.* For recent articles on the impact of the *Roe* decision, see generally Coleman, *Roe v. Wade: A Retrospective Look at a Judicial Oxymoron*, 29 St. Louis U.L.J. 7 (1984) (discussing the current state of confusion in the courts because of *Roe*); Ginsberg, *Some Thoughts on Autonomy and Equality in Relation to Roe v. Wade*, 63 N.C. L. REV. 375 (1985) (suggesting the *Roe* opinion may have actually led to greater anti-abortion measures).

103. See Shaw, *Death of 'Infant Doe': Why All the Surprise?*, Wash. Post, May



pliedly creates the right to withhold care from unwanted newborns.<sup>104</sup>

Similarly, courts that have ruled against the right of states to intervene in the parental decision to withhold treatment<sup>105</sup> have done so in contradiction to the Court's reasoning in *Roe*. There, the Court held that as the pregnancy of a woman progresses, the interests of the state in protecting and promoting that potential human life increase.<sup>106</sup> At the point the fetus becomes viable, or able to sustain life outside the mother's womb, the state's interests exceed the right of the mother to abort.<sup>107</sup> On this point, the Court noted that "[s]tate regulation protective of fetal life after viability thus has both logical and biological justifications."<sup>108</sup> Therefore, in matters regarding the appropriate treatment for handicapped infants, state courts should continue to recognize the substantial parental rights but should give greater cognizance to the states' right to intervene where a child's life is threatened. Because the Supreme Court has ruled that the state's interest in a viable fetus is significant enough to override a mother's decision to abort it, the state's interest should be even more significant where parents endanger the life of their newborn for reasons of the infant's handicap. To allow otherwise is to unjustifiably denigrate the handicapped infant to the status of

15, 1982, at A19, col. 2. The argument as stated is how can a healthy unborn fetus be legally aborted when a defective newborn be required to survive at all costs. *Id.* See also Weir, *supra* note 2, at 663 (quoting the Indiana Supreme Court Chief Justice: "We cannot pass a law saying doctors have to save every child that is born"). The fault of the argument, however, lies in its presumption that those opposing it desire to save 'all' defective infants. What is sought is not to save 'all' handicapped infants but only those who would have lived but for the parents' decision to withhold nutrition, hydration or medicine because of the infant's handicap. See *infra* text accompanying notes 179-83.

104. Logino, *supra* note 47, at 379. These critics state as their argument: "if it is permissible to abort a defective fetus, even after it is viable, the issue is whether it is impermissible to starve a defective newborn. The only distinction between the defective, viable fetus and the defective newborn is that the newborn is no longer *in utero*." *Id.* (emphasis in original).

105. See cases cited *supra* note 20.

106. *Roe*, 410 U.S. at 165. The Court summarized these negatively correlated interests by noting:

(a) For the stage prior to approximately the end of the first trimester, the abortion decision and its effectuation must be left to the medical judgment of the pregnant woman's attending physician.

(b) For the stage subsequent to approximately the end of the first trimester, the State, in promoting its interests in the health of the mother may, if it chooses, regulate the abortion procedure in ways that are reasonably related to maternal health.

(c) For the stage subsequent to viability, the State in promoting its interest in the potentiality of human life may, if it chooses, regulate and even proscribe, abortion. . . .

*Id.* at 164-65.

107. *Id.*

108. *Id.* at 163.

something less than a human being.

Second, the judiciary's trend threatens handicapped infants because the courts have not adequately considered the infant's constitutional rights. When confronted with a request from a state to intervene in a parents' decision to withhold medical treatment, the courts have applied several approaches. The best interests of the child approach, the substituted judgment approach, and the "Hofbauer" approach have all been applied to judge the decision to withhold treatment, but each differs in name only.<sup>109</sup> The underlying issue in applying any of the approaches is to determine whether the decision is compatible with the best interests of the child.<sup>110</sup>

The courts, however, in premising their holdings on the "best interests of the infant" standard are really applying a fiction.<sup>111</sup> The application of any of these approaches is illusory because of their inherent subjectivity, indicating that the infant's interests really depend on the person or court defining them.<sup>112</sup> Further, in defining

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109. Generally, three approaches are used. First, "the best interest of the child" approach assesses the decision from the perspective of the child. *E.g.*, *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979). *But see infra* note 116 for several sources criticizing the "best interest" standard. Second, the "substituted judgment" approach is used to determine whether the newborn would, if competent, make the same decision. *E.g.*, *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977). This approach reaches back to English law where the courts were empowered to "don the mental mantle of the incompetent" allowing them to act according to the same motives and interests as the competent individual would have used in deciding for himself. *Id.* at 752, 370 N.E.2d at 431. Third, the "Hofbauer" approach, *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979), is used where the parents and physician agree to a course of treatment but a third party argues that the treatment is inappropriate. *Id.* at 656, 393 N.E.2d at 1014, 419 N.Y.S.2d at 944. The court in using the "Hofbauer" approach, decides if the parents' decision provides an acceptable course of medical treatment in light of all the circumstances of the case. *Id.* While all purport to consider different aspects of the problem, they all conclude by weighing the same general interests and motives in deciding if treatment may be ordered over parental objectives. *See generally* Comment, *supra* note 38, at 517 (analyzing the three approaches).

110. Comment, *supra* note 38, at 517-18.

111. *See Bothman*, 92 Cal. App. 3d at 802, 156 Cal. Rptr. at 54 ("the underlying consideration is the child's welfare and whether his interests will be served"); *In re Kawarth*, 199 N.W.2d 147, 150 (Iowa 1972) (parental rights can be contravened if the best interests and welfare of the children in the state's custody and care reasonably require medical treatment); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765, 775 (1942) (natural law gives parents the right to give children such attention as in their best interests is needed).

112. Note, *Birth Defective Infants: A Standard for Non-Treatment*, 30 STAN. L. REV. 599, 606 (1979). *See also In re LaRue*, 244 Pa. Super. 218, 226-27, 366 A.2d 1271, 1275 (1976) (criticizing the "best interests of the child" standard as being too dependent on judges' and social workers' convictions). *See generally* J. GOLDSTEIN, A. FREUD & A. SOLNIT, *BEYOND THE BEST INTEREST OF THE CHILD* 54 (1973) (opinions using this standard are given "in name only" to actually fulfill the desires of competing adult complainants); Wald, *State Intervention on Behalf of "Neglected" Children: Standards for Removal of Children from Their Homes, Monitoring the Status of Children in Foster Care, and Termination of Parental Rights*, 28 STAN. L. REV.

these interests, as discussed in the three examples, the quality of life argument often misdirects the court's focus from protecting the infant's right to life to saving the parents the burden and anguish of raising a handicapped child.<sup>113</sup> If decisions that paradoxically allow handicapped infants to die under the guise of being in their own best interests are condoned, the word "person" in the Constitution<sup>114</sup> will insidiously and grievously be read to exclude defective newborns.

Third, handicapped infants' rights are not being fully protected because out of the limited number of state courts that have been called upon to resolve the conflict between parents and the state, no reported decision has ever imposed criminal liability on a parent for withholding treatment from a defective newborn.<sup>115</sup> The lack of any definitive ruling has caused the public to misinterpret the courts' failure to act. For instance, until the federal government intervened with legislation<sup>116</sup> that established guidelines regarding when treatment could be withheld from seriously ill or handicapped newborns, one national magazine asserted:

The courts have provided little guidance in the issue. . . . [T]hey have yet to rule definitively on the question of withholding treatment from grossly malformed newborns: no legal action has been brought against parents for refusing to authorize such treatment. As a result, the painful decision to treat or not to treat a deformed infant rests squarely on the shoulders of the parents and their physician.<sup>117</sup>

This language has as much import today as it did when it was published in 1974, because to date only one case exists where parents were charged with attempting to murder their defective newborn twins by withholding treatment from them.<sup>118</sup> The parents, however, were subsequently acquitted when the court held that there was in-

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625, 649-50 (1976) (asserting this standard is deficient because no state statute has identified factors for courts to consider in determining child's best interests).

113. See *In re LaRue*, 244 Pa. Super. at 226-27, 366 A.2d at 1275.

114. See, e.g., U.S. CONST. amend. V. In *Roe* the Court acknowledged that "the word 'person' as used [in Constitution] does not include the unborn." *Roe*, 410 U.S. at 158. It seems contrary to our nation's precepts that life is only to be guaranteed to our most healthy newborns.

115. But see *infra* note 118.

116. For a discussion of this legislation, see *infra* text accompanying notes 121-75.

117. 103 TIME MAG., Mar. 25, 1974, at 84.

118. In 1981, the State of Illinois brought charges of attempted manslaughter against two parents, and conspiracy charges against the physician and nurse involved in the birth of their malformed twins. See N.Y. Times, June 12, 1981, at 19, col. 1 (case opinion not published). The twins were born attached at the waist and sharing a common third leg. *Id.* They also had internal defects which included a shared stomach and bowel. *Id.* See also *Town Debates Siamese Twins' Case*, N.Y. Times, July 2, 1981, at 17, col. 1 (reporting on neighbors' reactions and discussing testimony from custody hearing).

sufficient cause to charge them with the offense.<sup>119</sup> Not in that case or any other, has a court attempted to delineate any guidelines for those parents endeavoring to make an appropriate decision regarding the care of their infant.<sup>120</sup>

These three reasons indicate the plight that handicapped infants face. The judiciaries' trend has misled the public to believe that the issue remains undecided and that parents and physicians are free to continue making decisions with little fear of liability. Fortunately for handicapped neonates, the federal government halted the courts' dangerous trend when it intervened in support of these innocent infants.

### THE GOVERNMENT'S RESPONSE

#### *The Initial Response—The Rehabilitation Act of 1973*<sup>121</sup>

Following the well publicized Infant Doe case,<sup>122</sup> President Reagan took a personal interest in the plight of the handicapped infant. On April 30, 1982, he directed the Secretary of the Department of Health and Human Services (HHS) to notify the nation's health care administrators that section 504 of the Rehabilitation Act of 1973<sup>123</sup> applied to the treatment of handicapped newborns.<sup>124</sup> Section 504, in part, reads: "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from

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119. See *Judge Acquits Siamese Twins' Parents of Attempted Murder*, N.Y. Times, July 29, 1981, at 22, col. 3. See also *Siamese Twin Boys Returned to Custody of Parents in Illinois*, N.Y. Times, Sept. 16, 1981, at 13, col. 2 (reporting that the judge returned the boys to the parents so they could share the infants' last few months together).

120. But see *Bothman*, 92 Cal. App. 3d at 802, 156 Cal. Rptr. at 51, where the court referred to several factors that it considered in upholding the parents' decision to withhold treatment.

121. 29 U.S.C. § 794 (1982).

122. For the official cite to the Infant Doe case, see *supra* note 20. For several newspaper articles discussing the events surrounding the Infant Doe Incident, see *Bloomington Herald-Telephone*, Apr. 16, 1982, at 1, col. 1; *Baby Dies Before Court Could Be Asked to Save It*, Boston Globe, Apr. 16, 1982, at 5, col. 1; *Evansville Couple Races the Clock, Law to Save "Condemned Baby"*, Evansville Courier, Apr. 15, 1982, at 1, col. 2; Washington Post, Apr. 16, 1982, at A16, col. 1; CBS Evening News (May 18, 1982), cited in *American Academy of Pediatrics*, 561 F. Supp. at 399; MacNiel Lehrer Report, *Saving Handicapped Newborns* (Transcript No. 1738 May 18, 1982), cited in *American Academy of Pediatrics*, 561 F. Supp. at 399.

123. 29 U.S.C. § 794 (1982).

124. Letter from President Ronald Reagan to Secretary Schweiker (Apr. 30, 1982), cited in Kuzma, *supra* note 91, at 386 n.91. Regarding the applicability of section 504 to the situation of withholding medical treatment from newborn infants, see *University Hospital*, 729 F.2d at 156 ("If Congress intended section 504 to apply in this manner, it chose strange language indeed"); *American Academy of Pediatrics*, 561 F. Supp. at 402 (the House nor the Senate ever suggested section 504 to be used to monitor medical treatment); Wash. Post, May 1, 1982, at A11, col. 3 (editorial regarding section 504's applicability).

participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ."<sup>125</sup> Shortly thereafter, the Department of HHS issued a formal notice entitled "Notice to Health Care Providers" listing the situations to which the section would apply.<sup>126</sup>

A year later on March 7, 1983, the Department of HHS, acting pursuant to a regulatory grant embodied in the Rehabilitation Act of 1973,<sup>127</sup> issued the first government regulation attempting to curb the withholding of treatment from handicapped infants.<sup>128</sup> The regulation established a Handicapped Infant Hotline whereby "any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical treatment should immediately contact either [the hotline] or their appropriate state child protection agency."<sup>129</sup> The regulation also required the posting of a notice in designated places within hospitals receiving federal funds<sup>130</sup> and authorized the Department of HHS to immediately investigate situations where treatment was allegedly being denied.<sup>131</sup>

125. 29 U.S.C. § 794 (1982).

126. Discriminating Against the Handicapped by Withholding Treatment or Nourishment, Notice to Health Care Providers, 47 Fed. Reg. 26, 27 (June 16, 1982). The notice read, in part:

Under Section 504 it is 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 medically contraindicated.

*Id.*

127. 29 U.S.C. § 794 (1982) (authorizing the head of each agency providing federal financial assistance to promulgate regulations necessary to carry out the Rehabilitation Act of 1973).

128. Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9630 (1983) (to be codified at 45 C.F.R. § 84) (*invalidated by American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983), *cert. granted sub nom. Heckler v. American Hospital Ass'n*, 53 U.S.L.W. 3881 (U.S. June 18, 1985)) [hereinafter cited as Interim Final Rule]. The rule, to have taken effect on March 22, 1983, was to establish procedures for timely investigation and immediate enforcement where necessary to protect those handicapped infants whose lives were being threatened by a discriminatory decision to withhold medical treatment. *Id.* at 9630.

129. Interim Final Rule, at 9631 (to be codified at 45 C.F.R. § 84).

130. *Id.* The notice was required to read: "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW" and be posted "in a conspicuous place in every delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery." *Id.*

131. *Id.* at 9632. The final rule significantly shortened the period of time in which the DHHS could intervene to force the hospital's compliance. The existing regulation, 45 C.F.R. § 80.8(d)(3) (1983), allowed for a ten day waiting period between the time of notifying the federal grant recipient of the alleged violation and the time the DHHS could physically intervene to enforce compliance. The interim final rule authorized immediate remedial action where the life or health of a handicapped infant was in danger. Interim Final Rule, *supra* note 128, at 9632. Additionally, it

Widespread criticism of the government's intervention quickly followed the publication of the Department of HHS's rules.<sup>132</sup> Subsequently, on April 14, 1983, the District Court for the District of Columbia ruled that the Department of HHS's regulations were an arbitrary and capricious agency response<sup>133</sup> established outside the procedural requirements of the Administrative Procedure Act<sup>134</sup> and, therefore, invalid. On July 5, 1983, the Department of HHS published new proposed regulations<sup>135</sup> conforming to the Administrative Procedure Act which to a great degree mirrored the former regulations.<sup>136</sup> Then on January 12, 1984, the Department of HHS

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lengthened the period of time during which the DHHS could recover information pertinent to the compliance investigation. *Id.* The existing regulation allowed the DHHS to obtain necessary information only during normal business hours. 45 C.F.R. § 80.6(c) (1983). Also, the interim final rule provided twenty-four hour access rights to the DHHS when it felt immediate access was necessary to protect a handicapped infant. Interim Final Rule, *supra* note 128, at 9632.

132. See generally Tift, *Debate on the Boundary of Life*, 121 TIME MAG., Apr. 11, 1983, at 68, 69 (listing general reactions of physicians, pro-life groups and President's Commission); Weir, *supra* note 2, at 663 (physicians' and hospital organizations' reactions to the interim final rules).

133. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983), *cert. granted sub nom. Heckler v. American Hospital Ass'n*, 53 U.S.L.W. 3881 (U.S. June 18, 1985) (the National Association of Children's Hospitals and Related Institutions and Children's Hospital Medical Center joined the American Academy of Pediatrics in bringing suit). In particular, the DHHS violated a sixty day notice requirement imposed by The Administrative Procedure Act, 5 U.S.C. § 553(b) (1982). See *American Fed'n of Gov't Employees v. Block*, 655 F.2d 1153, 1156 (D.C. Cir. 1981) (the greater the number of people effected by the regulation, the greater the need to preserve the right of comment).

134. *American Academy of Pediatrics*, 561 F. Supp. at 398. Generally, the Administrative Procedure Act, 5 U.S.C. §§ 551-706 (1982), provides that all authorities of the government, including the DHHS, are subject to judicial review. *Id.* § 701(b)(1). Further, section 706(2) provides a list of criteria the reviewing courts are to use in assessing the legality of an agency's action, finding, or conclusion. *Id.* § 706(2). See generally Comment, *supra* note 38, at 505-07 nn.65-75 (general discussion of the APA).

135. Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. § 84.61(b)-61(e)) (proposed July 5, 1983) [hereinafter cited as Health Care Notice]. These rules, unlike the interim final rules, see Interim Final Rule, *supra* note 128, provided for a sixty day notice and comment period as required by the Administrative Procedure Act. 5 U.S.C. § 553(b) (1982).

136. There were three minor changes in the proposed rules. The first change consisted of the notice requirement being made more specific. The size of the public notice was reduced from 14" x 17" to 8.5" x 11" and the placement of the notice was now required to be in the infant care wards' nurses' stations instead of in the infant care wards. See Health Care Notice, *supra* note 135, at 30,851. The second change was a requirement that state child protective agencies establish written procedures for responding to alleged cases of treatment being wrongly withheld. *Id.* at 30,846. The third change was in the form of a supplementary information and appendix section to the proposed rules attempting to clarify their intent and application. *Id.* at 30,845-51. The supplementary information and appendix section addressed four issues: first, the meaning of the term "handicaps" as it applies to infants was clarified, *id.* at 30,851; second, the conditions under which section 504 would be applicable was defined, *id.* at 30,847; third, the factual support for the rulemaking efforts was disclosed, *id.* at 30,845-50; and fourth, the substance of the rule and its anticipated ef-

published final rules in the Federal Register.<sup>137</sup> The Department of HHS acknowledged that the final rules embodied many of the recommendations found in the 16,739 letters<sup>138</sup> they received during the proposed rules' notice and comment period.<sup>139</sup>

Shortly after these rules were published, the Department of HHS responded to a complaint that an infant was being discriminatorily denied medical treatment.<sup>140</sup> The Secretary of the Department

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fects were explained. *Id.* at 30,850-51. These additions to the proposed rule were aimed at the very issues raised by the District of Columbia district court in holding the original rule invalid. *American Academy of Pediatrics*, 561 F. Supp. at 403.

137. Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, 49 Fed. Reg. 1622 (1984) (to be codified at 45 C.F.R. § 84) [hereinafter cited as Procedures and Guidelines].

138. *Id.* Interestingly, of the 16,739 responses received, 16,331 (97.5%) supported the rules while only 408 (2.5%) opposed them. *Id.* at 1623. A partial breakdown of the particular groups responding shows: nurses, 97.5% supported, 2.5% opposed; pediatricians or newborn care specialists, 27.7% supported, 72.3% opposed; hospital and health care related associations, 22.6% supported, 77.4% opposed; associations representing the handicapped, unanimous support; parents of handicapped persons, 95% supported, 5% opposed. *Id.*

139. The first change in the final rules was an "encouragement" for hospitals to create Infant Care Review Committee along with a suggested framework for establishing such committees. *Id.* at 1650-51. For a discussion of the purpose and structure of these committees, see *infra* note 163.

The second change dealt with the posting of public notices in the hospitals. The final rules altered the public notices' placement, size and wording. Procedures and Guidelines, *supra* note 137, at 1625-26. The final rules altered the public posting requirement by giving the hospitals a choice between two notices, both eliminating any inference of improper conduct by the hospital, and also reducing the size of notice from 8.5" x 11" to 5" x 7". *Id.* Further, the placement of the notices was changed from the requirement of being in the nurses' stations to "any location(s) where nurses and other medical professionals who are engaged in providing health care related services to infants will be aware of the content of the notice." *Id.* at 1626.

The third change, contained in the appendix to the final rules, was considered the most important change. *Id.* at 1653. In this section, the DHHS set forth interpretative guidelines for applying the rules to the handicapped infant's situation. For example, the DHHS indicated that futile treatment could be withheld without violating the law, if such withholding was based on "reasonable medical judgments" and not solely on the basis of an infant's handicap. *Id.* The guideline stated that "[f]utile treatment or treatment that will do more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant." *Id.*

The last change in the final rules dealt with the procedures the DHHS would use in responding to alleged claims of medical discrimination. *Id.* at 1654. These changes mainly added procedural safeguards for the parents and physicians not embodied in the proposed rules. Among these safeguards, for instance, was the understanding that the DHHS would not directly intervene with an on-site investigation unless, after notifying the hospital of the suspected violation of section 504, the hospital refused to cooperate in ensuring compliance. *Id.* at 1654. For an indepth analysis of the changes embodied within the final rules, see generally Comment, *supra* note 38, at 541-43 n.\*.

140. *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984). The baby, nick-named Baby Jane Doe by the media, was born on October 11, 1983 at St. Charles Hospital in Port Jefferson, New York. *Id.* at 146. She had several birth defects, the most serious of which was myelomeningocele, commonly known as spina bifida; microcephaly, an abnormally small head; and, hydrocephalus, an accumulation of fluid in the cranial fault. *Id.* Additionally, she exhibited a "weak face," a condition

of HHS, on a request from the Attorney General, petitioned the hospital involved for the infants' medical records.<sup>141</sup> After repeatedly being denied access to those records,<sup>142</sup> the Department of HHS filed suit alleging that the hospital's withholding of medical records was a violation of both section 504 and title 45, section 80.6(c) of the Federal Code of Regulations.<sup>143</sup> The court in *United States v. University Hospital*<sup>144</sup> held for the hospital, reasoning that the treatment was justifiably withheld from the infant.<sup>145</sup> Further, the court determined that the decision to withhold treatment was not the result of any discrimination, therefore, the hospital was justified in withholding the medical records.<sup>146</sup>

The United States Court of Appeals for the Second Circuit dealt a fatal blow to the government's method of intervention. It held that neither the legislative history,<sup>147</sup> the case law interpreting

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where the infant cannot close its eyelids or make a full suck with the tongue; a malformed brain stem; upper extremity spasticity; and a thumb entirely within her fist. *Id.* Due to the spina bifida, Baby Jane's rectal, bladder, leg, and sensory functions were also impaired. *Id.* The prognosis was that the infant would be so severely retarded that she would not be able to interact with her environment or other people. *Id.* Surgery was possible to correct the exposed spine and to lessen the crainal pressure due to the fluid accumulation. Such surgery, however, would not correct many of her handicapping conditions, including her mental retardation. *Id.* After consulting numerous medical professionals, clergy, and social workers, the parents decided to forego surgery and, instead, opted for a "conservative" medical treatment in the form of good nutrition, administration of antibiotics, and a dressing of the exposed spinal column. *Id.*

141. *Id.* at 147.

142. *Id.* These requests were made while the New York State Child Protective Service Agency was investigating the incident. Five days after the federal government brought suit against the hospital for refusing to comply with their requests, the State Child Protective Service Agency concluded that there was no cause for state intervention. *Id.* at 147-48. For an analysis of the purpose of state child protective service agencies, see *infra* note 156.

143. 45 C.F.R. § 80.6(c) (1984). This section of the code requires recipients of federal funds to provide the Department of HHS "access to such records as may be pertinent to ascertain compliance with" section 504.

144. 729 F.2d 144, 148-49 (2d Cir. 1984).

145. The court reasoned that if the recipient of federal funds was clearly not discriminating against the handicapped infants, HHS could not gain access to the records held by the recipient. *Id.* at 148. The court concluded "that the hospital 'failed to perform the surgical procedures in question, not because Baby Doe [was] handicapped, but because her parents refused consent to such procedures.'" *Id.* As for the parents' decision, the court stated that the refusal to withhold the surgical treatment was a reasonable one based on due consideration of the options available and on a genuine concern for the best interests of the infant. *Id.* at 149.

146. *Id.* at 160.

147. The court reasoned that the legislative history of the statute indicated that Congress never intended section 504 to apply to treatment decisions of this nature. *Id.* at 157. 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." *Id.* at 161 (citing *Montana Power Co. v. Federal Power Commission*, 445 F.2d 739 (D.C. Cir. 1970) (*en banc*), cert. denied, 400 U.S. 1013 (1971)).



section 504,<sup>148</sup> nor the purposes of the Rehabilitation Act of 1973 sustained the Department of HHS's purported authority to obtain the infant's medical records.<sup>149</sup> 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."<sup>150</sup> In response, Congress passed The Child Abuse Amendments of 1984<sup>151</sup> to provide this clear congressional directive.

### *The Modified Response—The Child Abuse Amendments of 1984*

In 1974, The Child Abuse Prevention and Treatment Act was signed into law.<sup>152</sup> The Act established The Department of the National Center on Child Abuse and Neglect.<sup>153</sup> In October, 1984, the act was amended when Congress passed the Child Abuse Amendments (the "CAA") which added a new state grant requirement and included "withholding medically indicated treatment" as a form of child neglect.<sup>154</sup> Thereafter, in order to receive grants under the CAA, states must establish programs or procedures within their child protective service systems designed to respond to reports of medical neglect including reports of the withholding of medically indicated treatment from handicapped infants with life-threatening conditions.<sup>155</sup>

148. *Id.* at 160. *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). *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).

149. *University Hosp.*, 729 F.2d at 161.

150. *Id.*

151. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984) (amending 42 U.S.C. §§ 5101-5115 (1982)).

152. Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5115 (1982). For a general overview of the history and passage of the Act, see S. REP. NO. 246, 98th Cong., 2d Sess. 2-5 (1984).

153. The National Center's primary responsibilities are to make state grants to implement child abuse and neglect treatment programs, fund public and private research organizations attempting to prevent, identify, and treat child abuse and neglect, and to coordinate federal child abuse and neglect programs. 42 U.S.C. § 5101 (1982). *See generally* Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14878 (1985) (to be codified at 45 C.F.R. § 1340) (a background summary of the NCCAN, its purpose and goals) [hereinafter cited as Final Rules].

154. Child Abuse Amendments of 1984, Pub. L. No. 98-457, §§ 121-23, 98 Stat. 1749, 1752-53 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5103 (1982)).

155. *Id.* § 122, 98 Stat. at 1752. *See also* Final Rules, *supra* note 153, at 14878. All fifty states have a Child Protective Service (CPS) system regardless of whether the state obtains federal grant money under the Act. *Id.* These agencies are desig-

The CAA's primary goal is to eliminate situations where medical treatment is withheld from a handicapped newborn because of the parents' or physician's subjective analysis of the infant's handicap and future quality of life.<sup>156</sup> Under the statute, medical treatment must be administered to an infant with life-threatening defects when reasonable medical judgment indicates that such treatment is likely to ameliorate or eliminate the infant's defects.<sup>157</sup> The CAA also define the withholding of such treatment as a form of "medical neglect" to be included in the statute's general category of child abuse and neglect.<sup>158</sup>

The CAA, however, list three exceptions to the requirement of administering medically indicated treatment to handicapped newborns. For example, such treatment need not be given where:

- A. the infant is chronically and irreversibly comatose;
- B. the provision of 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.<sup>159</sup>

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nated 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.* See generally Illinois Abused and Neglected Reporting Act, ILL. REV. STAT. ch. 23, § 2057 (Supp. 1984) (CPS system authorizing statute).

156. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121, 98 Stat. 1749, 1752 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5101 (1982)). "The term 'withholding of medically indicated treatment' as used in the statute, 'does not sanction decisions based on the subjective opinions about the future "quality of life" of a retarded or disabled person'." Final Rules, *supra* note 153, at 14889. Because of the diverse group of congressman, physicians, medical associations, and lay persons involved in composing the statute, it became known as the "Compromise Amendment." See S. REP. No. 246, 98th Cong., 2d Sess. 17 (1984) (legislative history of the amendment).

157. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121(3), 98 Stat. 1749, 1752 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5101 (1982)); see also Final Rules, *supra* note 153, at 14878 (implementing regulation using identical terminology).

158. See Final Rules, *supra* note 153, at 14888. The term "medical neglect" is not defined by the statute or by the final rule. *Id.* at 14887. The Department of HHS has determined, however, based on prior legislative history of the Child Abuse Prevention and Treatment Act, that "Congress understood and intended that 'medical neglect' is included in the category of 'child abuse and neglect'" and therefore within the meaning and purpose of the Act. *Id.* Further, and building on this logic, the "withholding of medically indicated treatment from disabled infants with life-threatening conditions" is a form of medical neglect. *Id.*

159. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 123, 98 Stat. 1749, 1752 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5103(4)(b)(2) (1982)).

Granted, the CAA provide rather subjective guidelines that allow for situations where physicians' opinions will differ about the appropriate treatment to render. It would be wholly unrealistic, however, to assert that legislation could ever resolve all of the problems associated with such a complex situation. Nevertheless, the CAA are unequivocal in their language that regardless of the differences of opinion, physicians and parents must at the very least provide the infant with appropriate nutrition, hydration, and medication.<sup>160</sup> The effect of this requirement is to preclude an infant, like Baby Doe, from starving to death.<sup>161</sup>

More generally, the CAA allow Congress to provide the states with additional funding for increased information and counseling services to parents about programs, services, and financial assistance available for handicapped infants and their families.<sup>162</sup> They also recommend that health care facilities establish Infant Care Review Committees that would educate parents and professionals, suggest internal policies, offer counseling, and provide review of cases involving handicapped infants.<sup>163</sup>

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160. *Id.* See also Final Rules, *supra* note 153, at 14892 (commenting on this section of the statute, stating: "it should be clearly recognized that the statute is completely unequivocal in requiring that all infants receive 'appropriate nutrition, hydration, and medication' regardless of their condition or prognosis").

161. For the official cite, see *In re Infant Doe*, *supra* note 20. See also *supra* text accompanying notes 88-89 (discussion of case).

162. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 123, 98 Stat. 1749, 1753 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5103(a)(4) (1982)). See also Final Rules, *supra* note 153, at 14888 (implementing congressional intent of providing additional funding).

163. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 124, 98 Stat. 1749, 1754 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5104 (1982)). See also Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14893, 14894 (1985) (proposed April 15, 1985) (proposed guidelines for the establishment of infant care committees) [hereinafter cited as Model Guidelines]. The purpose of these Infant Care Review Committees is:

1. To educate hospital personnel and families of disabled infants with life-threatening conditions;
2. To recommend institutional policies and guidelines concerning the withholding of medically indicated treatment from disabled infants with life-threatening conditions;
3. To offer counsel and review in cases involving disabled infants with life-threatening conditions.

*Id.* at 14894. The Department of HHS recommended that the ICRC membership include a practicing physician, a practicing nurse, a hospital administrator, a social worker, a representative of a disability group, a lay community member, and a member of the facility's organized medical staff to serve as chairperson. *Id.* It should be noted, however, that these ICRC's are encouraged, not mandatory, and are not meant to circumvent state intervention in the matter where necessary. *Id.* See generally Letter from the Catholic Health Association to The National Center on Child Abuse and Neglect (Feb. 8, 1985) (on file at The John Marshall Law Review Office) (commenting on the model guidelines and noting that, based on a 1984 study, 49% of Catholic hospitals in the United States had established some form of ICRC).

To implement the congressional directive embodied in the CAA, the Department of HHS published its Final Rules<sup>164</sup> on April 15, 1985 pursuant to the rule-making authority granted to it by the CAA.<sup>165</sup> These rules differ greatly from the Department's regulations which relied on section 504 of the Rehabilitation Act. First, unlike the former regulations,<sup>166</sup> these rules do not require a tenacious interpretation of the legislation authorizing them to determine their applicability to the handicapped infant setting.<sup>167</sup> Whereas the Rehabilitation Act was declared not to cover the withholding of treatment from infants,<sup>168</sup> the Child Abuse Amendments were specifically passed for that purpose.<sup>169</sup> Second, the former regulations created a whole new bureaucratic agency to oversee their implementation causing many commentators to nickname them the "Big Brother" rules.<sup>170</sup> The earlier regulations were so broad that they created a federally staffed "Baby Doe Hotline" to aid in their enforcement.<sup>171</sup> Comparatively, the current rules build exclusively on existing state agency procedures for their implementation.<sup>172</sup> The effect of this change is to foster cooperation between health care providers and state child protection agencies through existing relationships.<sup>173</sup> Third, unlike the former regulations, the current rules

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164. See Final Rules, *supra* note 153. During the notice and comment period subsequent to publishing its Notice of Proposed Rulemaking, 49 Fed.Reg. 48160 (1984) (proposed Dec. 10, 1984), the DHHS received nearly 16,000 letters from a wide range of associations and individuals. Final Rules, *supra* note 153, at 14879. Of the letters received, 15,000 strongly supported the Act's and the proposed rules' objective of safeguarding the handicapped neonate from being denied medically indicated treatment. *Id.*

165. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 124, 98 Stat. 1749, 1754 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5104 (1982)).

166. See Procedures and Guidelines, *supra* note 137.

167. See *University Hospital*, 729 F.2d at 159, where the court noted "the government's theory [on applicability of section 504 to the medical treatment situation] not only strains the statutory language but also goes beyond [C]ongress' overriding concern. . . ." *Id.*

168. *Id.*

169. For a summary of the statute and its purpose, see S. REP. NO. 246, 98th Cong., 2d Sess. 1-2 (1984).

170. For example, the conservative staff of the Wall Street Journal wrote an editorial entitled "Big Brother Doe" criticizing the federal intervention. Wall St. J., Nov. 3, 1983, at 26, col. 1. They could not have been more clear in their position when they wrote: "We are appalled by the hotline brainstorm [and] do not want the [ultimate] decisions made by some bureaucrat." *Id.*

171. See Procedures and Guidelines, *supra* note 137, at 1651 (DHHS rule creating "Infant Doe Hotline"). Cf. *American Academy of Pediatrics*, 561 F. Supp. at 399-400 (where the court chastised the Secretary of the DHHS for not considering the potential for abuse inherent in a federal "hotline").

172. Compare Final Rules, *supra* note 153, at 14881 ("procedural requirements [of these final rules] should build upon existing mechanisms at the state level, rather than creating a new system . . .") with Wall St. J., Nov. 3, 1983, at 26, col. 1 (criticizing the former regulations for creating another unmanageable bureaucracy).

173. See Final Rules, *supra* note 153, at 14881.

reinforce the underlying belief of Congress and of the Department of HHS that parents are the best decision makers concerning treatment for their disabled infant.<sup>174</sup> The Department of HHS noted that the parents' traditional role as decision maker will be respected and supported until a decision is made which contravenes the applicable standards of law that the CAA established.<sup>175</sup>

*The Federal Government's Response—A Critique of Success*

Many commentators assert that the CAA should be repealed to the extent that it applies to the traditional parent-physician decision-making process for various reasons. First, several commentators argue that the federal government is unconstitutionally interfering in private therapeutic matters. Second, others assert that the federal government is "playing doctor" by creating rigid medical standards of law to which physicians must conform. Third, some commentators fear that the potential for legal action would lead many doctors to practice "defensive" medicine which would only cause the baby more pain.

Regardless of the criticism, the federal government's intervention is both constitutional as well as praiseworthy in the protections that it affords handicapped infants who, until recently, had been totally at the mercy of their parents and doctors. As previously noted,<sup>176</sup> the parental right to make decisions regarding the care and rearing of children is constitutionally guaranteed. Many commentators argue that the federal government's intervention violates this constitutional guarantee because it denies parents their right of privacy to make medical treatment decisions for their severely handicapped newborns.<sup>177</sup> This argument fails, however, because the con-

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174. *Id.* at 14880-81, 14892.

175. Compare Procedures and Guidelines, *supra* note 137, at 1650-54 (final rules based on section 504 void of any such expressions) with Final Rules, *supra* note 153, at 14880, 14892 (current regulations based on Child Abuse Amendments of 1984 repeating the underlying intent of Congress).

176. See *supra* text accompanying notes 32-39.

177. See Final Rules, *supra* note 153, at 14879 (responses received from the public on proposed rules); J. LYONS, *supra* note 1, at 54 (considering the legislation an unprecedented government invasion into the medical decision-making process); Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, 42 YALE L. J. 645, 651 (1977) (discussing the requisites for constitutional legislation); Kuzma, *supra* note 91, at 383 (referring to the legislation as "substituted judgment-making" by the government); Comment, *supra* note 38, at 502, 541 (criticizing the government's interference); Note, *supra* note 5, at 158 ("[f]ederal regulations threaten to intrude upon a sensitive decision that should be the sole domain of parents and the physician."). Compare *The Rule is Wrong: Anonymous Tips Can Only Add to a Family's Anguish*, L.A. Daily J., July 19, 1983, at 13, col. 4 (editorial criticizing government's involvement), with *The Rule is Right: The Law Prohibits Discrimination Against Handicapped*, L.A. Daily J., July 19, 1983, at 13, col. 2 (editorial supporting government's involvement).

stitutional protections given to parents are not absolute.<sup>178</sup> Where a course of treatment threatens the infant's life, the state's interest in preserving that life outweighs the parents' right to privacy.

In attempting to further their argument, these commentators assert that the government established too broad a mandate in its requirement that all infants, regardless of their condition, be kept alive at all costs.<sup>179</sup> This is simply not true. The statute applies uniformly to all infants and requires that nutrition, water, and medication not be withdrawn.<sup>180</sup> Only where the parents' decision is contrary to reasonable medical judgment<sup>181</sup> or based discriminatorily on subjective opinions about the future "quality of life" of the handicapped baby will the state be allowed to intervene.<sup>182</sup> Generally, the new "legal standards" do not mandate "extraordinary" or heroic treatment, but an equal standard for handicapped and normal infants alike.<sup>183</sup> In effect, the statute acknowledges that a state has the right to intervene where because of an infant's handicap two different standards of medical care have been suggested.

Contrary to those commentators' argument that the CAA are unduly interfering with the practice of medicine,<sup>184</sup> both the CAA and the Department of HHS's final rules give great deference to physicians' recommendations regarding the proper course of treatment for their handicapped patients. In eliminating from the final rules the interpretive guidelines that appeared in the proposed

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178. See *supra* note 40 and accompanying text.

179. See *American Academy of Pediatrics*, 561 F. Supp. at 402 (court expressing doubts about legislation leading to heroic measures to sustain handicapped infants lives). See also Final Rules, *supra* note 153, at 14892 (responses received stating fears that legislation will prompt heroic measures to save all handicapped infants); Kuzma, *supra* note 91, at 383 (explaining the difficulty in creating neonatal legislation that will protect only a certain few due to ever changing conditions and circumstances of each case); Comment, *supra* note 38, at 532 (parents and infant are virtually deprived of the right to withhold medication); Note, *supra* note 5, at 148 ("[t]he beauty and value of life disappears when the law threatens defective children with extended torture each time medical science develops a new way to prolong the bare rudiments of life.").

180. See Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121, 98 Stat. 1749, 1752 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5101 (1982)).

181. *Id.* See also Final Rules, *supra* note 154, at 14892. See generally Letter from The Catholic Health Association to The National Center on Child Abuse and Neglect, at 3 (Feb. 8, 1985) (on file at The John Marshall Law Review Office) ("Long hours of difficult debate preceded the . . . agreement on [this] definition . . . [and] the . . . careful wording represents a significant contribution to a better understanding and appreciation of the requirements of law in this matter.").

182. For example, if surgery would be performed on a non-handicapped infant to correct a birth defect, it should likewise be performed on a handicapped infant with a similar defect.

183. Final Rules, *supra* note 153, at 14880. For criticism of this legislation see *supra* note 179.

184. Procedures and Guidelines, *supra* note 137, at 1653-54. See also *supra* note 178 (listing various sources which have criticized the federal legislation).

rules,<sup>185</sup> the Department of HHS emphatically stated that the correct standard of applying the statute is one of "reasonable medical judgment."<sup>186</sup> This judgment is defined as "a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved."<sup>187</sup> Therefore, the government is not "playing doctor" but allowing physicians to make recommendations that only they are capable of making so long as they are not subjective recommendations on the infant's potential quality of life.

Nevertheless, many commentators argue that the CAA will cause physicians to fear legal liability and will thereby alter the physicians' judgments.<sup>188</sup> Such "defensive" medicine, they allege, will

185. Procedures and Guidelines, *supra* note 137, at 1654. The appendix of the final rules listed four medical situations and the effect that section 504 would have on those situations. For example, two of these read:

- (i) Withholding of medically beneficial surgery to correct an intestinal obstruction in an infant with Down's Syndrome when the withholding is based upon the anticipated future mental retardation of the infant and there are no medical contraindications to the surgery that would otherwise justify withholding the surgery would constitute a discriminatory act, violative of section 504. . . .
- (iii) Withholding of medical treatment for an infant with anencephaly, who will inevitably die within a short period of time, would not constitute a discriminatory act because the treatment would be futile and do no more than temporarily prolong the act of dying.

*Id.*

The proposed rules were originally accused of being a "cook book approach" to the practice of medicine. Final Rules, *supra* note 153, at 14880. These interpretative guidelines were criticized because of their oversimplified analysis of the medical decision-making process. See Kuzma, *supra* note 91, at 382.

186. This is the underlying meaning of the term "medically indicated treatment." Final Rules, *supra* note 153, at 14889. The Department of HHS noted that the definition of this key term "does not sanction decisions based on subjective opinions about the future 'quality of life' of a retarded or disabled person." *Id.* Cf. *University Hospital*, 729 F.2d at 162 (Winter, J., dissenting). In *University Hospital*, Judge Winter argued that the government should be allowed to inquire whether a judgment to refuse medical treatment was in fact a bona fide medical judgment. He analogized the situation to one involving race discrimination, stating:

A judgment not to perform certain surgery because a person is black is not a bona fide medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a bona fide medical judgment. . . . [Similarly, a] denial of medical treatment to an infant because the infant is black is not legitimated by parental consent.

*Id.* But see Comment, *supra* note 38, at 534 (criticizing the government for creating two legal standards, one for non-handicapped infants and one for handicapped infants).

187. Final Rules, *supra* note 153, at 14888.

188. *Id.* at 14886. The prospect of civil and possibly criminal liability does exist for both the doctor and the hospital in cases where medical treatment has been wrongfully withheld. Where a physician performs nonemergency procedures without consent or against the consent of the parent or guardian, he might be tortiously liable for a battery to the child. See, e.g., *Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941). If the infant dies after a physician withholds medical care or fails to report the attempted withholding of treatment the physician may be guilty of involuntary manslaughter for violating either the state neglect or child abuse reporting statute. Robertson, *supra* note 6, at 225. Further, the physician might be subject to a homicide

only increase the pain a handicapped newborn must suffer. This argument, however, is illogical for three reasons. First, a doctor's fundamental duty is to preserve life. The *International Code of Medical Ethics*, for example, states that "[A] doctor must always bear in mind the obligation of preserving human life from conception."<sup>189</sup> Therefore, using the logic of the commentators' argument, physicians practice a form of defensive medicine as a result of their professional creed.

Second, the statute does not sanction a physician's use of heroic measures to sustain an infant's life. Instead, the CAA allow doctors great latitude in exercising what, in the doctor's opinion, is reasonable given the nature of the infant's condition.<sup>190</sup> The physician is not required to act defensively because physicians' recommendations to withhold treatment are only prohibited when the recommendations are based on subjective considerations of the newborn's future quality of life.<sup>191</sup>

Third, the CAA and the Department of HHS's regulations specifically recommend that hospitals and health care facilities create Infant Care Review Committees to aid in the decision-making process.<sup>192</sup> A doctor confronted with a severely ill or handicapped infant, instead of undertaking defensive medical procedures, could request from the committee a consensus as to the appropriate course of treatment to recommend. Understandably, as the regulations state, the committees are not a method to circumvent state intervention or even legal liability.<sup>193</sup> The purpose of the committees, in part, is to offer counsel and review of cases involving handicapped or

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conviction arising out of contractual obligations owed to the infant patient. See, e.g., *Jones v. United States*, 308 F.2d 307 (D.C. Cir. 1962). Under the theory of abandonment, once a physician-patient relationship is created and absent a special agreement or dismissal, the physician is under tort and contract obligations to continue to provide medical attention for as long as the condition persists. See, e.g., *McGulpin v. Bessmer*, 241 Iowa 1119, 43 N.W.2d 121 (1950). Likewise, courts could conceivably treat the infant as a third-party beneficiary of the contract between the parents and the physician. Under the law of third-party beneficiary contracts, the promisee is free to alter or release the promisor up until the third party's interests under the contract vest. See A. CORBIN, *THE LAW OF CONTRACTS* §§ 772-79c (6th ed. 21st printing 1981). For an in-depth analysis of the liability that all parties to a denial of medical treatment face, see generally Robertson, *supra* note 6, at 217-44.

189. *International Code of Medical Ethics* (1949), reprinted in 4 *ENCYCLOPEDIA OF BIOETHICS* 1749, 1750 app. (1978).

190. See *supra* notes 184-87 and accompanying text.

191. Final Rules, *supra* note 153, at 14889. See also *supra* note 184 and accompanying text.

192. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 124, 98 Stat. 1749, 1754 (1984) (amending the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5104 (1982)). See also Model Guidelines, *supra* note 163, at 14893 (implementing Congress' recommendation).

193. Final Rules, *supra* note 153, at 14896.



seriously ill newborns with life-threatening conditions.<sup>194</sup> If established with these goals in mind, the infant care review committee could do much in the way of guarding against "defensive" medical practices within the hospital. The final outcome, then, of the government legislation would be not to unconstitutionally interfere with parents at a time of severe anguish but to ensure, with as much consideration and compassion as possible, that the lives of our nation's youngest citizens are fully and fairly protected.

### CONCLUSION

A fundamental precept of our society has always been that the life of a handicapped or disabled person should not be prematurely terminated. Following several cases where newborn infants were allowed to die slow deaths after their parents refused proper medical treatment, the nation became aware that this fundamental precept was frequently being violated.

Even though parents traditionally have the right to decide matters concerning their children, these rights cease when the child's welfare is being unjustly compromised. Too often, the courts have refused to interfere with the parents' desire to let their handicapped newborn die. Under the amorphous guise that the parents are acting in the best interests of the infant, the courts have subtly breached their implicit duty to protect and preserve human life. In addition to being contrary to the underlying reasoning in *Roe*, the courts' failure to defend handicapped infants has led to confusion and misinterpretation. Instead of relying on judicial guidelines of when withholding treatment will be legal, parents and physicians have had to make their decisions blindly. The absence of clear guidelines only served to jeopardize the life of the infant while increasing the potential for greater anguish and embarrassment when the parties were called upon to justify their decision to a judge.

In the absence of any judicial guidance, the federal government was forced to intervene. While the government's earlier attempts were wrought with procedural as well as substantive defects, the Child Abuse Amendments of 1984 reflect a workable and pragmatic solution to the problem. In general, the statute places the burden on individual states to create ways to protect handicapped infants from premature death. Where death is imminent or treatment would only prolong the inevitable, states must ensure that infants receive at least medication, water, and nutrition. But, where death is avoidable through surgery or other therapeutic treatment that usually is given to normal infants, such treatment can no longer be denied to handi-

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194. *Id.* at 14894.

capped infants. The result of the CAA is to reinforce the notion that such a denial is not only abusive to an infant but also in violation of the infant's fundamental right to life. More importantly, the CAA serves as an essential reminder that infanticide, regardless of the asserted justifications, remains prohibited.

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