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## COMMENT

### WITHHOLDING TREATMENT FROM SERIOUSLY ILL AND HANDICAPPED INFANTS: WHO SHOULD MAKE THE DECISION AND HOW?—AN ANALYSIS OF THE GOVERNMENT'S RESPONSE

In recent decades, scientific and technological advances in neonatology<sup>1</sup> have dramatically increased survival possibilities<sup>2</sup> for critically ill infants, including premature infants<sup>3</sup> and infants born with congenital defects.<sup>4</sup> As a

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1. Neonatology is defined as "[t]he study of disorders of the newborn." T. STEDMAN, *STEDMAN'S MEDICAL DICTIONARY* 927 (4th unabr. lawyer's ed. 1976). In the past 17 years, neonatology has become a major subspecialty in pediatric care. Physicians who specialize in the care of newborns are generally referred to as "neonatologists." G. AVERY, *NEONATOLOGY PATHOPHYSIOLOGY AND MANAGEMENT OF THE NEWBORN* xix (2d ed. 1981). The major scientific and technological advances that have contributed to the development of the subspecialty are: increased knowledge of pathophysiologic mechanisms of disease in the newborn infant which produced development of therapies to treat infant diseases; development of machinery to monitor the infant's vital signs and biochemical status; and development of mechanical respirators designed exclusively for the newborn. *Id.* at 8, 20, 424. For a discussion of the history of neonatology, see generally *id.* at 3-11 (tracing the history of the care of the infant from the 1890's to the present).

2. Statistical studies reveal that between 1930 and 1970, the death rate for infants during the first 28 days of life declined by an average of 11.4% every 10 years. In contrast, for the 10 years between 1970 and 1980, the death rate for infants declined by 24%. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forgo Life-Sustaining Treatment, Ethical, Medical, and Legal Issues in Treatment Decisions* 197 n.1 (Mar. 1983) [hereinafter cited as *President's Commission*].

3. The length of a normal pregnancy is 40 weeks. Premature infants are described as infants born prior to the 38th week of pregnancy. G. AVERY, *supra* note 1, at 25, 230-61. Mortality rates for premature infants depend upon the degree of prematurity. Generally, the more premature the infant, the higher the mortality rate. Due to increased medical knowledge and advances in technology between 1970 and 1980, however, the mortality rates for premature infants have dropped significantly. *President's Commission, supra* note 2, at 197; see also G. AVERY, *supra* note 1, at 230-61 (discussion of the problems of premature infants and survival rates for premature infants).

4. "Congenital defects" is a broad term encompassing a wide variety of conditions. Defects include genetic defects in the development of the neurologic system, and severe perinatal trauma. The most frequent genetic defects are Down's Syndrome, Trisomy 18, and Trisomy 13. Down's Syndrome (Trisomy 21) is a chromosomal syndrome characterized by the presence of 47 rather than 46 chromosomes and moderate mental retardation. G. AVERY, *supra* note 1, at 872. Infants with Down's Syndrome often have an associated congenital heart defect and/or associated intestinal obstruction. *Id.* at 812, 880. Trisomy 18 is a chromosomal syndrome characterized by the presence of an extra chromosome 18 and mental retardation. *Id.* at 883. Infants with Trisomy 18 often have an associated cleft palate, congenital heart disease, and gastrointestinal tract and renal abnormalities. Early death is common. *Id.* Trisomy 13 is a chromosomal syndrome characterized by the presence of an extra chromosome 13 and marked mental and motor retardation. *Id.* Infants with Trisomy 13 usually have congenital heart disease and associated gastrointestinal tract and renal malformations. *Id.* Early death is common. J. GOODWIN, J.

result of these advances, the medical decision-making process concerning the appropriate medical care for such infants has become increasingly complex. It is difficult, and sometimes impossible, to predict whether treatment<sup>5</sup> will save these infants, merely prolong dying, or create serious impairments.<sup>6</sup> Deciding whether to treat an infant whose chances for survival are precarious and for whom hopes of a normal life seem limited presents not only a medical challenge, but also an agonizing dilemma for the parents.<sup>7</sup> The question of whether treatment should be rendered or withheld has increasingly become an integral part of the medical decision-making process.<sup>8</sup>

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GODDEN, & G. CHANCE, PERINATAL MEDICINE, THE BASIC SCIENCE UNDERLYING CLINICAL PRACTICE 37 (1976).

The most common defects in the development of the neurologic system are anencephaly, meningomyelocele (spina bifida), and hydrocephaly. Anencephaly is a disorder in which the brain fails to develop fully and skull bones are generally absent, leaving the brain and spinal cord fully exposed. G. AVERY, *supra* note 1, at 944-45, 979. Anencephalic infants usually die within the first days of life. *Id.* at 945. In meningomyelocele, the neural tube fails to close during fetal development, resulting in exposure and poor development of that portion of the spinal cord and nerves. *Id.* at 945, 981. Infants with meningomyelocele have varying degrees of bowel, bladder, and lower extremity paralysis, and often have an associated hydrocephaly. *Id.* at 981. Their mental function is often impaired. *Id.* at 982. Hydrocephaly is a disorder in which the flow of spinal fluid is obstructed, resulting in an accumulation of spinal fluid in the ventricles of the brain. *Id.* at 965. Surgery is required to relieve the accumulation. Varying degrees of mental retardation can result from continued pressure on the brain. *Id.* at 965-68. Severe perinatal trauma refers to interruption of blood flow from the mother to the infant during the process of labor and delivery, causing the infant to suffer brain damage from lack of oxygen. *Id.* at 184-85. The extent of the damage depends upon how long the blood supply was interrupted. *Id.* at 185. For a thorough discussion of congenital defects, see G. AVERY, *supra* note 1, at 870-89. See also Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 395-98 (1982) (describing what is meant by severely defective newborns); Mueller & Phoenix, *A Dilemma for the Legal and Medical Professions: Euthanasia and the Defective Newborn*, 22 ST. LOUIS U.L.J. 501, 501 (1978) (discussion of major infant defects); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 213-15 (1975) (discussion of infant defects) [hereinafter cited as Robertson, *Involuntary Euthanasia*]; Note, *Birth Defective Infants: A Standard for Non-Treatment*, 30 STAN. L. REV. 599, 599 nn.3-5 (1978) (discussion of infant defects) [hereinafter cited as Note, *Birth Defective Infants*].

5. Treatment is a broad term which can encompass all forms of medical therapy—provision of nutrition, medications, blood transfusions, use of mechanical respirators, and surgery—used to treat a seriously ill infant. For the most thorough treatise describing the treatment required for various forms of newborn illnesses, see generally G. AVERY, *supra* note 1.

6. For example, in some cases the prolonged use of mechanical respirators to treat lung disorders can cause permanent lung damage. See G. AVERY, *supra* note 1, at 398-405. The use of oxygen may cause blindness. *Id.* at 1135.

7. See *President's Commission*, *supra* note 2, at 198. One commentator has described the dilemma as two-sided:

[O]vertreatment may be as harmful and may violate the infant's interests as much as undertreatment. The dilemma is to decide whether a particular child ought to be treated—that is, whether treatment is owed because life, from the child's perspective, is a good, or whether nontreatment is required because survival may be reasonably viewed as not advancing his or her interests.

Robertson, *Dilemma in Danville*, 11 HASTINGS CENTER REP. 5, 6 (Oct. 1981).

8. See *President's Commission*, *supra* note 2, at 198.

Traditionally, decisions of whether or not to treat critically ill infants have been made within the privacy of the parent-physician relationship.<sup>9</sup> Most cases presented limited, if any, options for treatment.<sup>10</sup> As possibilities for treatment expanded, however, the medical decision-making process came under increased scrutiny. Consequently, concerned individuals attempted to define the parameters of acceptable medical decisions.<sup>11</sup> Despite several attempts at definition, the parameters remain undefined largely because each new medical development creates new questions. Analysis of decisions, therefore, must be made on a case-by-case basis.

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9. There are a limited number of cases in which the court has examined a decision to withhold treatment from a seriously ill newborn. See *infra* note 119.

10. See Robertson, *Involuntary Euthanasia*, *supra* note 4, at 214; Note, *Birth Defective Infants*, *supra* note 4, at 599-600.

11. A widely publicized study indicated that 43 out of 299 deaths in a neonatal intensive care nursery resulted from decisions to withhold treatment. Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890, 890 (1973) [hereinafter cited as Duff & Campbell]. The decisions to withhold treatment followed deliberations in which "parents and physicians . . . concluded that prognosis for meaningful life was extremely poor or hopeless." *Id.* The physicians later argued strongly that such decisions should be left to parents and physicians:

We believe the burdens of decision making must be borne by families and their professional advisers because they are most familiar with the respective situations. Since families primarily must live with and are most affected by the decisions, it therefore appears that society and the health professions should provide only general guidelines for decision making. Moreover, since variations between situations are so great, and the situations themselves are so complex, it follows that much latitude in decision making should be expected and tolerated.

Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, in DEATH, DYING, AND EUTHANASIA 91, 100 (D. Horan & D. Mall eds. 1977). Publication of the Duff and Campbell article prompted a Senate Committee Hearing. See *Medical Ethics: The Right to Survival, 1974: Hearing on the Examination of Moral and Ethical Problems Faced with the Agonizing Decision of Life and Death Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare*, 93d Cong., 2d Sess. 26 (1974). A number of physicians testified before the committee concerning the practice of withholding treatment and were not in agreement with respect to whether physicians, parents, or third parties should make the decision to withhold treatment. *Id.* at 1-32. Following this hearing, the federal government did not attempt to apply federal regulations to decisions concerning the withholding of treatment. The seminal article which attempts to define the legal parameters of the decision to withhold treatment from seriously ill newborns was written by Professor John A. Robertson, who described the practice of withholding treatment as "involuntary euthanasia" which he defined as:

the absence of consent of the person from whom treatment is withheld, as opposed to "voluntary euthanasia," where the subject gives full, knowing consent to another person's causing his death. . . . Involuntary euthanasia is passive and indirect, as where care or sustenance is withheld; voluntary euthanasia is active and direct as where the act that causes death is actually performed rather than omitted.

Robertson, *Involuntary Euthanasia*, *supra* note 4, at 214-15 n.16. Professor Robertson's article explored the criminal and civil liability of parents and physicians who made decisions to withhold treatment from seriously ill infants. *Id.*; accord Ellis, *supra* note 4; Foreman, *The Physician's Criminal Liability for the Practice of Euthanasia*, 27 BAYLOR L. REV. 54 (1975); Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of*

It is clear that parents<sup>12</sup> have the primary authority and responsibility to make decisions regarding medical care for their infants.<sup>13</sup> Outside intervention is permitted only when parents appear to fail in their duty to their infants.<sup>14</sup> In these instances, the state may seek to override a parental decision by demonstrating that the circumstances warrant state intervention.<sup>15</sup> Although the standards for determining whether state intervention is appropriate vary according to the facts involved in each decision, the courts have given fair consideration to the parental decision.<sup>16</sup>

Recently, the federal government intensified scrutiny of decisions regarding treatment of critically ill infants. In response to what the federal government perceived as a discriminatory decision to withhold medical care from an Indiana infant on the basis of the infant's handicap,<sup>17</sup> the Department of Health and Human Services (DHHS) has attempted to apply federal regulations to decisions regarding the medical care of handicapped infants.<sup>18</sup> Pursuant to its rulemaking authority granted under section 504 of the Rehabilita-

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*Choice*, 27 BAYLOR L. REV. 76 (1975); Mueller & Phoenix, *supra* note 4; Note, *Birth Defective Infants*, *supra* note 4. For an article discussing euthanasia generally, see Note, *Euthanasia: Criminal, Tort, Constitutional and Legislative Considerations*, 48 NOTRE DAME LAW. 1202 (1973). More recently, commentators have begun to explore the theological aspects of a nontreatment decision. See Paris, *Terminating Treatment of Newborns: A Theological Perspective*, 10 L. MED. & HEALTH CARE 120 (1982).

12. For purposes of this article, the term "parents" refers only to biological parents because decisions to withhold treatment from seriously ill infants are generally made by biological parents. The decision to withhold treatment is often made within hours of the infant's birth—long before an infant would be placed in the custody of adoptive parents or the state.

13. See *infra* notes 84-90 and accompanying text.

14. See *infra* notes 93-95 and accompanying text.

15. See *infra* note 136 and accompanying text.

16. See *infra* note 148 and accompanying text.

17. Following the death of Infant Doe in April 1982, see *infra* notes 23-38 and accompanying text, the Department of Health and Human Services (DHHS) issued a notice to health care providers in the nation's hospitals which stated in part: "There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's Syndrome." *Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice to Health Care Providers*, 47 Fed. Reg. 26,027 (1982).

18. Interim Final Rule, *Nondiscrimination on the Basis of Handicap*, 48 Fed. Reg. 9630 (1983), *invalidated in* *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983) [hereinafter cited as Interim Final Rule]; *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 for Handicapped Infants*]. For a full discussion of the regulations proposed by the DHHS, see *infra* notes 52-83 and accompanying text. Currently, the term "critically ill infant" refers to all infants who are critically ill regardless of the infant's underlying medical problems. As a result of federal regulation, however, there will now be two terms to describe critically ill infants: "critically ill nonhandicapped infants" and "critically ill handicapped infants." See *infra* notes 69-113 and accompanying text.

tion Act of 1973,<sup>19</sup> the DHHS issued proposed regulations<sup>20</sup> which provide for the withdrawal of funding from federally financed hospitals if care is withheld from handicapped infants.<sup>21</sup> Through the implementation of these regulations, the DHHS is seeking to ensure that appropriate treatment is delivered to handicapped infants.<sup>22</sup>

This Comment will discuss the events that prompted promulgation of the proposed rules and the current standards for analyzing parental decisions regarding medical care for their infants. Further, this Comment will suggest that the rules promulgated by the DHHS pursuant to section 504 of the Rehabilitation Act of 1973, authorizing federal intervention in the decision-making process, have created a distinction between handicapped and non-handicapped infants which is of questionable legal and medical validity. First, this distinction alters the manner in which the physician makes the initial medical decision. Second, this distinction forces courts to establish a new standard to resolve medical decision-making conflicts when the infant is handicapped. As a result of these two changes, the constitutionally protected rights of parents to participate in the medical decision-making process are effectively eliminated. Finally, this distinction generates significant definitional problems and promotes uncertainty in determining when the rules are applicable. After examining the rules and their impact, an alternative is suggested which protects parental participation in the decision-making process and ensures that all infants will receive appropriate treatment.

### I. THE FACTS OF THE *INFANT DOE* CASE

In April 1982, Infant Doe was born at Bloomington Hospital in Bloomington, Indiana.<sup>23</sup> Shortly after Infant Doe's birth, it became apparent that

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19. 29 U.S.C. § 794 (1973). As originally enacted, § 504 of the Rehabilitation Act of 1973 provided:

No otherwise qualified handicapped individual in the United States, as defined in section 706(6) of this title shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

*Id.* Relying on the plain language of the Act, the Department of Health, Education, and Welfare (HEW) did not promulgate any regulations to implement § 504. In a suit against HEW, however, the United States District Court for the District of Columbia held that Congress intended for implementing regulations to be issued and ordered HEW to issue regulations. *See Cherry v. Matthews*, 419 F. Supp. 922 (D.D.C. 1976). Congress subsequently amended § 504 in 1978 to include rulemaking authority. Section 119, Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. No. 95-602, 92 Stat. 2955, 2982 (codified as amended at 29 U.S.C. § 794 (Supp. V 1981)). Implementing regulations are currently embodied in 45 C.F.R. § 84 (1983).

20. Health Care for Handicapped Infants, *supra* note 18.

21. *Id.* at 30,851.

22. *Id.* at 30,846.

23. *In re Infant Doe*, No. GU 8204-00 (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.

he had Down's Syndrome,<sup>24</sup> esophageal atresia with an associated tracheoesophageal fistula (TEF),<sup>25</sup> and a possible aortic coarctation.<sup>26</sup> The presence of the esophageal atresia and TEF precluded oral feedings because whatever the infant ingested would be taken into his lungs, causing the infant to suffocate.<sup>27</sup> In order for the infant to survive, surgery was needed to correct the defects.<sup>28</sup> The Does' obstetrician consulted with two obstetricians and three pediatricians to determine the proper course of treatment.<sup>29</sup> The three pediatricians recommended that the infant be transferred to Riley Children's Hospital in Indianapolis for corrective surgery.<sup>30</sup> The three obstetricians recommended that the infant remain at Bloomington Hospital and be allowed to die.<sup>31</sup> Confronted with these options, the Does decided to forego treatment and allow the infant to die.<sup>32</sup>

The Does' decision generated a storm of controversy and national media exposure.<sup>33</sup> Within twenty-four hours of the decision, the matter was before

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Sup. Ct. May 27, 1982) (case moot by infant's death), *cert. denied*, 104 S. Ct. 394 (1983), reprinted in Margaret M. Heckler, *To Be Secretary, Department of Health and Human Services—Additional Consideration: Hearing Before the Senate Comm. on Labor and Human Resources*, 98th Cong., 1st Sess. 73-76 (1983) [hereinafter cited as *In re Infant Doe*].

24. See *supra* note 4.

25. See G. AVERY, *supra* note 1, at 798-99. The esophagus is the passage from the mouth to the stomach. Esophageal atresia is a congenital defect in which the upper esophagus ends in a blind pouch. In 90% of the infants who have esophageal atresia, there is an associated TEF. TEF is a congenital defect where the upper portion of the lower esophagus connects with the trachea (the air passage from mouth to lungs) rather than with the upper esophagus. In 20% of the infants born with these defects, there is an associated congenital heart defect. *Id.*

26. See *id.* at 458. The aorta is a major blood vessel which supplies blood from the left ventricle of the heart to the blood circulation system of the body. Coarctation of the aorta is a congenital heart defect in which the aorta is poorly developed, resulting in a narrowing of the aorta in varying degrees. There are often other heart defects associated with coarctation of the aorta. *Id.*

There are two types of coarctation of the aorta: simple and complex. In infants with simple coarctation who respond to medical therapy, corrective surgery may be delayed until childhood. *Id.* at 458-59. Over 95% of the infants born with simple coarctation survive past the first year. *Id.* Infants born with complex coarctation, however, require surgery within the first weeks of life. *Id.* at 460. The survival rate with surgery is 50%. Further, survivors require close medical attention throughout life and may require additional surgery. *Id.*

27. *In re Infant Doe*, *supra* note 23, at 73; see *supra* note 25.

28. *In re Infant Doe*, *supra* note 23, at 74. Corrective surgery may be performed immediately if the infant's condition permits, or may be performed in stages. See G. AVERY, *supra* note 1, at 801-03. Surgery is curative in about 85% of infants who have esophageal atresia with TEF. *Id.* at 803.

29. *In re Infant Doe*, *supra* note 23, at 74.

30. *Id.*

31. *Id.*

32. *Id.*; see Pless, *The Story of Baby Doe*, 309 NEW ENG. J. MED. 664 (1983). The medical records of Infant Doe were sealed by the court to protect the anonymity of the parents. Therefore, the medical facts of the *Infant Doe* case were not publicly known until September 1983 when Dr. Pless made them public in the New England Journal of Medicine. The Does made their decision based upon the diagnosis stated in the text. Autopsy results revealed, however, that Infant Doe had Down's Syndrome with a reparable esophageal atresia and TEF. The aorta was normal. *Id.* at 664.

33. *In re Infant Doe*, *supra* note 23, at 73-76; see Pless, *supra* note 32, at 664. The infant

the Indiana courts.<sup>34</sup> The issue, as framed by the court's declaratory judgment, was "[Whether] Mr. and Mrs. Doe, as natural parents of Infant Doe, have the right, after having been fully informed of the consequences, to determine the appropriate course of treatment for their minor child?"<sup>35</sup> The court answered in the affirmative and ordered the hospital to follow the Does' decision.<sup>36</sup> After the Indiana Supreme Court affirmed the decision,<sup>37</sup> Bloomington prosecutors sought an emergency stay of the Indiana Court Orders from the United States Supreme Court. The infant died, however, before the prosecutors could reach Washington.<sup>38</sup>

## II. LEGISLATIVE HISTORY

In the month following Infant Doe's death, President Ronald Reagan sent a memorandum to Richard Schweiker, then Secretary of the DHHS, which ensured continuing national attention to the case and ignited the current controversy.<sup>39</sup> The memorandum directed Schweiker to notify the nation's health care providers that section 504 of the Rehabilitation Act of 1973 (Act)<sup>40</sup> protects all handicapped individuals,<sup>41</sup> including infants.<sup>42</sup> Schweiker issued

was given medication for pain and restlessness. The Does visited and held their infant frequently until his death six days later.

34. See *Baby Dies Before Court Could Be Asked to Save It*, Boston Globe, Apr. 16, 1982, at 5, col. 1, cited in Shapiro, *Statute, Medical Treatment of Defective Newborns, An Answer to the "Baby Doe" Dilemma*, 20 HARV. J. ON LEGIS. 137, 148 (1983); *Evansville Couple Races the Clock, Law to Save "Condemned Baby"*, Evansville Courier, Apr. 15, 1982, at 1, cited in Strong, *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, 11 L. MED. & HEALTH CARE 168, 168 n.6 (1983); Waco Tribune Herald, Apr. 22, 1982, at 5A, cited in Note, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699, 699 n.3 (1983); Washington Post, Apr. 16, 1982, at A.16, col. 1, cited in Note, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEX. TECH. L. REV. 569, 570 n.10 (1983); CBS Evening News (May 18, 1982); Mac-Neil Lehrer Report, Saving Newborns (Transcript 1738 May 18, 1982).

35. *In re Infant Doe*, *supra* note 23, at 75.

36. *Id.*

37. *Id.*

38. *Id.*; see Weir, *The Government and Selective Nontreatment of Handicapped Infants*, 309 NEW ENG. J. MED. 661, 661 (1983).

39. Weir, *supra* note 38, at 661.

40. 29 U.S.C. § 794 (1982). Section 504 provides:

No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . .

*Id.* The purpose of the Act is "to develop and implement, through research, training and services, and the guarantee of equal opportunity comprehensive and coordinated programs of vocational rehabilitation and independent living." *Id.* § 701.

41. As defined in the Act, a handicapped individual is "any person who (i) has a physical or mental impairment which substantially limits one or more of such a person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." *Id.* § 706(7)(B).

42. M. SMITH, HANDICAPPED NEWBORNS: CURRENT ISSUES AND LEGISLATION, CONGRESSIONAL RESEARCH SERVICE REPORT, July 28, 1982, cited in Weir, *supra* note 38, at 661 n.11.



a general statement notifying health care providers that federal law prohibits medical discrimination against handicapped infants.<sup>43</sup> On the same day, the DHHS office for Civil Rights issued a written notice to the administrators of the nation's 6,400 hospitals.<sup>44</sup> The notice referred to the event in Bloomington, recited the terms of section 504, and set forth an interpretation of the passage as it applied to infants.<sup>45</sup> The notice further advised that health care providers would violate section 504 if they facilitated a decision to withhold treatment from an infant because the infant was handicapped.<sup>46</sup> Finally, the notice indicated that noncompliance with the requirements of section 504 could result in the termination of federal financial assistance.<sup>47</sup>

The DHHS notice generated swift and divergent reactions. Medical organizations opposed federal intervention.<sup>48</sup> The president of the National Right to Life Committee supported the action.<sup>49</sup> An Indiana Supreme Court

43. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HHS NEWS (May 18, 1982). Schweiker stated:

In the aftermath of the recent death of a handicapped newborn child in Bloomington, Indiana, there has been a great deal of justified public concern about the protection of newborn infants with birth defects and their right as human beings to receive appropriate medical treatment. President Reagan and I share this concern, and the President has instructed me to make absolutely clear to health care providers in this nation that federal law does not allow medical discrimination against handicapped infants.

*Id.*

44. Discriminating Against the Handicapped by Withholding Treatment or Nourishment, Notice to Health Care Providers, 47 Fed. Reg. 26,027 (June 16, 1982).

45. *Id.* The notice indicated that under § 504, it is unlawful for a recipient of federal funding to withhold nutritional sustenance or medical or surgical treatment to correct a life-threatening condition from a handicapped infant if: "(1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated." *Id.*

46. *Id.* The notice indicated that neither counseling parents to withhold treatment because an infant is handicapped nor allowing an infant from whom treatment has been withheld to remain in the hospital would constitute facilitation of discriminatory conduct. The notice further indicated that hospitals would be responsible for any discriminatory conduct of physicians. *Id.*

47. *Id.*

48. See Weir, *supra* note 38, at 663. The American Hospital Association issued a formal statement promising to make every effort to avoid federal regulation, denying that hospitals had been guilty of facilitating discrimination and denouncing the notice as a "simplistic solution" to a complex situation. *Id.* The American Academy of Pediatrics stated:

[T]he effort . . . to solve this complex problem through strict interpretation and enforcement of the letter of section 504 may have the unintended effect of requiring treatment that is *not* in the best interest of handicapped children. Handicapped persons . . . need health care providers who will carefully examine the appropriateness of specific medical intervention. . . . It will frequently be the case that the use of a specific technology or procedures will *not* be in the best interest of the handicapped person. Withholding a medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients.

*Id.* (emphasis in original).

49. *Id.* J.C. Willke, M.D., president of the National Right to Life Committee, stated: Fatal discrimination against Down's syndrome and other handicapped infants has been increasing for years in this country. This discrimination consists of denial of

justice felt that the notice was unnecessary.<sup>50</sup> One hospital administrator stated, "We take it for what it is—a non-binding opinion."<sup>51</sup>

Ten months later, the DHHS took another step to implement the president's directive. On March 7, 1983, pursuant to rule-making authority granted under section 504,<sup>52</sup> the DHHS published an interim final rule in the Federal Register.<sup>53</sup> The rule was to become effective on March 22, 1983.<sup>54</sup> The purpose of the rule was to create mechanisms for timely investigation and immediate enforcement action, when necessary, to protect a handicapped infant whose life might be endangered by a discriminatory decision to withhold treatment.<sup>55</sup> To achieve the rule's purpose, the DHHS provided for three procedural modifications of section 504 implementing regulations.<sup>56</sup> The first modification created a notice requirement.<sup>57</sup> Specifically, health care providers were required to post a notice describing the federal regulation in a conspicuous place in each hospital area responsible for delivery of care to infants.<sup>58</sup> The second modification provided the DHHS with authority to take immediate action to protect infants.<sup>59</sup> The third modification provided the DHHS with twenty-four hour access to hospitals and hospital records to conduct investigations.<sup>60</sup>

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medical treatment, even food and water, which would be routinely provided to non-handicapped infants. The ethic which promotes infanticide is related to the elitist "quality of life" argument used to justify abortion-on demand.

*Id.*

50. *Id.* Richard Given, Chief Justice of the Indiana Supreme Court, stated: "There'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's born." *Id.*

51. *Id.*

52. See *supra* note 19.

53. See Interim Final Rule, *supra* note 18.

54. *Id.* at 9630.

55. *Id.*

56. *Id.* The implementing regulations of § 504 are currently embodied in 45 C.F.R. § 84 (1983).

57. Interim Final Rule, *supra* note 18, at 9630.

58. *Id.* at 9631. The notice specified that: "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IS . . . PROHIBITED BY FEDERAL LAW. . . . Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should contact . . . [DHHS]." *Id.* (emphasis in original). The notice was to be 8" x 14" and displayed conspicuously in each delivery, maternity, and pediatric ward and each nursery, including each intensive care nursery. *Id.*

59. *Id.* at 9630, 9632. Existing regulations require a 10-day waiting period between the time the DHHS notifies a recipient of its failure to comply and the time the DHHS makes a referral to the Department of Justice, or takes other legal action to obtain compliance. 45 C.F.R. § 80.8(d)(3) (1983). The Interim Final Rule created a narrow exception to the 10-day waiting period when, in the judgment of the DHHS officials, immediate remedial action would be necessary to protect the life of a handicapped individual.

60. Interim Final Rule, *supra* note 18, at 9632. Regulations existing at the time limited the DHHS's access to facilities and information pertinent to ascertaining compliance with § 504 to normal business hours. 45 C.F.R. § 80.6(c) (1981). The interim rule provided the DHHS with 24 hour access to facilities and pertinent information when, in the judgment of the DHHS

Once again, DHHS action generated divergent reactions and attracted media attention.<sup>61</sup> On March 18, 1983, four days before the rule was to become effective, the American Academy of Pediatrics filed suit against the Secretary of the DHHS to enjoin the Interim Final Rule.<sup>62</sup> The United States District Court for the District of Columbia denied a temporary restraining order, but granted expedited review.<sup>63</sup> On April 8, 1983, the court heard arguments and six days later held the rule invalid as violating the requirements of the Administrative Procedure Act (APA).<sup>64</sup>

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officials, immediate access was necessary to protect the life or health of a handicapped infant. Interim Final Rule, *supra* note 18, at 9630.

Members of the DHHS team and a "Regional Baby Doe Coordinator" were to be prepared to travel to a hospital site within 24 hours of the receipt of a complaint on the hotline. Plaintiff's Points and Authorities in Support of Declaratory and Permanent Injunctive Relief at 4, *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Squad members would be provided with copies of the "Baby Doe" complaint investigation procedures. *Id.* If the team leader determined through preliminary on-site interviews that an infant was in "imminent danger," the procedures required the team leader to "immediately negotiate with the hospital to provide the required treatment." *Id.* In order to prepare to seek injunctive relief in federal district court, the procedures indicated that the team leader must initiate further interviews with "the parents, physicians, nurses (delivery room, operating room, recovery room, nursery), and [a]ny witnesses to delivery or any other aspect of the birth (e.g., aides, students, interns, residents, orderlies, technicians)." *Id.*

61. See, e.g., Tift, *Debate on the Boundary of Life*, TIME MAG., Apr. 11, 1983, at 68, 69 (discussing the rules and describing the varied reactions of physicians, pro-life groups and President's Commission).

62. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). The National Association of Children's Hospital and Related Institutions and Children's Hospital National Medical Center joined the American Academy of Pediatrics in bringing the suit. *Id.*

63. *Id.* at 396.

64. *Id.* at 403-04. The Administrative Procedure Act (APA), 5 U.S.C. §§ 551-706 (1982), provides that the action of "each authority of the Government of the United States," which includes the DHHS, is subject to judicial review. *Id.* § 701(b)(1). Judicial review is precluded only where there is a statutory prohibition on review or where "agency action is committed to agency discretion by law." *Id.* § 701(a); see *Citizens to Preserve Overton Park, Inc. v. Volpe*, 401 U.S. 402, 410 (1971). Section 504 of the Rehabilitation Act of 1973 contains no prohibition on judicial review of agency action. 29 U.S.C. § 794 (1982). Further, DHHS action under § 504 does not qualify for an exemption as an action that is committed to agency discretion by law. That narrow exception applies only where statutes are drawn so broadly that, in a given case, there is no law to apply. See, e.g., *Overton Park*, 401 U.S. at 410 (describing the parameters of the "agency discretion" exception).

Section 706 of the APA defines the scope of review of agency actions. 5 U.S.C. § 706 (1982). Section 706 provides that a reviewing court "shall decide all relevant questions of law, interpret constitutional and statutory provisions and determine the meaning or applicability of the terms of an agency action." *Id.* Further, § 706(2) provides a reviewing court with the authority to hold unlawful and set aside agency actions, findings, and conclusions that fail to meet the six standards of § 706(2). These standards require the court to set aside agency action if the court finds the action to be:

- (A) arbitrary, capricious, an abuse of discretion, or otherwise not in accordance with law;
- (B) contrary to constitutional right, power, privilege, or immunity;
- (C) in excess of statutory jurisdiction, authority, or limitations, or short of a statutory right;

First, the court invalidated the rule as an arbitrary and capricious agency action prohibited by section 706(2)(A) of the APA.<sup>65</sup> In reaching this conclusion, the court questioned the underlying factual basis used to justify the regulatory action.<sup>66</sup> Further, the court found that the Secretary had given insufficient consideration to relevant factors which should have been considered prior to the creation of a hotline and other mechanisms for immediate investigations in the health care setting.<sup>67</sup> Finally, the court ruled that the text of the rule failed to define adequately what would constitute a viola-

(D) without observance of procedure required by law;

(E) unsupported by substantial evidence in a case subject to sections 556 and 557 of this title or otherwise reviewed on the record of an agency hearing required by statute; or

(F) unwarranted by the facts to the extent that the facts are subject to trial de novo by the reviewing court.

*Id.* § 1706(2); see *Overton Park*, 401 U.S. at 413-14. See generally K. DAVIS, ADMINISTRATIVE LAW TEXT 508-24 (3d ed. 1972) (describing circumstances in which agency actions are reviewable).

65. *Heckler*, 561 F. Supp. at 399. The text of § 706(2)(A) outlines a narrow standard of review. *Overton Park*, 401 U.S. at 416. To make a finding that an agency action fails to meet § 706(2)(A), a reviewing court must consider whether the agency action was based upon consideration of relevant factors and whether the action represented a clear error in judgment. *Id.* The inquiry into the facts underlying an agency decision to act must be "searching and careful." *Id.* A reviewing court, however, "is not empowered to substitute its judgment for that of the agency," if there is a rational basis for the agency's action. *Id.*; see *Heckler*, 561 F. Supp. at 399.

66. *Heckler*, 561 F. Supp. at 400. In the court's opinion, the record failed to suggest a "widespread denial of proper newborn care such as would justify the type of regulation selected." *Id.* The evidence demonstrated that the underlying factual bases used to support the regulation were: a sensationalized television documentary entitled "Death in the Nursery," which reviewed past publicized cases where medical treatment had been withheld from infants with birth defects; newspaper accounts of those cases; a Mac-Neil Lehrer broadcast; some medical surveys conducted in the 1970's which showed disparate practices in withholding of treatment; and investigations conducted during the period the rule was operative which failed to reveal any evidence of impropriety. *Id.* at 399.

67. *Id.* at 399-400. First, the Secretary failed to consider the disruptive effects of a "hotline" upon the ongoing treatment of newborns. The court noted:

[A]ny anonymous tipster, for whatever personal motive, can trigger an [intrusive] investigation. . . . In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of "Baby Doe" stands on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

*Id.* at 399 (emphasis added). Second, the Secretary failed to consider that an infant's interest may not be served by a rule which contemplates removal of the infant from the hospital and termination of federal assistance to an entire hospital because parents refuse medical care for their infant. *Id.* Third, the Secretary failed to give consideration to the "advantages and disadvantages of relying on the wishes of parents who, knowing the setting in which the child may be, in many ways are in the best position to evaluate the infant's best interests." *Id.* at 400. Fourth, no attempt was made to determine whether treatment would be appropriate for a terminally ill infant. *Id.* Finally, the funding of the extensive care mandated by the regulation and the allocation of medical resources among newborns were also not considered by the Secretary. *Id.*

tion, and thus, the rule was "virtually without meaning beyond its intrinsic *in terrorem* effect."<sup>68</sup>

Second, the court relied on the rulemaking requirements of section 553 of the APA as another ground for invalidating the rule.<sup>69</sup> Section 553 prohibits rulemaking without benefit of a notice and comment period, especially when a rule will affect a large number of people or change established practices.<sup>70</sup> Section 553 further provides for a thirty-day delay between the promulgation of a rule and its effective date.<sup>71</sup> The Secretary, by promulgating the rule without public notice and providing only a fifteen-day delay before the effective date, violated both requirements.<sup>72</sup>

After invalidating the rule, the court indirectly indicated that the rule may represent an assumption of authority beyond the scope of section 504<sup>73</sup> and may impinge on the constitutional interests of parents, infants, and health

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68. *Id.* For example, the rules provided that it would be a violation of federal law to deny an infant classified as handicapped "customary medical care." *Id.* As the court noted, however, "there is *no customary standard of medical care* for the treatment of severely defective infants." *Id.* (emphasis in original).

69. *Id.* The rulemaking process defined by § 553 of the APA is referred to as "informal" or "notice and comment" rulemaking. W. GELLHORN, *ADMINISTRATIVE LAW AND PRACTICE* 248 (2d ed. 1982). In the absence of specific directions in an agency's enabling legislation, § 553 of the APA, 5 U.S.C. § 553 (1982), applies whenever a statute merely authorizes an agency to issue regulations and the regulations will affect the rights of private individuals. W. GELLHORN, *supra*, at 248. Since the only specific direction in the rulemaking portion of § 504 of the Rehabilitation Act of 1973 is the requirement that the Secretary submit copies of proposed regulations to appropriate authorizing committees of Congress and that such regulation may take effect no earlier than 30 days after the date of submission, 29 U.S.C. § 794 (Supp. V 1982), § 553 of the APA applies to the DHHS's rulemaking endeavors. *See* W. GELLHORN, *supra*, at 248.

When the DHHS issues rules, three procedural requirements of § 553 of the APA must be met. First, the DHHS must give notice of proposed rulemaking in the Federal Register. 5 U.S.C. § 553(b) (1982). The notice must include "either the terms or substance of the proposed rule or a description of the subjects and issues involved," *id.* § 553(b)(3), as well as reference to the legal authority for issuing the rule, *id.* § 553(b)(2), and information about public participation, *id.* § 553(b)(3). Second, following publication, the DHHS must give interested individuals an opportunity to participate through the submission of written comments, and with its final rules issue a concise general statement of their basis and purpose. *Id.* § 553(c). Third, the DHHS must publish the rules not less than 30 days before their effective date. *Id.* § 553(d).

70. *Heckler*, 561 F. Supp. at 398.

71. *Id.* at 400; *see supra* note 70.

72. *Heckler*, 561 F. Supp. at 400. The rules were published on March 7, 1983, and, without benefit of notice and comment, were to take effect on March 22, 1983. Additionally, the court rejected the Secretary's arguments that the rulemaking effort was not subject to § 553, or, in the alternative, that the circumstances justified waiver of § 553 requirements as "without merit." *Id.* at 401. For a discussion of circumstances in which § 553 does not apply to agency rulemaking, *see generally* W. GELLHORN, *supra* note 69, at 245-47 (describing exemptions which give agencies discretion to determine level of public participation in rule-making endeavors).

73. *Heckler*, 561 F. Supp. at 401. It was the court's view that the legislative history did not suggest that § 504 would be applicable to monitor medical care of defective newborns or establish standards for preserving a particular quality of life. *Id.* As the court noted, "Many would argue that had Congress intended section 504 to reach so far into such a sensitive area

care providers.<sup>74</sup> The court, however, declined to address these issues in a pre-enforcement judicial review.<sup>75</sup>

On July 5, 1983, the DHHS published a revised set of proposed rules in the Federal Register and provided for a sixty-day notice and comment period.<sup>76</sup> The proposed rule duplicated the substance of the invalidated rule,<sup>77</sup> with only minor changes in the posting procedure.<sup>78</sup> Further, the DHHS added a requirement that state child protective service agencies were to establish written procedures for identifying, investigating, and reporting to the DHHS cases of treatment being withheld.<sup>79</sup> This requirement appeared to shift investigative responsibility primarily, but not exclusively, to state agencies.<sup>80</sup> Finally, DHHS added a supplementary information section<sup>81</sup> and an appendix<sup>82</sup> to the proposed rules which attempted to clarify the intent of the notice.<sup>83</sup>

of moral and ethical concern, it would have given some evidence of that intent." *Id.* at 402.

In 1980, following the death of an infant who had Down's Syndrome and an intestinal obstruction, the DHHS and the hospital involved agreed to amend the hospital's written consent procedures. As amended, the procedures assured that cases involving lack of parental consent to medically indicated treatment for handicapped infants would be reported to the state protective services agency in the same manner as similar cases involving nonhandicapped children. The DHHS apparently felt that the case did not warrant the type of action now contemplated by the Secretary. Further, it appears that as late as 1980, the DHHS recognized that intervention in decision-making was properly within the jurisdiction of only state child protective agencies. See *Protection and Advocacy Agency v. Kapiolani Children's Hospital*, HEALTH AND HUMAN SERVICES DOC. NO. 09-79-3158 (1980), cited in *Health Care for Handicapped Infants*, *supra* note 18, at 30,847-48 and in *President's Commission*, *supra* note 2, at 225-26 n.95.

74. *Heckler*, 561 F. Supp. at 402-03. Two constitutional challenges to the statute had been advanced. The first challenge was that the statute was "vague and overbroad," thereby making it difficult for health care providers to determine what kind of conduct that statute was meant to prohibit. *Id.* at 402. The second challenge was that by not providing adequate procedural safeguards to curb investigations resulting from anonymous hotline complaints, the statute conflicted with parents' and physicians' due process rights and rights to privacy. *Id.* at 402-03.

75. *Id.* The court determined that resolution of the issues should await application of the regulation to particular conduct. *Id.*

76. *Health Care for Handicapped Infants*, *supra* note 18. The comment period extended from July 5, 1983 to September 5, 1983. *Id.* at 30,846.

77. See *supra* notes 63-75 and accompanying text. Compare Interim Final Rule, *supra* note 18 (invalidated rule) with *Health Care for Handicapped Infants*, *supra* note 128 (proposed rule).

78. The required size of the notice was changed from 14" x 17" to 8 1/2" x 11". The place where the notice was to be displayed was changed from actually in infant care wards to the nurses' stations of infant care wards. See *Health Care for Handicapped Infants*, *supra* note 18, at 30,851.

79. See *id.*

80. See *id.*

81. See *id.* at 30,846-51. The supplementary information section attempts to clarify the meaning of handicaps as applied to infants, *id.* at 30,851, and defines when § 504 would be applicable, *id.* at 30,847. Further, the section reviews the factual basis used as support for the rulemaking efforts. *Id.* at 30,847-48. Finally, the section explains the substance of the rule. *Id.* at 30,849-51.

82. See *id.* at 30,851-52.

83. See *id.* The appendix indicates that a clear violation of § 504 would occur if a federally

### III. PARENTAL AUTHORITY TO MAKE DECISIONS CONCERNING MEDICAL CARE FOR THEIR CHILDREN

#### A. Background

##### 1. Parental Authority

The parental right and duty to make decisions regarding medical care for an infant is derived from several sources. Generally, parents have a constitutionally protected right to control the care and upbringing of their children.<sup>84</sup> Although this right is not explicitly guaranteed by the United States Constitution, the Supreme Court has repeatedly asserted that parents have a constitutionally protected interest in raising their children free from unwarranted government interference.<sup>85</sup> The Court has further recognized a con-

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assisted hospital denied care to a handicapped infant that would be provided but for the infant's handicap. *See id.* Following this statement, the Secretary set forth three examples of withheld care which would constitute a violation of § 504: 1) denial of treatment for any complications associated with Down's Syndrome, including corrective surgery of an associated intestinal obstruction, esophageal atresia, or heart defect; 2) denial of care that would be given to a handicapped infant, on grounds that a particular child is potentially mentally impaired, blind, deaf, paralyzed, or lacking limbs; or 3) denial of treatment for correctable physical anomalies associated with spina bifida (meningomyelocele), when the denial is based on anticipated mental impairment, paralysis, or incontinence rather than on reasonable medical judgment that treatment would be futile. *See id.* at 30,852. Additionally, the supplementary information section clearly imposed an affirmative duty on all federally financed programs to ensure handicapped infants receive nondiscriminatory treatment. *See id.* at 30,847.

84. Constitutional protection of parental rights to make decisions concerning their children has developed under two basic analyses: the fourteenth amendment guarantee of due process, *see infra* note 85, and the right of privacy recognized under the first, fourth, fifth, ninth, and fourteenth amendments, *see infra* note 86. *See generally* Keiter, *Privacy, Children and Their Parents: Reflections on and Beyond the Supreme Court's Approach*, 66 MINN. L. REV. 459, 488-94 (1982) (discussing constitutional bases of parental responsibility doctrine); Levy, *The Rights of Parents*, 1976 B.Y.U. L. REV. 693 (discussing concept of right of family privacy as it relates to child neglect laws); Richards, *The Individual, the Family, and the Constitution: A Jurisprudential Perspective*, 55 N.Y.U. L. REV. 1 (1980) (discussing Court's failure to articulate a line of constitutional principles to justify its decisions concerning the conflicting rights of children, parents, and society).

85. The fourteenth amendment of the United States Constitution protects the right of free parental choice in matters affecting childrearing. *See Wisconsin v. Yoder*, 406 U.S. 205, 213-14 (1972) (state compulsory education law, as applied to Amish, violated parental rights to direct their children's upbringing; Court recognized that parents have a fundamental interest in guiding the religious future and education of their children); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925) (compulsory education statute which barred parents from sending their children to a religious school invalidated as constituting an unreasonable interference with the rights of parents and guardians to control the upbringing and education of their children); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (Court invalidated a criminal statute which prohibited teaching German to elementary school children as interfering with parental rights recognized by the liberty clause of the fourteenth amendment); *see also Quilloin v. Walcott*, 434 U.S. 246, 255 (1978) ("It 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.'"). Central to the Court's fourteenth amendment analysis is the recognition that parents bear primary responsibility for decisions regarding childrearing. *See, e.g., Wisconsin*

stitutional right of privacy which extends to certain aspects of the family relationship, ranging from the decision to conceive children to matters of childrearing and education.<sup>86</sup> In addition to recognizing a parental right to control the care and upbringing of their children, the Court has recognized a corollary parental duty to care for and protect children throughout their minority.<sup>87</sup> This duty includes the protection of their children's health by recognizing the symptoms of illness and providing for proper medical care.<sup>88</sup> Moreover, in most states, child abuse and neglect statutes assign parents

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v. *Yoder*, 406 U.S. 205, 232 (1972) (American tradition clearly establishes that parents have the primary role in the upbringing of their children); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (responsibility for childrearing resides first with the parents).

86. See, e.g., *United States v. Orito*, 413 U.S. 139 (1973) (right of privacy includes right of marriage, procreation, motherhood, childrearing, and education); *Paris Adult Theater I v. Slaton*, 413 U.S. 49 (1973) (the 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 (1973) (constitutional right of privacy protects a decision to have an abortion during the first trimester); *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (right of privacy protects the freedom of an unmarried person to use contraceptives); *Griswald v. Connecticut*, 381 U.S. 479 (1965) (zone of privacy created by the Bill of Rights protects married couples' right to use contraceptives). For discussions concerning the right of privacy, see generally Huff, *Thinking Clearly About Privacy*, 55 WASH. L. REV. 777 (1980); Note, *Roe and Paris, Does Privacy Have a Principle?*, 26 STAN. L. REV. 1161 (1974).

Lower court opinions indicate that the right of privacy is broad enough to encompass the right to decline medical treatment. See, e.g., *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978) (competent adult has right of privacy to refuse or discontinue medical treatment that would artificially and temporarily prolong life), *aff'd*, 379 So. 2d 359 (Fla. 1980); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (right of privacy protects incompetent and competent individuals against unwarranted infringement of bodily integrity); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (incompetent person possesses same right of privacy to decline medical treatment as does competent adult), *cert. denied*, 429 U.S. 922 (1976). For a discussion of the right to decline medical treatment, see Comment, *The Right to Refuse Medical Treatment: Under What Circumstances Does It Exist?*, 18 DUQ. L. REV. 607 (1980); Note, *The Right of Privacy and the Terminally-Ill Patient: Establishing the "Right-to-Die"*, 31 MERCER L. REV. 603 (1980).

87. See *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) ("The child is not the mere creature of the State; those who nurture him and direct his destiny have the right coupled with the high duty, to recognize and prepare him for additional obligations.").

88. *Parham v. J.R.*, 442 U.S. 584, 602 (1979). Although the Supreme Court has never established conclusively that the authority to make decisions regarding medical treatment is within the ambit of parental rights, dicta in *Parham* suggests such a conclusion is justified. Chief Justice Burger's majority opinion quoted *Pierce* for the proposition that parents have a duty to prepare their children for additional obligations, adding, "Surely, this [duty] includes a 'high duty' to recognize symptoms of illness and to seek and follow medical advice . . . [s]imply because the decision of a parent is [disagreeable or involves risks] does not automatically transfer the power to make the decision from the parents to . . . the state." *Id.* at 602-03. Further, lower court opinions generally note parental constitutional rights and duties when analyzing medical decisions. See, 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); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1962); *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).



the duty of providing necessary medical care for their children.<sup>89</sup> Finally, parents possess the primary authority under tort law to make decisions concerning medical care for their children because an infant is incapable of consenting to treatment.<sup>90</sup>

## 2. *Limits on Parental Authority*

Although parents have a constitutionally protected right to control the care and upbringing of their children, the right is not absolute.<sup>91</sup> Certain compelling situations may warrant limitation of recognized parental authority to act as primary decision-maker.<sup>92</sup> For example, when it appears that a

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89. Child abuse and neglect statutes assign parents the duty to provide medical care in a variety of formulations ranging from requirements to provide child support and necessities, to prohibitions against endangering the life or health of minors. Some statutes specifically assign parents the duty to provide medical care. For a complete listing and analysis of child neglect laws as of 1976, see S. KATZ, M. MCGRATH & R. HOWE, *CHILD NEGLECT LAWS IN AMERICA* (1976). For an overview of state neglect laws, including tables that indicate which state statutes authorize state intervention upon parental failure to provide medical care, see Katz, Howe, & McGrath, *Child Neglect Laws in America (Pts. I-IV)*, 9 *FAM. L.Q.* 1, 3, 7, 51, 73 (1975).

90. Tort law provides that an intentional touching of another's body without consent constitutes a battery. See, e.g., W. PROSSER, *LAW OF TORTS* § 9 (4th ed. 1971). Courts have consistently held that medical treatment in the absence of informed consent or an emergency is an actionable battery. See, e.g., *Canturbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972); *Oakes v. Gilday*, 351 A.2d 85 (Del. Super. Ct. 1976); *Bly v. Rhoads*, 216 Va. 645, 222 S.E.2d 783 (1976). Further, the general rule is that absent emergency circumstances, physicians need parental consent before they can give medical treatment to an infant. See, e.g., *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) (court stated general rule and indicated four exceptions to the rule: emergency, emancipation, parents too remote to consent, and child close to maturity); *accord Younts v. St. Francis Hosp. & School of Nursing, Inc.*, 205 Kan. 292, 300-01, 469 P.2d 330, 337 (1970). The rule recognizes that children,

by reason of their youth[,] are incapable of intelligent decision, as the result of which public policy demands legal protection of their personal as well as their property rights. . . . Hence it is not at all surprising that, generally speaking, the rule has been considered to be that a surgeon has no legal right to operate upon a child without the consent of his parents or guardian.

*Bonner*, 126 F.2d at 122. For a discussion of the parental consent requirement, see G. ANNAS, L. GLANTZ & B. KATZ, *THE RIGHTS OF DOCTORS, NURSES AND ALLIED HEALTH PROFESSIONALS* 91 (1981); Brown & Truitt, *The Right of Minors to Medical Treatment*, 28 *DE PAUL L. REV.* 289, 298-303 (1979); Clarke, *The Choice to Refuse or Withhold Medical Treatment: The Emerging Technology and Medical-Ethical Consensus*, 13 *CREIGHTON L. REV.* 795, 817-20 (1980); Note, *Judicial Limitations on Parental Autonomy in the Medical Treatment of Minors*, 59 *NEB. L. REV.* 1093, 1096 (1980) [hereinafter cited as Note, *Judicial Limitations*]; Note, *Birth Defective Infants*, *supra* note 4, at 610.

91. In *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979), the court stated that although there is a parental autonomy interest, "parental rights . . . do not clothe parents with life and death authority over their children." *Id.* at 744, 379 N.E.2d at 843; see e.g., *Prince v. Massachusetts*, 321 U.S. 158 (1944) (upheld parent's conviction for violating child labor laws by allowing children to distribute religious pamphlets on public streets).

92. One commentator describes the basic needs of every child as including "food, clothing, shelter, medical care and education." Note, *Birth Defective Infants*, *supra* note 4, at 603 n.6. Parental failure to provide these necessities could result in state intervention. *Id.* at 610.

parental decision will jeopardize the health, educational development, emotional well-being, or safety of an infant, the common law doctrine of *parens patriae*<sup>93</sup> provides the state with the right and duty to intervene to protect the infant. More recently, the passage of child abuse and neglect statutes provides the state with statutory authority to intervene when necessary to protect a child.<sup>94</sup> These statutes define minimum parental duties and provide for state intervention when parents fail to fulfill a duty owed to their child. Further, most statutes allow for state intervention in health care decisions by imposing a duty on parents to provide necessary medical care for their children.<sup>95</sup> Ordinarily, it is for the parents in the first instance to decide what medical care is necessary. The state, however, has the power to intervene in the medical decision-making process pursuant to its statutory authority or its authority as *parens patriae*.

*B. Analysis and Impact of Rules on Parental Right  
in the Medical Decision-making Context*

Despite precedent according parents the right, duty, and authority to act as primary decision-makers for their infants, the DHHS has established a new standard for medical decision-making.<sup>96</sup> Although, at first reading, the proposed DHHS rules ostensibly preserve the current decision-making process,<sup>97</sup> close scrutiny reveals that they effect subtle changes and render parental participation illusory. The changes are most apparent when the decision involves a seriously ill infant whose prognosis, with treatment, is uncertain.

Currently, the physician's role in the medical decision-making process is to evaluate the medical needs of the infant and provide parents with reasonable medical judgments concerning recommendations for the infant's care.<sup>98</sup> Specifically, the physician must examine the infant, formulate a

93. See *infra* note 136 and accompanying text.

94. See *supra* note 89.

95. See *id.*

96. See Health Care for Handicapped Infants, *supra* note 18, at 30,851. The appendix to the rule explains that:

[I]t is unlawful . . . 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 the treatment or nutritional sustenance medically contraindicated.

*Id.*

97. See *id.* at 30,847. The supplementary information section indicates that the rules preserve the customary medical decision making process in any treatment decision: the physician must determine whether the treatment would be medically beneficial to the patient, and if the benefits are outweighed by the risk associated with treatment. *Id.* The sentence immediately following this assertion, however, indicates that subjective judgments that a patient's life may not be worth living would violate the rules. Often, these judgments are inextricably intertwined in the medical decision-making process. See *infra* notes 205-18 and accompanying text.

98. See, e.g., *In re Hofbauer*, 47 N.Y.2d 648, 655, 393 N.E.2d 1009, 1014, 419 N.Y.S.2d

diagnosis, and determine what treatment would be appropriate. The physician then presents recommendations to the parents. Based upon the physician's recommendations, the parents make the initial decision as to what care will be provided.<sup>99</sup>

When the infant is seriously ill and prognosis, with treatment, is uncertain, the physician's role in evaluating and formulating recommendations is crucial to the parents. By virtue of technical skills, professional training, and experience, the physician is in the best position to explain the medical realities of the situation to the parents.<sup>100</sup> Part of the physician's explanation may include informing the parents of the medical reality that treatment may afford the infant a dim prognosis for long-term survival or cure.<sup>101</sup> In these instances, the physician and parents may freely discuss the benefits and risks of treatment and explore the issue of whether treatment should be withheld.<sup>102</sup> After reviewing the recommendations and carefully weighing all the alternatives with the physician, the parents have the primary responsibility to accept or reject treatment for their infant.<sup>103</sup>

Under the proposed rules, the medical decision-making process is subtly, but dramatically, changed. As a threshold matter, the proposed rules provide that an infant classified as handicapped may not be denied treatment.<sup>104</sup>

936, 940 (1979) (recognizing physician's role in providing recommendations as to treatment options for the child). See generally G. AVERY, *supra* note 1, at 14-15 (describing roles of parents and physicians in medical decision-making for infants); Duff & Campbell, *supra* note 11, at 892-93 (describing physician's role in decision making); Robertson, *Involuntary Euthanasia*, *supra* note 4, at 224 (discussing physician's role in providing information to parents).

99. See *supra* note 98 and accompanying text.

100. See G. AVERY, *supra* note 1, at 14-15.

101. See *id.*

102. See *id.* But see *President's Commission*, *supra* note 2, at 212-14. In some cases, physicians may be unable to reach a decision to recommend withholding treatment. *Id.* In other cases, physicians may believe they must make the decision to shield parents from feeling guilty over a decision to withhold treatment. *Id.* As one physician stated:

[I]t is important, that we make a recommendation of what is to be done. That is not to say that we don't feel the parents have a decision to make, but it is a decision with us and not a decision of their own. And we usually have felt it is our duty to make a decision, and then have them agree with us, rather than to have them feel they have made the decision completely on their own.

*Id.* at 210 n.56 (citing testimony of Ann Fletcher, M.D., transcript of the 16th meeting of the President's Commission (Jan. 9, 1982), at 17). In still other cases, physicians may exclude parents from the decision entirely or manipulate the parents' decision by offering a narrow range of choices. *President's Commission*, *supra* note 2, at 211. See generally R. STINSON & P. STINSON, *THE LONG DYING OF BABY ANDREW* (1983) (parents describing their experience of having a child in a neonatal intensive care unit); Bridge, *The Brief Life and Death of Christopher Bridge*, 11 HASTINGS CENTER REP. 17, 18 (Dec. 1981) (parents discussing dissatisfaction concerning the amount of information they received concerning their critically ill infant); Duff & Campbell, *supra* note 11, at 893 (report of study on decisions to withhold treatment to neonates describing the ways in which parental decisions may be manipulated); Stinson, *On the Death of a Baby*, ATL. MONTHLY, July 1979, at 64 (article by parents of a premature infant describing their feelings of exclusion from decision-making concerning their son).

103. G. AVERY, *supra* note 1, at 14-15.

104. See *supra* note 96. The standard appears limited. By virtue of the confusion encom-

Noncompliance with the rules will invite an investigation of the case,<sup>105</sup> possible court action,<sup>106</sup> and a risk that federal funding will be withdrawn from the health care facility.<sup>107</sup> Because the physician makes the initial evaluation of the infant and advises the parents of treatment options, the physician becomes the first person responsible for ensuring that treatment decisions are in compliance with the rules. Consequently, the physician's role as evaluator of the infant's condition and advisor to the parents is expanded to include the role of primary rule enforcer. In addition, by virtue of the changes in the physician's role, the rules operate to shift the responsibility for making the initial decision regarding care for the infant from the parents to the physician.

In order to fulfill the responsibility of ensuring compliance with the rules, the physician performing an evaluation of the infant must include in that evaluation a determination of whether the infant is handicapped, and therefore, within the purview of the rules. If the physician determines that the infant could be classified as handicapped, the physician must formulate recommendations for treatment according to the standards provided by the rules. The rules specifically mandate that treatment may not be withheld on the basis of an infant's handicap,<sup>108</sup> and indicate that, when an infant is classified as handicapped, subjective considerations concerning the handicap do not constitute reasonable medical judgment.<sup>109</sup> The physician, therefore, must formulate any recommendations carefully to ensure that they do not present the appearance of being improperly based upon the infant's handicap or appear tainted by subjective considerations concerning the infant's handicap.

Further, when the infant is classified as handicapped, and is seriously ill with an uncertain prognosis, the rules not only restrict the scope of the physician's recommendations, but the scope of the discussion between the parents and the physician as well. The rules impose an obligation on health care providers to take all necessary steps required to ensure treatment of the

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passed in the rules, however, *see infra* notes 205-218 and accompanying text, treatment may not be denied to an infant classified as handicapped.

105. Health Care for Handicapped Infants, *supra* note 18, at 30,849, 30,851. The rules provide for immediate investigation of hotline complaints. *Id.*

106. *Id.* at 30,848, 30,851. The rules indicate that court action must be taken where appropriate to compel provision of nourishment and medical treatment to an infant. *Id.*

107. *Id.* at 30,849. Disclosure of medical records to agency investigators to ensure compliance with § 504 is one of the requirements a federally funded hospital must comply with in order to continue to receive federal funding. *Id.*

108. *Id.* at 30,852. Violations of the rules occur when a federally funded program denies care that would be provided *but for* the infant's handicap. *Id.*

109. *Id.* at 30,847. "[N]on-medical considerations, such as subjective judgments that an unrelated handicap makes a person's life not worth living," interjected in the decision-making process are not legitimate grounds for a medical judgment and reliance on non-medical considerations would violate the rules. *Id.* It is often difficult, however, to separate the effects of the handicap from the medical decision. *See infra* notes 205-18 and accompanying text.

handicapped infant.<sup>110</sup> Consequently, to remain in compliance with the rules, the physician may not freely explore with the parents the issue of withholding treatment, despite the fact that treatment may offer little or no hope of an underlying cure or long-term survival.<sup>111</sup> When the infant is classified as handicapped, the physician is obligated to discard any notions of withholding treatment before talking to the parents.<sup>112</sup> Further, because the physician must take all necessary steps to ensure treatment of the handicapped infant, the physician must not assist the parents in making a non-treatment decision.<sup>113</sup> Rather, the physician must recommend treatment or risk the sanctions imposed by the rules. By virtue of this subtle, but dramatic change, parental rights to make decisions are rendered illusory because parents effectively have no right to refuse treatment when the infant is handicapped. Either the parents must acquiesce to the physician's decision to treat the infant or find themselves in court seeking the right to intervene in the decision-making process. Thus, absent judicial approval parents have no right to make a decision to withhold treatment from their handicapped infant.

As a result of the changes in the medical decision-making process when the infant is handicapped, the rules effectively create two standards for medical decision-making. One standard, applicable to non-handicapped infants, accords parents the right to make a decision to withhold treatment based upon extensive discussion concerning all options with the physician. The other standard, to be used when the infant is classified as handicapped, abrogates parents' rights to make decisions and shifts the decision to the physician. This second standard, however, eliminates meaningful discussions between the parents and physician. To regain their right to make a decision, the parents are forced to seek judicial reaffirmation of the principle that parents possess the primary right to make decisions concerning the medical care of their children.

#### IV. LEGAL FRAMEWORK FOR CONFLICT RESOLUTION IN THE MEDICAL DECISION-MAKING PROCESS

Medical decision-making conflicts between parents and the state usually

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110. Health Care for Handicapped Infants, *supra* note 18, at 30,848-49. The supplementary information section provides:

[W]hile recipients may be restricted in their provision of treatment by the lack of parental consent, it is no less their obligation to operate their program without discrimination. This includes the obligation to report to appropriate officials . . . parental refusal to consent to the provision of necessary medical treatment and to cooperate with those officials while continuing to provide all care not disallowed by the parents.

*Id.* Court action must be taken if necessary to compel provision of treatment. *Id.* at 30,851.

111. Counselling parents to make a decision to withhold treatment from a handicapped infant is considered to be facilitation of discrimination and is disallowed by the rules. *See supra* note 46.

112. *See supra* note 46.

113. *See id.*

arise when parents have decided to refuse treatment of their child which a physician, hospital, or other third party believes is necessary. The treatment refused most often falls into one of three categories. The first category, "life-saving treatment," is treatment that is immediately necessary to preserve the infant's life and results in a good prognosis for a long and healthy life after treatment.<sup>114</sup> The second category, "therapeutic treatment," is treatment that is not immediately necessary for saving the life and carries some risk, but will provide a benefit to the child.<sup>115</sup> The third category, "life-prolonging treatment," is treatment that is highly intrusive, has painful side effects, may or may not cure the underlying condition, and has an uncertain prognosis.<sup>116</sup>

Parental refusal of treatment is commonly based on religious grounds,<sup>117</sup> fear that the risk of treatment will outweigh the benefits to the child,<sup>118</sup> or

114. For purposes of this Comment, the definition of "life-saving" is based on a review of cases in which treatment has been refused. See *infra* notes 149 & 150 and accompanying text. Another commentator refers to this type of situation as "life-threatening." See Comment, *Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State*, 58 N.Y.U. L. REV. 157, 157 n.4 (1983) ("the term 'life-threatening' generally refers to situations presenting imminent danger of death unless treatment is provided") [hereinafter cited as Comment, *Choosing for Children*].

115. See *infra* note 149 and accompanying text. This definition was created for purposes of this Comment and refers to treatment falling between "life-saving" and "life-prolonging."

116. See *infra* note 150 and accompanying text. Another commentator defines life-prolonging treatment as "treatment that extends one's lifespan despite the fact that imminent death is not anticipated." Comment, *Choosing for Children*, *supra* note 114, at 157 n.4; see also Brown & Truitt, *supra* note 90, at 301 n.63 ("[l]ife-sustaining treatment refers to measures which prolong life or delay death in situations involving critical injuries or severe birth defects which would either result in eventual death or a lingering vegetable state.").

117. Most cases involve parents who are Jehovah's Witnesses who believe blood transfusions violate God's law, and therefore, will not consent to treatment which necessitates blood transfusions for their children. See, e.g., *Jehovah's Witness v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968); *People ex. rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952); cf. *In re Karwarth*, 199 N.W.2d 147 (Iowa 1972) (father opposed surgical removal of tonsils and adenoids from his three minor children because of his religious faith); *Craig v. State*, 220 Md. 590, 155 A.2d 684 (1959) (parents failed to provide medical assistance for their child because of their belief in divine healing); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (1962) (parents, Jehovah's Witnesses, consented to surgery for their infant but requested no blood transfusions), *cert. denied*, 371 U.S. 890 (1968); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970) (mother, a Jehovah's Witness, refused to consent to blood transfusions necessary for corrective surgery for her 15-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 (1962) (parents, Jehovah's Witnesses, refused blood transfusions necessary to save the life of their three-year-old son who had been severely burned); *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972) (parents, Jehovah's Witnesses, refused to consent to surgery for their son which would require blood transfusions).

118. See, e.g., *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (father, through adherence to belief that mental healing would cure illness, instilled fear of surgery in 14-year-old son and both refused surgery to repair son's cleft lip and palate); *In re Vasko*, 238 A.D. 128, 263 N.Y.S. 552 (1933) (parents arbitrarily refused to consent to removal of two-year-old child's malignant eye); *In re Rotkowitz*, 175 Misc. 948, 25 N.Y.S.2d 624 (N.Y. Dom. Rel. Ct. 1941)

a belief that life-prolonging treatment is inappropriate.<sup>119</sup> The state, upon notification of refusal of treatment on such grounds, will challenge the parents' decision as a breach of parental duty or statutory neglect.<sup>120</sup> Typically, the state will seek legal custody of the child and appointment of a guardian ad litem<sup>121</sup> in order to override the parents' decision and ensure that the child receives the necessary care.<sup>122</sup>

A court presented with a request to override the parents' decision must first decide whether the state should be allowed to intervene. In general, parents are presumed to act in their child's best interest.<sup>123</sup> The burden of overcoming this presumption tends to be placed on the state by common law and by statute.<sup>124</sup> As a result, courts generally afford parental preferences

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(father persisted in failing to explain his reason for refusing to consent to corrective foot surgery for his child); *In re Tuttendario*, 21 Pa. D. 561 (1911) (parents objected to surgery out of fear that the child would die if he underwent a major surgical procedure); *In re Hudson*, 13 Wash. 673, 126 P.2d 765 (1942) (mother refused consent to amputation of her 11-year-old daughter's grossly malformed left arm because of fear that surgery would prove fatal).

119. See, e.g., *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978) (parents refused chemotherapy and radiation therapy for their leukemic 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, 888 (1981) (father refused brain surgery for his 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 936 (1979) (parents refused chemotherapy and radiation therapy as treatment for their son who had Hodgkins disease, asserting nutritional therapy was more appropriate); *In re Green*, 12 Crime and Delinquency 377 (Child Div., Milwaukee County Ct. Wisc. 1966) (mother refused complicated and controversial treatment for sickle cell anemia, an incurable disease).

Courts have rarely confronted situations in which parents refuse life-prolonging treatment for their infants. See, e.g., *In re Infant Doe*, *supra* note 23 (parents of an infant afflicted with Down's Syndrome and other defects refused life-prolonging surgery and medical care); *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct. Cumberland County, Me. Feb. 14, 1974) (parents refused surgery for infant who had multiple defects); *In re Teague*, 140-212-81886 (Cir. Ct. Balt., Md. filed Dec. 4, 1974) (parents refused surgery to correct spinal column defect); *In re McNulty*, No. 1960 (P. Ct. Essex County, Mass. Feb. 15, 1978) (parents refused heart surgery for infant); *In re Obenauer* (Juv. & Dom. Rel. Ct. Mon., N.J. Dec. 22, 1970) (parents refused surgery to correct duodenal atresia in their infant with Down's Syndrome); *Weber v. Stony Brook Hosp.*, 52 U.S.L.W. 2267 (Oct. 28, 1983) (parents and physicians agreed surgery should be withheld from severely defective infant; third party intervened). With the exception of *In re Infant Doe* and *Weber*, these cases are discussed in Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 Mo. L. REV. 337, 365 (1981). See also *President's Commission*, *supra* note 2, at 216 n.77, 222 n.87, 224 n.92, 225 n.94 (discussing *Houle*, *Teague*, *McNulty*, and *Obenauer*).

120. For an analysis of the state's intervention in medical decision-making disputes, see Comment, *Choosing for Children*, *supra* note 114. See also Note, *Judicial Limitations*, *supra* note 90.

121. A guardian ad litem is defined as a "special guardian appointed by the court to prosecute or defend, in behalf of an infant or incompetent, a suit to which he is a party, and such guardian is considered an officer of the court to represent the interests of the infant or incompetent in the litigation." BLACK'S LAW DICTIONARY 635 (5th ed. 1979).

122. See Note, *Judicial Limitations*, *supra* note 90, at 1100.

123. See e.g., *Parham v. J.R.*, 442 U.S. 584, 602-03 (1979) (reaffirming presumption that parents generally act in their child's best interests).

124. See, e.g., *Custody of a Minor*, 375 Mass. 733, 794, 379 N.E.2d 1053, 1063 (1978) (applying

significant deference and will override them only upon demonstration that a parental decision threatens the child's well-being.<sup>125</sup> Thus, in the typical medical conflict, the state must bring the action and prove that intervention is necessary. When it is shown that a parental decision threatens a child's well-being, the interests of the state and of the child may mandate intervention.<sup>126</sup>

Courts have used three approaches to resolve the conflict created by a state's request to intervene in the medical decision-making process. Regardless of which approach the court selects, the underlying issue in all cases is to determine when and under what circumstances treatment may be ordered over parental objections. The first approach is to determine whether a decision is compatible with the "best interest of the child."<sup>127</sup> The second approach is to use a "substituted judgment" to determine whether the child would, if competent, make the same decision.<sup>128</sup> The third approach, the *Hofbauer* approach, is used in the limited context where parents and a physician agree upon a course of treatment, but a third party challenges the decision as inappropriate.<sup>129</sup> Under the *Hofbauer* approach, the courts determine whether decisions made by the parents will provide medically acceptable treatment for the child.

Although the best interest of the child and substituted judgment approaches are conceptually distinct, both require the court to analyze the circumstances under which the decision was made.<sup>130</sup> These circumstances include the child's underlying condition and prognosis, with and without treatment, the mode of treatment considered, the rationale for parental refusal, and the state's interest in intervention. Both approaches focus primarily on protection of the child's interest. The distinction, however, lies in the interest that will be protected and the manner in which the decision will be made.<sup>131</sup> In contrast, the *Hofbauer* approach emphasizes analyzing the propriety of the course of treatment chosen.<sup>132</sup> Yet, this analysis involves consideration of many of the same factors used in the first two approaches.<sup>133</sup>

state statute, court held that a child may be taken from parental custody on a showing that the child is without necessary physical care and the parents are unwilling to provide the required care), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979).

125. See, 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) (parental prerogative treated with great deference); *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979) (parents' choice as to a mode of medical treatment for their child must be accorded great deference).

126. *Custody of a Minor*, 375 Mass. 733, 744, 379 N.E.2d 1053, 1063 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979).

127. See *infra* notes 135-150 and accompanying text.

128. See *infra* notes 155-189 and accompanying text.

129. *In re Hofbauer*, 47 N.Y.2d 648, 656, 393 N.E.2d 1009, 1014, 419 N.Y.S.2d 936, 941 (1979); see *infra* notes 192-204 and accompanying text.

130. See *infra* notes 135-189 and accompanying text.

131. See *id.*

132. See *infra* notes 192-204 and accompanying text.

133. See *id.*



Although the DHHS rules appear to preserve these existing approaches to judicial conflict resolution, a close examination reveals otherwise. When the infant is classified as handicapped, the rules impose a standard for resolution which, by its terms, precludes fair consideration of parental preferences and prevents normal application of the existing approaches. The appendix to the rules states that it is unlawful to withhold treatment from an infant classified as handicapped if "(1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated."<sup>134</sup> Accordingly, when faced with a dispute over a parental decision to withhold treatment from a seriously ill infant whose prognosis, with treatment, is uncertain, the court must initially determine whether the infant is handicapped within the meaning of the rules. If the infant is determined to be handicapped, the court must incorporate the standard imposed by the rules into the process of judicial conflict resolution. Incorporation of that standard, however, necessarily changes the manner in which existing judicial approaches are applied.

#### A. *The Best Interest of the Child Approach*

##### 1. *Background*

Courts have traditionally used the "best interest of the child" approach to analyze parental decisions to refuse medical treatment of their children. This standard has been used whether treatment was life-saving, therapeutic, or life-prolonging. Under the "best interest" approach, a court will attempt to reach a decision which will advance the best interest of the child.<sup>135</sup> Typical-

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134. Health Care for Handicapped Infants, *supra* note 18, at 30,851.

135. The best interest approach is commonly used whenever the court must make determinations regarding children. For example, the best interest approach has been used in post-divorce child custody proceedings to determine jurisdiction, *see, e.g.*, *Martin v. Martin*, 45 N.Y.2d 739, 380 N.E.2d 305, 408 N.Y.S.2d 479, *reargument denied*, 45 N.Y.2d 839, 381 N.E.2d 630 (1978); *Marriage of Settle*, 276 Or. 759, 556 P.2d 962 (1976); UNIFORM CHILD CUSTODY JURISDICTION ACT § 3(2), 9 U.L.A. 116 (1979), and to determine custody, *see, e.g.*, *In re Marriage of Bowen*, 219 N.W.2d 685 (Iowa 1974) (best interest standard used to transfer custody from mother to father); *Painter v. Bannister*, 258 Iowa 1390, 140 N.W.2d 152 (1966) (best interest standard used to determine whether custody should be given father or grandparents), *cert. denied*, 385 U.S. 949 (1967); UNIFORM MARRIAGE AND DIVORCE ACT § 402, 9A U.L.A. 197-98 (1979). In addition, the best interest standard has been used in adoption and legitimation proceedings. *See, e.g.*, *Quilloin v. Walcott*, 434 U.S. 246, 254 (1978) (best interest standard used to deny biological father's request to veto child's adoption). Finally, the standard has been used in proceedings to determine whether medical treatment is appropriate. *See, e.g.*, *In re Phillip B.*, 92 Cal. App. 3d 796, 802, 156 Cal. Rptr. 48, 54 (1979) ("The underlying consideration is the child's welfare and whether his best interests will be served by the medical treatment"); *In re Kawarth*, 199 N.W. 2d 147, 150 (Iowa 1972) (parental rights cannot be invoked to refuse medical treatment if the best interests and welfare of children in care and custody of the state reasonably require medical treatment); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765, 775 (1942) (natural law gives parents the right to the custody and control of minor children and may give to those children such attention as may seem in their best interests).

ly, in a medical decision-making conflict, the parents have made a decision that they believe is in the child's best interest. The state, however, seeks to intervene in that decision by asserting its view of what would be in the child's best interest. The approach is premised on the state's duty, under the doctrine of *parens patriae*, to care for and protect the best interest of the incompetent child.<sup>136</sup> Confronted with such a conflict between the parent and the state, the court is required to determine which view is more related to the child's best interest.<sup>137</sup> The "best interest" standard is an amorphous standard that can be defined only in relation to the facts of a particular case.<sup>138</sup> Once these facts are examined, however, the court focuses on sanctioning the decision most compatible with the newly defined child's best interest.<sup>139</sup>

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136. *Parens patriae*, defined as "parent of the country," BLACK'S LAW DICTIONARY 1003 (5th ed. 1979), originated in English common law and arose from recognition of the king's "royal prerogative to act as guardian to persons with legal disabilities such as infants, idiots and lunatics." *Id.* Courts have further defined *parens patriae* as referring to the state's role as sovereign and guardian of incompetents and minors. *See, e.g.,* Johnson v. Johnson, 18 N.H. 422, 431, 114 A.2d 1, 5 (1955) (*parens patriae* is a right of sovereignty and imposes a duty on the sovereignty to protect the public interest and to protect infants and incompetents); State v. Perricone, 37 N.J. 463, 475, 181 A.2d 751, 758 ("a sovereign right and duty to care for a child and protect him from neglect, abuse and fraud during his minority"), *cert. denied*, 371 U.S. 890 (1962). At common law, courts exercised *parens patriae* power to protect the interests of a child when parents failed in their duty to provide reasonable care for their children. *Perricone*, 37 N.J. at 475, 181 A.2d at 758. More recently, however, the principle of *parens patriae* has been incorporated into child abuse and neglect statutes. *Id.* For a discussion of the history of *parens patriae* and its role in protecting children, see Areen, *Intervention Between Parent and Child, A Reappraisal of the State's Role in Child Neglect and Abuse Cases*, 63 GEO. L.J. 887, 887-93 (1975); Custer, *The Origins of the Doctrine of Parens Patriae*, 27 EMORY L.J. 195 (1978); Thomas, *Child Abuse and Neglect, Part I: Historical Overview, Legal Matrix and Social Perspective*, 50 N.C.L. REV. 293, 313-28 (1972); Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985, 989-90 (1975); Note, *Parent and Child—State's Right to Take Custody of a Child in Need of Medical Care*, 12 DE PAUL L. REV. 342, 344-46 (1963); Note, *Judicial Power to Order Medical Treatment for Minors Over Objections of Their Guardians*, 14 SYRACUSE L. REV. 84, 84-85 (1962); Note, *The Parens Patriae Theory and Its Effect on the Constitutional Limits of Juvenile Court Powers*, 27 U. PITT. L. REV. 894, 894-99 (1966).

137. *See* Note, *Birth Defective Infants*, *supra* note 4, at 606.

138. For criticism of the best interest of the child standard, see *In re LaRue*, 244 Pa. Super. 218, 226-27, 366 A.2d 1271, 1275 (1976) ("best interest" standard is too dependent upon the convictions of social workers and judges). *See also* J. GOLDSTEIN, A. FREUD & A. SOLNIT, *BEYOND THE BEST INTEREST OF THE CHILD* 54 (1973) (many decisions are in "name only" for the best interest of the child because they are fashioned primarily to meet needs and wishes of competing adult claimants or to protect policies of child care agencies); Foster, *Adoption and Child Custody: Best Interests of the Child?*, 22 BUFFALO L. REV. 1, 3 (1973) (absent articulation of specific elements comprising a child's best interest, the phrase is a meaningless cliché); 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. 623, 649-50 (1976) (standard is deficient because no state statute identifies specific factors for a court to consider in determining a child's best interest); Note, *Birth Defective Infants*, *supra* note 4, at 606 ("the standard is in many ways a fiction, because the child's interests depend on who is defining them").

139. *See* Note, *Birth Defective Infants*, *supra* note 4, at 607.

In making its determination, the court performs a tripartite analysis. The court must first examine the medical decision itself. This involves identification of the child's condition and prognosis, the nature and extent of the treatment proposed, and the impact that refusal would have on the child's condition.<sup>140</sup> The court must then identify the competing interests involved. These include the interests of the child, the parents, and the state.<sup>141</sup> In the health care context, the child's interest is generally defined as being an interest in health or life;<sup>142</sup> the parents' interest is defined as an interest in parental autonomy in decision-making;<sup>143</sup> the state's interests are defined as the protection of the welfare of children, the preservation of life, and the promotion of ethical integrity of the medical profession.<sup>144</sup> Finally, the court must balance the competing interests involved and reach a decision that best protects the interests of all the parties. Resolution of the conflict should balance the child's interest against those of the parents and the state. In practice, however, the resolution process appears to balance only two interests in a given case—either the child's against the parents' or the parents' against the state's. Which of these two balancing approaches the court selects

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140. One court has stated that:

Several relevant factors must be taken into consideration before a state insists upon medical treatment rejected by the parents. The state should examine the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation for treatment by the medical profession; the risks involved in medically treating the child; and the expressed preferences of the child. Of course, the underlying consideration is the child's welfare and whether his best interests will be served by the medical treatment.

*In re Phillip B.*, 92 Cal. App. 3d 796, 802, 156 Cal. Rptr. 48, 51 (1979), *cert denied*, 445 U.S. 949 (1980). Typically, court opinions begin with a review of the child's condition. See e.g., *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1968); *In re Clark*, 21 Ohio Op. 2d 86, 185 N.E.2d 128 (1962). For a thorough discussion suggesting how these facts should be analyzed, see Comment, *Choosing for Children*, *supra* note 114, at 185-88.

141. Although courts have uniformly balanced these interests in making decisions, see *infra* notes 145-48, formal identification of the three interests first appeared in a commentary. See Note, *State Intrusion into Family Affairs: Justification and Limitations* 26 STAN. L. REV. 1383, 1383-84 (1974) (the issue places three sets of interests in conflict: (1) rights of the parents; (2) responsibilities of the state; and (3) needs of the child). In *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979), the court granted judicial recognition of this analysis. 375 Mass. at 747, 379 N.E.2d at 1062. Subsequent commentary indicates adherence to the tripartite interest analysis suggested above. See Areen, *supra* note 136, at 890-94, n.24; Horowitz, *Of Love and Laetrile: Medical Decision Making in a Child's Best Interests*, 5 AM. J.L. & MED. 271-83 (1979); Comment, *Choosing for Children*, *supra* note 118, at 166-84; Note, *In re Hofbauer: May Parents Choose Unorthodox Medical Care for Their Child?*, 44 ALB. L. REV. 818, 837-47 (1980) [hereinafter cited as Note, *May Parents Choose?*]; Note, *Judicial Limitations*, *supra* note 90, at 1107-14; Note, *Birth Defective Infants*, *supra* note 4, at 602-05.

142. See Note, *Birth Defective Infants*, *supra* note 4, at 607.

143. See *Custody of a Minor*, 375 Mass. 733, 747-48, 379 N.E.2d 1053, 1062-63 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979).

144. 375 Mass. at 754-55, 379 N.E.2d at 1066.

appears to depend upon the child's condition and the parents' reason for refusal.

For example, when a parent refuses treatment based upon religious grounds, courts uniformly balance the parents' first amendment interest against the child's competing interest in life.<sup>145</sup> In these cases, the child's interest frequently prevails.<sup>146</sup> If the parents' refusal is based on other grounds,<sup>147</sup> however, the court balances the parents' interest in controlling matters of childrearing against the state's competing interests in protecting the welfare of children, preserving life, and preserving the ethical integrity of the medical profession.<sup>148</sup> Although the central focus remains on the child, the real battle is over who should control the decision—the parents or the state. In this type of balancing, the result appears dependent upon the child's condition or the type of medical care required. To illustrate, courts are generally reluctant to override parental decisions when the treatment is concededly beneficial to the child, but not immediately necessary and one which exposes the child

145. In expressing this balancing process, one court stated:

[P]arents . . . have a perfect right to worship as they please. . . . But this right . . . ends where somebody else's right begins. Their child is a human being in his own right, with a soul and body of his own. He has rights of his own—the right to live and grow without disfigurement.

*In re Clark*, 21 Ohio Op. 2d 86, 90, 185 N.E.2d 128, 132 (1962); see also *supra* note 117.

146. See, e.g., *Jehovah's Witness v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967) (court may order a blood transfusion over parent's religiously grounded objections), *aff'd*, 390 U.S. 598 (1968); *People ex rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769 (court ordered a blood transfusion over parent's religiously grounded objections), *cert. denied*, 344 U.S. 824 (1952); *In re Kawarth*, 199 N.W.2d 147 (Iowa 1972) (court affirmed juvenile court order requiring operations to be performed on three children despite father's objections); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (court sustained order for compulsory blood transfusion for infant despite objections of parents who were Jehovah's Witnesses), *cert. denied*, 371 U.S. 890 (1968); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970) (court ordered corrective surgery and transfusions for child with facial lesion despite parents' religious objections), *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 (1962) (court ordered transfusions for three-year-old child over mother's objections). *But see Craig v. State*, 220 Md. 590, 155 A.2d 684 (1959) (court refused to order medical treatment over parents' religiously based objections); *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972) (court upheld parents' religious objections to surgery to repair severe curvature of the spine).

147. See *supra* notes 118 and 119.

148. In *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 740-41, 370 N.E.2d 417, 425 (1977), the court reviewed decisions concerning the competent adult's rights to decline medical treatment and identified four competing state interests: "(1) the preservation of life; (2) the protection of interests of innocent third parties; (3) the prevention of suicide; and (4) maintaining the ethical integrity of the medical profession." *Id.* More recently, in *Custody of a Minor*, 375 Mass. 733, 754-55, 379 N.E.2d 1053, 1066 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979), the court identified the competing state interests when the patient is a child: (1) protecting the welfare of children living within its borders; (2) preservation of life; and (3) protecting the ethical integrity of the medical profession. For a discussion of the state interests, see generally Clarke, *supra* note 90, at 813-17 (describing state interests); Comment, *Choosing for Children*, *supra* note 114, at 169-70 (describing state interests generally); Note, *Birth Defective Infants*, *supra* note 4, at 604-05 (reciting state interests).

to risk.<sup>149</sup> If the treatment is immediately necessary, whether life-saving or life-prolonging, the courts will override the parents' decision because the child's interest in life allows no other outcome.<sup>150</sup> Regardless of the ultimate decision, the cases analyzed under the best interest approach stand for the proposition that, even in the state's exercise of *parens patriae* power, there must be respect for the rational decision of the parents who are seeking to protect their child.

## 2. Analysis of Proposed Rules and Best Interest of Child Approach

When the infant is classified as handicapped, the court's analysis under a best interest approach is modified significantly. First, the court's examina-

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149. See, e.g., *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (court refused to order corrective surgery for 14-year-old boy's cleft lip and palate); *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972) (court upheld parent's refusal to consent to surgery to correct their 17-year-old son's spinal curvature because child's life was not in danger and risks involved in surgery were high); *In re Tuttendario*, 21 Pa. D. 561 (1911) (court upheld parents' right to refuse corrective, but not life-saving, surgery that would prevent their seven-year-old son from becoming crippled from rickets); *In re Frank*, 41 Wash. 2d 294, 248 P.2d 553 (1952) (parental failure to treat child's speech impediment not ground for depriving father of custody); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942) (court upheld parents' refusal to consent to amputation of their 11-year-old daughter's grossly malformed arm because the court found sufficient risk in surgery to justify mother's objection). But see *In re Ray*, 95 Misc. 2d 1026, 408 N.Y.S.2d 737 (N.Y. Fam. Ct. 1978) (court ordered psychiatric treatment for 10-year-old girl on theory that state may intervene when treatment will have a beneficial effect); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970), (court ordered surgery to correct facial deformity on a 15-year-old despite parental objections and despite the fact that the physician testified that the surgery would be more safely performed when the child was older), *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).

150. For cases where the court ordered life-saving treatment, see *Jehovah's Witness v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967) (court may order transfusion for children when necessary to save life), *aff'd*, 390 U.S. 598 (1968); *People ex rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952) (transfusion ordered where danger of death or permanent retardation would follow without treatment); *Morrison v. State*, 252 S.W.2d 97 (Mo. Ct. App. 1952) (transfusion ordered where danger of death would follow without treatment); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (upheld order for transfusion where danger of death would follow without treatment), *cert. denied*, 371 U.S. 890 (1968); *In re Vasko*, 238 A.D. 128, 263 N.Y.S. 552 (1933) (court ordered surgical removal of two-year-old child's malignant eye); *In re Brooklyn Hosp.*, 45 Misc. 2d 914, 258 N.Y.S.2d 621 (N.Y. Sup. Ct. 1965) (transfusions ordered for five-year-old child suffering from burns); *In re Clark*, 21 Ohio Op. 2d 86, 185 N.E.2d 128 (1962) (court ordered transfusion for severely burned three-year-old child).

For cases in which the court ordered life-prolonging treatment, see *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct. Cumberland County, Me. Feb. 14, 1974) (court ordered surgery on infant who had multiple birth defects); *In re Teague*, 212-81886 (Cir. Ct. Balt., Md. filed Dec. 4, 1974) (court ordered surgery to repair infant's spina bifida); *In re McNulty*, No. 9190 (P. Ct. Essex County, Mass. 1978) (court ordered heart surgery for infant); *In re Obenauer* (Juv. & Dom. Rel. Ct. Mon. N.J. Dec. 22, 1970) (court ordered surgery to repair duodenal atresia in an infant with Down's Syndrome). But see *Weber v. Stony Brook Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983) (court refused to order surgery in infant who had microcephaly,

tion of the decision necessarily changes. Traditionally, the court identified the child's condition and prognosis, the nature and extent of treatment proposed, and the impact that refusal would have on the child's condition. When the infant is handicapped, however, the court must further analyze whether the decision was based on the infant's handicap and whether the handicap renders the treatment medically contraindicated.<sup>151</sup> This analysis is limited to an objective medical inquiry because the rules reject subjective consideration in medical decision-making.<sup>152</sup> If the court determines that the decision to withhold treatment was based on the infant's handicap, further interest analysis and balancing is precluded because the rules expressly prohibit decisions made on the basis of handicap.<sup>153</sup> The court is, therefore, required to enter an order compelling treatment. Stopping the analysis at this point effectively precludes any consideration of parental preferences and abrogates parents' rights to participate in the decision-making process.

On the other hand, if the court determines that the decision to decline treatment for the handicapped infant does not appear to be based on the infant's handicap, the court may proceed to perform an interest analysis and balance all the interests. Yet, the DHHS rules have necessarily altered the interest analysis and balancing process. Because the rules specifically evince an intent to ensure that handicapped infants receive treatment, the infant's best interest must be presumptively defined as an interest in receiving treatment. In addition, by virtue of the rules, the state's interest is also an interest in treatment.<sup>154</sup> Defining the infant's and state's interest in this manner makes both interests identical and necessarily skews the court's balancing process toward providing treatment.

For example, under a typical best-interest analysis, the infant, parents, and state have three separate interests which are granted equal weight at the outset of the balancing process. The manner in which the interests are ultimately balanced depends upon the circumstances of the case. Generally, the court, seeking to protect the child, will balance the decision in favor of either the state's interest or the parents' interest, depending upon which interest most closely corresponds to the child's interest. When the infant is classified as handicapped, however, the balance is skewed toward treatment because the state and infant's interest are identical. The two interests will, therefore, outweigh the single countervailing parents' interest from the

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hydrocephaly and spina bifida); *In re Infant Doe*, *supra* note 23 (court refused to order surgery to correct esophageal atresia with TEF in infant with Down's Syndrome), *cert. denied*, 52 U.S.L.W. 3361 (Nov. 8, 1983); *In re Green*, 12 Crime and Delinquency 377 (Child Div., Milwaukee County Ct. Wisc. 1966) (court refused to order treatment for child's incurable sickle cell anemia).

151. Health Care for Handicapped Infants, *supra* note 18, at 30,851.

152. *Id.* at 30,847.

153. *Id.* at 30,852.

154. *Id.* at 30,846. The Rules specifically indicate that the DHHS will rely heavily on the cooperation of state and local agencies to ensure enforcement of the rules, thereby making the state interest that of ensuring treatment.

outset of the balancing process. Further, since the rules reject consideration of parental preferences in decisions when the infant is handicapped, the court will be unable to accord significant weight to a parental decision to decline treatment. As a result, the balancing process is illusory because the court's decision is predetermined by virtue of the way the interests must be defined.

## B. *The Substituted Judgment Approach*

### 1. *Background*

The "substituted judgment"<sup>155</sup> approach permits the court to protect the right of the incompetent individual or the child to decline medical treatment.<sup>156</sup> In the context of medical decision-making conflicts, this approach arose primarily in response to the issue of whether potentially life-prolonging treatment should be withheld from an individual who is incapable of making decisions.<sup>157</sup> Courts recognized that imposing life-prolonging treat-

155. Substituted judgment may be defined as the doctrine which requires a surrogate to attempt to reach a decision that an incompetent person or child would make if he or she were able to choose. The doctrine of substituted judgment originated in English common law and was used to provide a means to authorize a gift from an incompetent person's estate to individuals whom the incompetent person was not otherwise obligated to support. To accomplish its purpose, an English court attempted to substitute itself, as nearly as possible, for the incompetent and act according to the same motives and considerations as would have moved the competent individual. In effect, the court would "don the mental mantle of the incompetent." *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 752, 370 N.E.2d 417, 431 (1977). More recently, the doctrine of substituted judgment has been incorporated into the context of medical decision-making for incompetents and children. See *infra* notes 176-189 and accompanying text. In essence, the doctrine of substituted judgment in medical decision-making conflicts demands that "the decision [u]ltimately reached . . . should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person." *Saikewicz*, 373 Mass. at 752-53, 370 N.E.2d at 431. For commentary which discusses substituted judgment, see *President's Commission, supra* note 2, at 44-45, 132-34; Clarke, *supra* note 90, at 824-26; Mueller & Phoenix, *supra* note 4, at 522; Shapiro, *supra* note 34, at 140-41; Comment, *Withholding Treatment From Defective Newborns: Substituted Judgment, Informed Consent and the Quinlan Decision*, 13 GONZ. L. REV. 781, 791-95 (1979); Note, *Judicial Limitations, supra* note 90, at 1108-09.

156. The right to decline life-prolonging medical treatment is based in the constitutionally protected right of privacy and in common law notions of bodily integrity. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 738-39, 370 N.E.2d 417, 424 (1977); *In re Quinlan*, 70 N.J. 10, 38-39, 355 A.2d 647, 663, *cert. denied*, 429 U.S. 922 (1976). In addition, statutes in several states provide for a "right to die" and allow individuals to direct a physician to withhold treatment. See, e.g., Westfall, *Beyond Abortion: The Potential Reach of a Human Life Amendment*, 8 AM. J.L. & MED. 97, 118 (1983). For commentary discussing the right to decline medical care, see Brant, *supra* note 119; Comment, *The Right to Refuse Medical Treatment: Under What Circumstances Does It Exist?*, 18 DUQ. L. REV. 607 (1980); Note, *The Right of Privacy and the Terminally Ill Patient: Establishing the "Right to Die"*, 31 MERCER L. REV. 603 (1980).

157. *In re Quinlan*, 70 N.J. 10, 38-39, 355 A.2d 647, 663 (1975), *cert. denied*, 429 U.S. 922 (1976), marked the first case in which a court used the doctrine of substituted judgment to allow a decision to discontinue life-prolonging treatment for an incompetent adult. Since

ment which a competent adult could freely refuse does not always serve the best interests of an incompetent adult.<sup>158</sup> To resolve this problem, courts began to incorporate the substituted judgment approach into their analyses of medical decision-making conflicts.

For example, in *In re Quinlan*,<sup>159</sup> the New Jersey Supreme Court held that the right to refuse highly intrusive and life-prolonging treatment is a valuable incident of the right to privacy.<sup>160</sup> This privacy right should not be discarded because an individual's condition prevents conscious exercise

the *Quinlan* decision, a number of courts have used the substituted judgment doctrine to analyze a decision to decline life-prolonging treatment for incompetent individuals. See *infra* note 171. The earliest cases using substituted judgment, however, involved requests for surgery to be performed on mentally incompetent individuals. See *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. Ct. App. 1969) (court applied substituted judgment to order kidney transplant from mentally incompetent ward of the state to his brother); *In re Weberlist*, 79 Misc. 2d 753, 360 N.Y.S.2d 783 (N.Y. Sup. Ct. 1974) (court ordered nonemergency surgery requested by the state for an institutionalized 22-year-old mentally retarded man to enable the man to work and decrease his dependency).

158. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 746, 370 N.E.2d 417, 428 (1977).

159. 70 N.J. 10, 355 A.2d 647 (1975), *cert. denied*, 429 U.S. 922 (1976). In *Quinlan*, the New Jersey Supreme Court was confronted with the question of whether life-prolonging treatment should be withdrawn from a 22-year-old girl who was in an irreversible chronic vegetative state, had no awareness of her surroundings, and existed at a primitive reflex level. For reasons still unclear, Karen Ann Quinlan had stopped breathing for two 15-minute periods and could not be resuscitated. As a result, Karen suffered extensive neurologic damage and was dependent upon a respirator, tube feedings, medications, catheters, and around-the-clock care to stay alive. Confronted with the knowledge that no form of treatment was available which could cure or restore Karen to cognitive life, Karen's parents requested discontinuation of the respirator. The physicians refused to comply with the parents' request. Consequently, the Quinlans commenced legal action, seeking appointment as legal guardian for Karen and express power to authorize discontinuance of the respirator. The New Jersey Supreme Court relied on the constitutional right of privacy as the basis for its decision to grant the father and guardian the right to authorize discontinuance of the respirator, but rejected the parents' arguments based on first amendment freedom of religion and eighth amendment prohibitions against cruel and unusual punishment. *Id.* at 37-42, 355 A.2d at 662-64.

160. *Id.* at 40, 355 A.2d at 663. In reaching its decision, the court determined that the constitutionally protected right of privacy is "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions." *Id.* at 40, 355 A.2d at 663. The court then balanced the right to decline medical treatment for Karen against the asserted competing state interests in the preservation of life and the defense of the physician's right to administer medical treatment according to his best judgment. Weighing the balance in favor of the right to decline treatment, the court stated:

We think that the State's interest [in treatment] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest. It is for that reason that we believe Karen's choice, if she were competent to make it, would be vindicated by the law. Her prognosis is extremely poor,—she will never resume cognitive life. And the bodily invasion is very great. . . . If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right to privacy, as we believe it to be, then it should not be discarded solely on the basis that



of choice.<sup>161</sup> In the court's opinion, the only practical way to preserve the right was to allow the parents and guardians to render their best judgment as to whether their child, if competent, would decline treatment.<sup>162</sup> In allowing this substituted judgment, the court held that an incompetent person has the same right to refuse treatment as a competent adult, even though someone else actually makes the decision.<sup>163</sup>

The doctrine of substituted judgment received extensive consideration in *Superintendent of Belchertown State School v. Saikewicz*.<sup>164</sup> In *Saikewicz*, the Massachusetts Supreme Court was confronted with the issue of whether painful and invasive chemotherapy treatments should be ordered for a sixty-seven year-old profoundly retarded man who had been recently diagnosed as having

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her condition prevents her conscious exercise of the choice.

*Id.* at 42, 355 A.2d at 664. Recognition of the fact that the state interest in the preservation of life weakens when the treatment is characterized as highly intrusive and merely life prolonging marks a subtle, but dramatic, departure from the best interest analysis. Traditionally, under a best interest analysis, courts did not distinguish between forms of treatment. Further, the state's interest in life almost universally outweighed the right to decline treatment. *See supra* notes 148-50 and accompanying text.

161. *In re Quinlan*, 70 N.J. 10 (1975), 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

162. *Id.* The court imposed the qualification that any decision made by the physician, guardian, and family to discontinue treatment had to be submitted to a hospital "ethics" committee. *Id.* at 55, 355 A.2d at 671-72. If the committee agreed that there was no reasonable possibility of Karen ever emerging from her vegetative state, the life support system could be withdrawn and such action would be without civil or criminal liability on the part of any of those involved in the decision. *Id.*

The qualifications imposed by the court resulted from the special circumstances of the *Quinlan* case. As a threshold matter, the court noted that recognition of the right to decline life-prolonging treatment was contrary to prevailing medical practice which provided for discontinuing treatment only when the patient was legally dead. Further, at the time, there was little in the way of pre-existing legislative and judicial guidance regarding the rights and liabilities of those involved in a decision to withhold life-prolonging treatment. *Id.* Nonetheless, the court recognized that advances in medical technology had created a serious dilemma for the medical profession. Specifically, the court asked:

When does the institution of life-sustaining procedures, ordinarily mandatory, become the subject of medical discretion in the context of administration to persons *in extremis*? And when does the withdrawal of such procedures, from such persons supported by them, come within the orbit of medical discretion? When does a determination as to either of the foregoing contingencies court the hazard of civil or criminal liability on the part of the physician or institution involved?

*Id.* at 43, 355 A.2d at 665 (emphasis in original).

In the court's view, primary reliance on ethics committees to review decisions to withhold treatment would offer several advantages. These included the fact that the committee would be readily accessible, would allow for dialogue, and could operate to screen decisions. In addition, the court stated that requiring application to courts to confirm decisions would be a gratuitous encroachment on the medical profession and would be impossibly cumbersome. In the court's opinion, such decisions should come before the court only if there is a justiciable controversy. *Id.* at 50, 355 A.2d at 669. *But see Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (courts are the most appropriate forum to analyze decisions to decline medical treatment).

163. *In re Quinlan*, 70 N.J. at 42, 355 A.2d at 664.

164. 373 Mass. 728, 370 N.E.2d 417 (1977).

leukemia.<sup>165</sup> The treatments offered little hope of recovery, but non-treatment meant certain death within weeks or months.<sup>166</sup> In reaching the decision to allow treatment to be withheld, the court affirmed the *Quinlan* holding and endorsed the use of the doctrine of substituted judgment in this context.<sup>167</sup> The rationale supporting the decision was to ensure that competent and in-

165. *Id.* Saikewicz had an I.Q. of 10, a mental age of two years and eight months, and had resided in state institutions since 1923. With chemotherapy, Saikewicz had a 30-50% chance for remission from leukemia; remission means abatement of symptoms. The toxic side effects of chemotherapy, however, included pain, discomfort, depressed bone marrow, anemia, increased chance for infection, bladder irritation, and loss of hair. Because of his retardation, Saikewicz would be unable to understand or cooperate fully with the treatment. *Id.*

166. Remission would last from two to 13 months at which time chemotherapy would have to be reinstated. Left untreated, Saikewicz would live a matter of weeks or months. According to testimony, a decision to withhold treatment would not result in pain and death would come without discomfort. *Id.* at 734, 370 N.E.2d at 422.

167. *Id.* at 739-40, 370 N.E.2d at 424. The Massachusetts Supreme Court considered three issues: (1) the nature of the right of individuals, competent or incompetent, to refuse potentially life-prolonging treatment; (2) the manner in which an incompetent individual is to be accorded the status in law of a competent person with respect to the exercise of the right to refuse treatment; and (3) the procedures to be followed in reaching the decision. *Id.* at 737, 370 N.E.2d at 423.

The court resolved the first two issues by stating that the substantive rights of the competent and incompetent person are identical in regard to the right to decline potentially life-prolonging treatment. Both possess a constitutional right of privacy which encompasses the right to decline medical treatment where the illness is incurable. *Id.* at 739, 370 N.E.2d at 424. To accord the incompetent person the status in law of a competent person and allow for exercise of the right to decline the treatment, the court adopted the substituted judgment doctrine used in *Quinlan*. *Id.*

The court resolved the third issue by articulating the procedures to be followed in reaching a decision for an incompetent person. The court rejected the *Quinlan* court's view that decisions to withhold treatment should be referred to an ethics committee for review and held that judicial review would provide more appropriate procedural safeguards. In contrast to the *Quinlan* court, the *Saikewicz* court stated:

We do not view the judicial resolution of this most difficult and awesome question—whether life-prolonging treatment should be withheld from a person incapable of making his own decision as constituting a “gratuitous encroachment” on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent “the morality and conscience of our society,” no matter how highly motivated or impressively constituted.

*Id.* at 759, 370 N.E.2d at 435. For criticism of the requirement of judicial review of decisions to withhold treatment see Kindregan, *The Court as a Forum for Life and Death Decisions: Reflections on Procedures for Substituted Consent*, 11 SUFFOLK U.L. REV. 919, 928-31 (1977); Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 AM. J.L. & MED. 238, 240 (1978).

Following the *Saikewicz* decision, the Massachusetts Supreme Court slightly limited the requirement of judicial review of decisions to withhold treatment to those situations in which the patient is confronted with a substantial choice. *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978). The court noted the limitation because the medical profession had interpreted *Saikewicz* to require judicial approval of orders not to attempt resuscitation of an incompetent terminally ill patient. *Id.* at 469, 380 N.E.2d at 136. In the *Dinnerstein* court's opinion, if the patient was terminally ill and suffered a cardiac or respiratory arrest, the deci-

competent individuals were afforded the same dignity and worth and the same panoply of rights to refuse medical treatment.<sup>168</sup> The only distinction between the competent and incompetent person is how their rights are exercised. In the case of the incompetent person, the right must be exercised through another person.<sup>169</sup> The person exercising substituted judgment is charged with the responsibility to effectuate as nearly as possible the individual's actual values and preferences. This process involves considering both the factors which favor treatment and the factors which favor withholding treatment.<sup>170</sup> A recurring theme in both *Quinlan* and *Saikewicz* is the notion that, to the greatest extent possible, the individual should make personal decisions and exercise free choice regarding medical treatment.<sup>171</sup>

After recognizing the right to decline life-prolonging medical treatment and allowing for the use of substituted judgment to exercise that right, the *Saikewicz* court indicated that the decision to refuse treatment for an in-

sion of whether or not to resuscitate should remain with the physician. *Id.* at 472, 380 N.E.2d at 138.

168. *Saikewicz*, 373 Mass. at 751, 370 N.E.2d at 431.

169. *Id.* at 736-37, 370 N.E.2d at 423.

170. *Id.* at 752, 370 N.E.2d at 431. The court stated that:

[t]he primary test is subjective in nature—that is, the goal is to determine with as much accuracy as possible the wants and needs of the individual involved. . . . While [when the individual is retarded] it may thus be necessary to rely to a greater degree on objective criteria, such as the supposed inability of profoundly retarded persons to conceptualize fear of death, the effort to bring the substituted judgment into step with the values and desires of the affected individual must not, and need not, be abandoned.

*Id.* at 750-51, 370 N.E.2d at 430-31. In *Saikewicz*, the court identified the fact that most people would elect chemotherapy and the chance of a longer life as the factor weighing in favor of treatment. Factors identified as weighing against treatment were the patient's age, the side effects of treatment, the low chance of remission, the certainty that treatment would cause immediate suffering, and the patient's inability to cooperate with treatment. The court explicitly rejected the notion that quality of life considerations played any part in balancing the factors. After weighing all the factors for and against treatment, the court determined that the decision made by the probate judge to withhold treatment was appropriate. For commentary discussing what factors should be considered by a court analyzing a decision to withhold treatment from a child, see Comment, *Choosing for Children*, *supra* note 114, at 185-88.

171. For cases following *Saikewicz* which recognize the right of adults, competent and incompetent, to refuse treatment, see *In re Severns*, 425 A.2d 156 (Del. Ch. 1980) (court authorized order not to resuscitate 55-year-old auto accident victim in an irreversible coma); *Satz v. Perlmuter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980) (court permitted removal of respirator as desired by competent 73-year-old adult terminally ill with Lou Gehrig's disease); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980) (court used substituted judgment to authorize termination of dialysis treatment for 78-year-old mentally incompetent man who was in kidney failure and had organic brain disease); *Eichner v. Dillon*, 73 A.D.2d 43, 426 N.Y.S.2d 517 (1980) (court authorized removal of respirator for 83-year-old man in an irreversible coma who had expressed disapproval for life-prolonging measures when he was competent), *modified*, 52 N.Y.2d 363, 420 N.E.2d 64, 436 N.Y.S.2d 266 (1981). *But see In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981) (court overruled mother's decision to discontinue treatment and blood transfusions for her 52-year-old retarded son with untreatable cancer, but analogized the transfusions required to treat anemia to the provision of nourishment).

competent must be analyzed in the same manner as a decision made by a competent individual.<sup>172</sup> Specifically, a reviewing court must determine not only whether the incompetent individual would decline treatment, but also whether the circumstances are appropriate for the exercise of the right to decline life-prolonging medical treatment.<sup>173</sup> The court's analysis of the circumstances is similar to that required under a best interest analysis. The question of whether the exercise of substituted judgment is appropriate depends upon a careful balancing of the individual's decision against countervailing state interests.<sup>174</sup>

Recently, some courts have employed the substituted judgment approach in cases involving children after recognizing that a child's best interests are not necessarily served by imposing treatment which would not be imposed on a competent adult who refused treatment.<sup>175</sup> *Custody of a Minor*,<sup>176</sup> decided in 1978, marked the first such instance in which a court used the doctrine of substituted judgment to analyze a parental decision to refuse conventional medical care for their child. In *Minor*, the issue before the court was the extent of parental rights to choose the type of medical treatment their leukemic child should receive.<sup>177</sup> Withholding conventional treat-

172. *Saikewicz*, 373 Mass. at 752-53, 370 N.E.2d at 431.

173. *Id.*

174. *Id.* The *Saikewicz* court identified four countervailing state interests which must be assessed when a person declines treatment: an interest in the preservation of life; an interest in protecting innocent third parties; an interest in the prevention of suicide; and an interest in maintaining the ethical integrity of the medical profession. *Id.*

In the court's view, the state's interest in preserving life is the most significant interest to be balanced against a decision to decline life-prolonging treatment. Nevertheless, the *Saikewicz* court recognized that when circumstances indicate that treatment will be only life-prolonging, the state interest pales in significance. As the court noted: "There is a substantial distinction in the State's insistence that human life be saved where the affliction is curable, as opposed to the State interest where . . . the issue is not whether but when, for how long, and at what cost to the individual that life may be briefly extended." *Id.* at 742, 370 N.E.2d at 425-26. *But see supra* note 150 (under a best interest analysis, no distinction is made between life-saving and life-prolonging treatment).

The court dispensed with the state interest in preventing suicide stating that the act of declining life-prolonging medical treatment does not constitute suicide. *Id.* at 743, 370 N.E.2d at 426 n.11. The court further noted that the third interest is only implicated when innocent parties, such as children, would suffer emotional and financial damage from an adult's decision to refuse treatment. *Id.* at 742-43, 370 N.E.2d at 426. Finally, the court indicated that recognition of the right to decline life-prolonging treatment would not endanger the ethical integrity of the medical profession because allowing individuals to refuse treatment in situations where treatment offers little or no hope for cure comports with existing medical mores. *Id.* at 743-44, 370 N.E.2d at 426-27.

175. *See infra* notes 176-90 and accompanying text.

176. 375 Mass. 733, 379 N.E.2d 1053 (1978), *aff'd*, 378 Mass. 732, 393 N.E.2d 836 (1979).

177. In 1977, 20-month-old Chad Green was diagnosed as having acute lymphocytic anemia. 375 Mass. at 737, 379 N.E.2d at 1056. The only known medically effective treatment for Chad's type of leukemia was a three-year chemotherapy program which involved three phases. Chad underwent the first phase of treatment and tests indicated that he was in remission. During the second phase of treatment, the Green family moved and requested that their new physician administer chemotherapy with a special diet which included laetrile. Although the physician

ment would not mean immediate death, but the possibility for long-term survival was uncertain.<sup>178</sup> The court recognized that, in the context of medical decision-making for children, the best interest approach and substituted judgment approach are essentially coextensive;<sup>179</sup> each involves consideration of the same factors and similar analyses. The distinguishing feature is that the substituted judgment approach recognizes the *child's right* to refuse life-prolonging treatment.<sup>180</sup> In other words, unlike the decision in the best interest approach, which is made *for* the child, the decision under substituted judgment is viewed as being made *by* the child.<sup>181</sup>

In 1982, the Massachusetts Supreme Court upheld the use of the substituted judgment analysis to decline medical treatment for an infant in *Custody of a Minor*.<sup>182</sup> The issue before the court was whether the juvenile court erred in employing a substituted judgment analysis to allow for the withholding of treatment from an infant.<sup>183</sup> The infant, terminally ill, was abandoned by his mother at birth and was a ward of the state.<sup>184</sup> The Department of Social Services and the guardian ad litem refused to consent to the physi-

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advised the parents that the diet would be ineffective, he granted the request. At the end of the second phase, Chad was still in remission. During the third phase, the parents, without the knowledge of the physician, discontinued the oral medications Chad required. When tests indicated Chad was no longer in remission, the physician confronted the Greens. Despite repeated requests by the physician to reinstitute treatment with oral medication, the parent's refused. Pursuant to an order of temporary guardianship for supervision of medical treatment, chemotherapy was reinstated and Chad was again in remission. The Greens petitioned the court for full custody of Chad and permission to supplement chemotherapy with laetrile. *Id.* at 737, 379 N.E.2d at 1056. For a thorough discussion of *Minor*, see Note, *Judicial Limitations*, *supra* note 90.

178. *Minor*, 375 Mass. at 737, 379 N.E.2d at 1057. Medical studies indicated that a cure would be possible in 50% of such cases. *Id.* The court identified several factors weighing in favor of treatment. First, treatment offered a substantial chance for cure in a child of Chad's age. Second, there was no effective alternative treatment and the side effects of chemotherapy were minimal. The court further noted that Chad appeared healthy and with treatment would be able to carry on normal activities of childhood. Without treatment, Chad would almost certainly die. On the other hand, the court found only two factors weighing against treatment: first, the possibility that chemotherapy would cause serious side effects; second, Chad's inability to understand the importance of chemotherapy. The court concluded that neither factor was substantial enough to outweigh continuation of chemotherapy.

179. *Id.* at 753, 379 N.E.2d at 1065. The court characterized the best interest approach as objective in nature, whereas the substituted judgment approach was characterized as subjective in nature because the court is required to determine the actual preferences. *See supra* note 170.

180. *Minor*, 375 Mass. at 753, 379 N.E.2d at 1065. Although the court did not explicitly state that a child has a constitutionally protected right to decline life-prolonging treatment, the court cited *Saikewicz* for the proposition that substituted judgment "seeks to ensure that the personal decisions concerning the conduct of individual affairs remain, to the greatest extent possible, with the individual . . . [and recognizes] the free choice and moral dignity of the incompetent person." *Id.*

181. *Id.*

182. 385 Mass. 697, 434 N.E.2d 601 (1982).

183. *Id.* at 698 n.1, 434 N.E.2d at 602 n.1.

184. *Id.* at 701, 434 N.E.2d at 604. The four-month-old infant was suffering from an inoperable heart defect and would not survive the first year of life, with or without treatment.

cian's request for a "no code" order.<sup>185</sup> The hospital, therefore, requested the juvenile court to determine whether such an order was appropriate.<sup>186</sup> After reviewing the evidence which weighed against treatment,<sup>187</sup> the juvenile court used substituted judgment analysis and held that, if competent, the infant would decide to forego the use of heroic measures and that no countervailing state interest would prohibit the entry of a "no code" order.<sup>188</sup> In affirming the juvenile court holding, the Massachusetts Supreme Court recognized that a terminally ill infant possessed the right to decline life-prolonging treatment.<sup>189</sup>

## 2. *Analysis of the Proposed Rules and the Substituted Judgment Approach*

When an infant is classified as handicapped, incorporation of the standards imposed by the DHHS rules into the substituted judgment approach effectively forecloses meaningful use of the approach. The rules provide that treatment may not be withheld on the basis of a handicap and may not be withheld if medically indicated. Pursuant to the rules, the court's inquiry is limited to an objective medical inquiry which does not encompass subjective considerations. Because the rules reject subjective considerations and because determination of the infant's actual preferences is, by nature, subjective,<sup>190</sup> the court may not allow the exercise of the infant's right to decline treatment. Further, since the underlying purpose of the rules is to ensure that handicapped infants receive treatment,<sup>191</sup> a court would find it

185. A "no code" order is placed in a terminally ill patient's chart directing a hospital and its staff not to attempt to resuscitate the patient in the event of a cardiac or respiratory arrest. *Id.* at 698, 434 N.E.2d at 602.

186. *Id.*

187. *Id.* at 699-700, 434 N.E.2d at 603. There were several factors which weighed against treatment. First, there was no medical treatment available or soon to become available to treat the infant's underlying heart defect. Death would occur within the first year of life. Second, the measures used to resuscitate the infant would be highly invasive and cause the infant to suffer substantial pain. Third, the measures would cause neurologic and liver damage. Finally, the medical testimony concerning the infant's poor prognosis was unanimous. *Id.*

188. *Id.* at 703, 434 N.E.2d at 605.

189. *Id.* at 708, 434 N.E.2d at 608. The court identified six factors which made the circumstances suitable for the use of substituted judgment: (1) the child was a ward of the state; (2) the child was not competent to make the decision; (3) the parents had abandoned the child; (4) the child had an incurable condition and the prognosis for successful treatment was negative; (5) the medical opinions as to the child's condition and future were unanimous; (6) attempts to resuscitate the child would be painful and intrusive. As the court stated: "[T]his issue is best resolved by requiring a judicial determination in accordance with the substituted judgment doctrine enunciated in *Saikewicz*." *Id.*

190. *See supra* note 179 and accompanying text.

191. Health Care for Handicapped Infants, *supra* note 18, at 30,846. As required by the Administrative Procedure Act, the Secretary indicated that the purpose of the rule is to modify existing regulations in order to "allow timely reporting of violations, expeditious investigation, and immediate enforcement action when necessary" to protect an infant whose life is endangered by discrimination in a program or actively receiving federal financial assistance. *Id.*

difficult to endorse a substituted judgment that the infant would prefer non-treatment. In effect, therefore, incorporation of the standards imposed by the DHHS rules deprives the infant of the right to decline life-prolonging treatment and denies parents the right to attempt to exercise that right for the infant.

### C. *The Hofbauer Approach*

#### 1. *Background*

*In re Hofbauer*<sup>192</sup> provides a third approach which may be used to analyze parental decisions regarding medical care for their children. The *Hofbauer* approach is appropriately employed in the limited situations where parents and physicians agree on a course of treatment, but a third party challenges the treatment as inappropriate.<sup>193</sup> The *Hofbauer* case involved a neglect proceeding brought against the parents of a child with Hodgkins disease.<sup>194</sup> The narrow issue before the court was whether the parents of the child failed to exercise minimum care by entrusting their child's care to a physician who

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192. 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

193. The *Hofbauer* approach is premised on the fact that the child is receiving treatment from a licensed physician. *Id.* at 655, 393 N.E.2d at 1014, 419 N.Y.S.2d at 940. Therefore, the approach is inapplicable to cases in which parents refuse treatment, *see supra* notes 145-49, or seek to provide unconventional treatment for their child which is not endorsed by any physician, *see* *Custody of a Minor*, 378 Mass. 732, 748, 393 N.E.2d 836, 846 (1979) (on rehearing of the *Minor* case, the Massachusetts Supreme Court distinguished *Hofbauer*, noting that, in *Hofbauer*, the nutritional therapy was recommended by a physician, whereas in the *Minor* case, the parents' request for nutritional therapy was unsupported by any physician).

194. 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979). In 1977, seven-year-old Joseph Hofbauer was diagnosed as having Hodgkin's disease. *Id.* at 652, 393 N.E.2d at 1011, 419 N.Y.S.2d at 938. Left untreated, Hodgkin's disease is almost always fatal. *Id.* The Hofbauers rejected the physician's recommendation of conventional radiation and chemotherapy treatments for Joseph and, instead, elected to take Joseph to a medical clinic in Jamaica for nutritional therapy, an unconventional form of treatment which included the use of laetrile. *Id.* Upon the Hofbauers' return, the state instituted neglect proceedings against the Hofbauers for failing to choose conventional treatment for Joseph. *Id.* at 652, 393 N.E.2d at 1012, 419 N.Y.S.2d at 938.

At the initial hearing, the court ordered that Joseph be placed in temporary custody of the state and admitted to the hospital for conventional treatment. *Id.* One month later, Joseph's parents petitioned for return of custody. *Id.* at 653, 393 N.E.2d at 1012, 419 N.Y.S.2d at 938. The proceedings were suspended for six months because the Hofbauers entered into a stipulation agreement which provided for a return of custody and authorized Joseph to come under the care of a physician who advocated nutritional therapy. *Id.* The stipulation agreement further provided that one other physician would consult on the case and both physicians would submit medical reports to the court periodically. *Id.* The family court ultimately found that Joseph was not a neglected child because his parents had made conscientious efforts to provide him with a viable alternative to medical treatment administered by a physician, and therefore, dismissed the petition. *Id.* at 654, 393 N.E.2d at 1012-13, 419 N.Y.S.2d at 939. The appellate division and the Massachusetts Supreme Court unanimously affirmed. *Id.* For a discussion of the *Hofbauer* decision, see Horowitz, *supra* note 141, at 271-75; Pendergast, *The Judicial Dilemma of Laetrile and a Possible Solution*, 30 MERCER L. REV. 573, 580-81 (1979); Note, *May Parents Choose?*, *supra* note 141, at 824-38.

advocated treatment not widely embraced by the medical community.<sup>195</sup> The parents had chosen an unconventional course of nutritional therapy rather than the more conventional radiation and chemotherapy suggested by the child's original physician.<sup>196</sup> The court ultimately upheld the parents decision and allowed the unconventional treatment to continue.<sup>197</sup>

The *Hofbauer* analysis represents a dramatic departure from the analysis required under the best interest or substituted judgment approaches.<sup>198</sup> Under the *Hofbauer* approach, the issue in medical decision-making conflicts is defined as "whether the parents have provided an acceptable course of medical treatment in light of all the surrounding circumstances."<sup>199</sup> To answer that question, the court recommended a four-part inquiry.<sup>200</sup> The court must first determine whether the parents have sought accredited medical assistance; second, whether the parents are aware of the seriousness of their child's condition; third, whether the parents are aware of the possibility of cure offered by the treatment chosen; and fourth, whether or not the treatment recommended by their physician is rejected by all responsible medical authority.<sup>201</sup>

Under the *Hofbauer* approach, parental rights and preferences are given

195. *Hofbauer*, 47 N.Y.2d at 654, 393 N.E.2d at 1013, 419 N.Y.S.2d at 939.

196. *Id.* at 652, 393 N.E.2d at 1012-13, 419 N.Y.S.2d at 938.

197. *Id.* at 657, 393 N.E.2d at 1014, 419 N.Y.S.2d at 941-42. The court based its holding on several factors. First, review of testimony revealed that there was a sharp conflict in medical opinion as to the efficacy of the mode of treatment being administered to Joseph. *Id.* at 653-54, 393 N.E.2d at 1012, 419 N.Y.S.2d at 939. Some physicians felt the mode of treatment ineffective, others felt the mode of treatment effective. *Id.* Second, the treating physician had consulted with numerous other physicians regarding Joseph's care and did not rule out the possibility of resorting to conventional therapy should nutritional therapy prove ineffective. *Id.* Third, the parents had justifiable concerns about the deleterious effects of conventional therapy. *Id.* Fourth, there was evidence that the nutritional therapy was controlling the disease and was less toxic than conventional therapy. *Id.* Finally, the parents indicated they would resort to conventional therapy, if necessary and recommended by the treating physician. *Id.*

198. The best interest approach focuses on arriving at a decision which is most compatible with the best interests of the child. See *supra* notes 135-40 and accompanying text. The substituted judgment approach focuses on arriving at a decision which the child would make if competent to do so. See *supra* notes 155-89 and accompanying text. In contrast, the *Hofbauer* approach focuses on whether or not the decision made by the parents will provide medically acceptable treatment for the child.

199. 47 N.Y.S.2d 648, 656, 393 N.E.2d 1009, 1014, 419 N.Y.S.2d 936, 941 (1979). In the court's opinion, the most significant factor in determining whether a child is being deprived of adequate medical care, and is thus a neglected child, is whether the parents have attempted to provide reasonable medical care for their child. *Id.*

200. *Id.* The court refused to cast the issue in terms of whether or not parents have made a correct decision because, in the court's opinion, the present state of the practice of medicine seldom permits the definitive conclusions which would necessarily follow the question of whether the parents' decision was right or wrong. *Id.* In addition, the court rejected the idea of using its judgment to determine the exact method or degree of medical care which should be provided to the child because such an analysis would be too subjective. *Id.* Instead, the court viewed the issue as more properly cast in terms of whether the plan for treatment recommended by the physician and chosen by the parents is acceptable in light of the facts of the case. *Id.*

201. *Id.*



significant deference.<sup>202</sup> This deference stems from the court's recognition of parental rights and the normal pattern of decision-making.<sup>203</sup> Under the *Hofbauer* analysis, the state should only be allowed to intervene when parents have failed to make reasonable efforts to ensure that acceptable medical treatment is being provided to their child.<sup>204</sup>

## 2. *Analysis of Proposed Rules and Hofbauer Approach*

When the infant is classified as handicapped, the standards imposed by the DHHS rules effectively preclude the court from using the *Hofbauer* approach to analyze a decision to withhold treatment. If the infant is classified as handicapped, the handicap becomes one of the surrounding circumstances and triggers application of the rules. The rules operate to exclude parental preferences and mandate treatment despite the fact that life-prolonging treatment may offer little hope for an underlying cure. Accordingly, further judicial inquiry into parental awareness of the infant's condition and prognosis and the acceptability of the physician's recommendations becomes irrelevant. Treatment must be ordered despite the fact that the parents' decision to withhold treatment is an informed decision based upon competent medical advice. In effect, when the infant is classified as handicapped, the DHHS rules would make a court's attempted use of the *Hofbauer* analysis an exercise in futility.

### D. *Impact of Proposed Rules on Legal Framework for Conflict*

#### 1. *Resolution—Two Standards for Conflict Resolution*

Application of the DHHS rules to the existing approaches for judicial resolution of medical decision-making conflicts establishes a new standard for conflict resolution. As a result, there are now two standards for the judicial resolution of medical decision-making disputes. One standard, applicable to non-handicapped infants, allows the use of the existing judicial approaches which accord significant deference to parental preferences and recognize the right of parents to act as primary decision-makers for their

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202. *Id.* at 656, 393 N.E.2d at 1013, 419 N.Y.S.2d at 940. Although the court recognized that the state may intervene when a parental decision jeopardizes the child's health or welfare, the court indicated that a reviewing court must accord significant deference to a parental choice concerning the mode of medical treatment to be undertaken for the child and the physician selected to administer the treatment. *Id.*

203. *Id.* at 655, 393 N.E.2d at 1014, 419 N.Y.S.2d at 940. The court stressed that parents, in making the sensitive decision regarding their child's treatment, must rely on the recommendations and competency of a licensed physician because "the physician is both trained and in the best position to evaluate the medical needs of the child." *Id.*

204. *Id.* If the parents have undertaken reasonable efforts to ensure that acceptable medical treatment is being provided to their child according to the *Hofbauer* standards, it appears that a reviewing court would be reluctant to override a parents' decision or conclude as a matter of law that the parents are neglectful.

infants. The second standard, applicable to handicapped infants, alters these existing conflict resolution approaches and effectively precludes the consideration of parental preferences and the recognition of the parents' rights to act as primary decision-makers for their infants. While a parental decision that life-prolonging treatment would not be in their infant's best interest is given significant deference under the traditional best interest analysis, the DHHS rules would characterize such a decision as impermissibly subjective and incompatible with the child's interest in treatment. Thus, the court is denied the opportunity to give fair consideration to parental preferences under the best interest approach. Under the substituted judgment approach, the DHHS rules deprive the parents of the opportunity to exercise the infant's right to decline life-prolonging treatment because the subjective analysis required to determine what the infant's decision would be is forbidden by the rules. Finally, the DHHS rules make the *Hofbauer* approach virtually meaningless because the rules reject the consideration of parental preference and abrogate the parents' right to make a decision based upon competent medical advice. In light of prevailing precedent, to the extent that the rules operate to deny parental rights, the new standard created by the DHHS rules may be properly characterized as an arbitrary and capricious denial of constitutionally protected parental rights to control the care and upbringing of their children.

## 2. Proposed Rules and Interpretational Problems

Because the proposed rules operate to deny parents the right to participate in the decision-making process, the physician is left to determine the appropriate course of treatment. A close examination of the rules, however, reveals that they offer little guidance to the physician.

The distinction between when section 504<sup>205</sup> applies and when it does not apply is poorly conceptualized, creates confusion, and promotes misapplication of the rules. The confusion is most likely to occur in three situations: 1) when the infant's handicap is inextricably intertwined with the decision-making process; 2) when a decision is made regarding extremely low birth-weight infants; and 3) when the health care practitioner is trying to determine how broadly to read the proscription against clear violations.

The first situation is illustrated by the case of an infant suffering from Trisomy 18, a genetic defect similar to Down's Syndrome (Trisomy 21).<sup>206</sup>

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205. Section 504 of the Rehabilitation Act of 1973 provides the legal authority for the DHHS to intervene in the medical decision-making process through promulgation of the rules. Section 504 provides:

No otherwise qualified handicapped individual in the United States, as defined in 706(6) of this title shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

U.S.C. § 794 (1973 & Supp. V 1981).

206. See *supra* note 4.

Trisomy 18 is invariably associated with profound mental retardation and severe heart defects. Infants who have Trisomy 18 usually die within the first year of life. There have been, however, rare occurrences of long-term survivors. If the infant has a heart lesion that is potentially correctible with surgery, should surgery be performed? If the decision is not to perform surgery on a potentially correctible heart lesion, there could be a violation of section 504 because surgery would have been performed "but for" the handicap of Trisomy 18.<sup>207</sup> On the other hand, the decision not to perform surgery arguably would not violate section 504 because prolonging the infant's life a few months longer, through surgery, could legitimately be considered to be of dubious medical benefit.<sup>208</sup>

The second area of confusion concerns whether section 504 applies to the treatment of an extremely low birth-weight infant.<sup>209</sup> Provision of nourishment and fluids to such an infant may properly be considered extraordinary care. Extremely low birth-weight infants generally cannot receive nourishment by mouth because their digestive tracts are too immature.<sup>210</sup> Consequently, nourishment must be provided by intravenous therapy, which is fraught with problems. Long-term intravenous therapy is required until the infant's digestive tract has developed sufficiently for the infant to take nourishment by mouth.<sup>211</sup> Because the infant's veins are minute, it is difficult to insert and maintain intravenous lines.<sup>212</sup> The type of intravenous solution required to provide adequate nutrition for growth is extremely complex and may produce untoward and life-threatening side effects.<sup>213</sup> Thus,

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207. Health Care for Handicapped Infants, *supra* note 18, at 30,852. The appendix states that a clear violation of § 504 occurs when treatment is denied which would be provided "but for" the infant's handicap. *Id.* at 30,852.

208. Section 504 would not apply to any case in which care or treatment is withheld on the basis of legitimate medical judgment. That is, treatment of dubious medical benefit, futile acts or therapy, or treatment which merely prolongs the process of dying for an infant born terminally ill, would not be required. Health Care for Handicapped Infants, *supra* note 18, at 30,852.

209. See G. AVERY, *supra* note 1, at 230-61. Extremely low birthweight infants are born between 23 and 26 weeks of pregnancy, and weigh between 500 grams (1 lb. 2 oz.) and 750 grams (1 lb. 10 oz.). In 1975, only 8% of these infants survived. *Id.* at 240-41. As a result of advances in neonatal care, however, the survival rate for infants at the higher end of the weight spectrum is improving, although treatment often causes significant mental, motor, visual and lung impairments. *Id.* at 240.

210. *Id.* at 243. The intestinal tract of an infant is incapable of accepting and absorbing an adequate milk intake until the infant reaches 32 weeks of gestation.

211. *Id.* at 243. Intravenous therapy may be necessary for up to 60 days or more. *Id.*

212. *Id.* at 64-65. Intravenous lines may be inserted in peripheral or central veins. Peripheral veins are those just under the skin. Central veins, such as the jugular vein, are deep and generally much larger than peripheral veins. Peripheral veins in these infants are minute and fragile thereby making it difficult to maintain intravenous feedings. Use of central veins is limited because of the danger of infection. *Id.*

213. *Id.* at 65. The type of solution used is called hyperalimentation and includes amino acids to promote growth, glucose and lipid (fat) to meet caloric expenditures, and added vitamins and minerals. The composition of the fluid is determined by the infant's needs which are assessed almost daily through biochemical blood and urine analysis. Hyperalimentation may cause life-threatening infections. This occurs either because the solution itself provides a medium in which

medical decisions regarding care of such an infant must encompass the feasibility of providing nourishment. If the practitioner's decision not to institute intravenous fluid therapy on an extremely low birth-weight infant, whose survival was improbable despite attempts at nourishment, was based on the exercise of reasonable medical judgment, section 504 might not be violated.<sup>214</sup> Yet, since a decision to withhold nourishment is not an option for medical judgment under the DHHS rules, a strong argument can be made that such a decision would be a violation of section 504.<sup>215</sup>

The third area of confusion surrounding the application of section 504 surfaces when the practitioner attempts to determine how broadly to read the proscriptions against certain decisions. The appendix to the DHHS rules indicates that it would be a clear violation of section 504 not to perform surgery to correct an intestinal atresia, an esophageal atresia, or an operable heart lesion on an infant with Down's Syndrome unless an additional complication medically warrants a decision not to operate.<sup>216</sup> It is unclear, however, whether the rules require surgery to be performed if the infant has all three conditions and surgery is unlikely to succeed. A broad reading of the language in the example suggests that surgery must be performed; a narrow reading suggests surgery may not be required.

Furthermore, the rules are replete with vague terminology and, in most instances, the determination of whether or not section 504 applies depends upon how the terminology is defined. For example, discriminatory denial of food and customary medical care constitutes a violation of section 504, but there is no indication of what standard of customary medical care is to be employed.<sup>217</sup> Regardless of which standard is employed, in view of the rapid advances in neonatal care, customary care is an amorphous concept difficult to apply with certainty.<sup>218</sup> In light of the ambiguities inherent in the rules, it is difficult for the sophisticated health care practitioner to determine when a section 504 violation will occur.

Finally, enforcement procedures for section 504 are inappropriate. Notice and complaint procedures were apparently selected as a means of enforcing

bacteria and yeast can grow easily or because the hypertonicity of the solution erodes a peripheral vein causing an infiltration of the solution into subcutaneous tissue, burning the tissue and providing a source of infection. *Id.* at 65, 243-45.

214. Health Care for Handicapped Infants, *supra* note 18, at 30,852. Decisions to withhold extraordinary care from these infants would not implicate § 504 if the decision is based on "reasonable medical judgment concerning the improbability of success in a course of treatment, or risks and potential harm in the course of treatment."

215. *Id.* "At the same time, the basic provision of nourishment, fluids and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment." *Id.*

216. *Id.* For a discussion of the conditions encompassed in the example, see *supra* note 4.

217. For example, does the local community standard of customary medical care apply or does the national medical center standard of customary medical care apply? Application of community standards to community hospitals and national standards to medical centers would lead to uneven and disparate application of § 504.

218. Other terms requiring further definition to be meaningful include "food," "extraordinary medical care," and "routine nursing care."

section 504 because of the success of those procedures in the civil rights context. There are not enough similarities between the two contexts, however, to justify such a conclusion. For example, in the health care context an investigation would take place in an intensive care setting rather than in a hearing. The time for investigation would be measured by minutes and hours rather than weeks or months. Further, the level of expertise required of the investigator would be extremely high because medical decisions rest on highly technical and complex considerations rather than matters of general knowledge. Finally, such an investigation would impinge upon sensitive relationships between physicians and agonized parents who are under stress—a type of stress that does not exist in the civil rights context. Investigations could require detailed explanation of the decision-maker's rationale, consume hours of staff time, and disrupt patient care. DHHS investigations conducted during the period in which the interim rule was operative support these distinctions.<sup>219</sup>

#### V. SUGGESTED APPROACH

Determining when and under what circumstances treatment may be withheld from a seriously ill infant presents a complex and agonizing dilemma for those involved in the decision-making process. In addition, as medical science and technology create new treatment possibilities, the determination becomes even more complex. At the threshold of each new development, it is often difficult to determine whether treatment will save the infant's life or be merely painfully life-prolonging. Those involved in the decision-making process can

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219. In March 1983, the DHHS conducted an investigation into the care being delivered to conjoined (Siamese) twins, having two heads and one trunk. The investigation was triggered by an unidentified caller from another town who had read of the twins' birth and, suspecting they might be denied food or medical care, called the hotline. In addition to dealing with trauma caused by the birth of the infants, the parents were forced to deal with the investigators and with the local newspaper accounts of the investigation. On April 1, based on newspaper reports and belief that the hospital was intentionally harming children, one family removed its seriously ill child from the hospital.

The DHHS conducted a broader investigation at Vanderbilt University Hospital because the call which triggered the investigation charged that 10 named children at the hospital were not being provided proper treatment or food. The investigators met with the children's attending physician, the chief pediatric resident, and an associate director of nursing from 9:30 to 11:45 p.m., during which time the care given each child was discussed. Following the meeting, the investigators and physicians made rounds to visit each child. The next day, the investigators examined medical records and interviewed the nursing staff, hospital administrative staff, and the chief resident from 8:00 a.m. to 4:00 p.m. The impact of the investigation on the hospital and the care provided was significant. Because the investigators had the infants' medical charts, one infant could not be discharged from an intensive care unit, transfer of children from the pediatric intensive care unit to surgery was delayed, and laboratory tests had to be reordered. Further, the chief of pediatrics, a pediatric resident, six nurses, and the associate nursing director spent a total of 44 hours, which would have been spent delivering patient care, with the investigators. Both investigations resulted in findings that the care the children were receiving was "exemplary." Letter from James Stain, M.D., to Members of the American Academy of Pediatrics (June 29, 1983) (discussing the requirements of the proposed rules).

only rely on their best judgment, in light of prevailing knowledge, to determine whether treatment is appropriate.

Because of the inherent complexity of the situation, regulation of the decision-making process as suggested by the DHHS rules is difficult and inappropriate. The goal of ensuring that non-discriminatory treatment is provided to all handicapped infants is laudatory. Nevertheless, an artificial distinction between handicapped and non-handicapped infants promotes uncertainty and trammels the rights of those involved. Moreover, such a narrow focus does little to resolve the issue underlying all decisions regarding treatment of seriously ill infants. That underlying issue is the procedural safeguards which are necessary to ensure that the bedside decision is well-informed and affords the infant the opportunity to receive care most appropriate to meet its special needs.

A reasonable alternative to the approach suggested by the DHHS should eliminate the distinction between handicapped and non-handicapped infants, provide procedures which would ensure that parents are provided with accurate information regarding treatment options, allow for review of decisions to withhold treatment when appropriate, and protect the interests of all involved. Professional medical associations and health care institutions should develop procedures to be used in situations when a decision to withhold treatment is contemplated.<sup>220</sup> Specifically, procedures should be developed to (1) provide a mechanism to ensure that decisions are made based upon complete and current information as to the type of treatment available for the infant's condition, and (2) provide mechanisms for review of decisions to withhold treatment.<sup>221</sup>

In order to ensure that decisions are made based upon complete and current information, when a pediatrician contemplates withholding treatment from a seriously ill infant, the procedure should require consultation between the pediatrician and a physician who specializes in the care of critically ill infants. If a specialist is on staff at the hospital, consultation is easily accessible. If no specialist serves on the staff, the procedure would require telephone consultation with a neonatologist.<sup>222</sup>

In addition to requiring consultation, the procedures should provide a review of decisions to withhold treatment. The most appropriate body to

220. This alternative is also recommended by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. See *President's Commission*, *supra* note 2, at 227; see also *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1975) (recommending the use of ethics committees to review decisions to withhold treatment), *cert. denied*, 429 U.S. 922 (1976). But see *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (decisions to withhold treatment are more properly reviewed by judiciary).

221. See *President's Commission*, *supra* note 2, at 227.

222. Because most community hospital pediatricians currently transfer critically ill infants to tertiary care facilities for care, telephone consultation with neonatologists is not an uncommon practice. Consequently, telephone consultation could provide an easily accessible and realistic approach to ensuring that the pediatrician presents current information to the parents. See G. AVERY, *supra* note 1, at 40.

conduct such a review would be that of the Internal Review Board. The Board, composed of representatives from various health care disciplines, would review decisions to withhold life-prolonging treatment. The type of review required would vary with the facts of the particular case. At the very least, consultation should be required to confirm a diagnosis that the infant's condition is obviously fatal. In cases where the prognosis is less certain, the board would review the entire decision-making process. The review would verify that the decision was based upon current information and confirm the propriety of the decision. Further, if the board viewed the decision as inappropriate, the board would have the authority to refer the case to child-protective services or the court for timely dispute resolution. Because there would no longer be a distinction made between handicapped and non-handicapped infants, the court would be free to use existing legal analyses for conflict resolution. Each analysis provides maximum protection for the infant, yet preserves the parents' rights to participate in the medical decision-making process.

The proposed alternative offers several advantages over the DHHS approach. The alternative promotes informed decision-making and allows parents to explore all available options for treatment. Review of the decision is readily accessible to those involved and provides minimal disruption of patient care.<sup>223</sup> Use of the review board provides protective screening to ensure that decisions are based upon worthy motives.<sup>224</sup> Conflict resolution relies on the prevailing mechanisms for judicial review. Finally, the proposed alternative provides maximum protection for the infant while preserving the parents' rights to participate in the decision-making process.<sup>225</sup>

## VI. CONCLUSION

The DHHS rules were drafted in response to a specific instance of the withholding of treatment from an infant. Understandably, sensationalized accounts of this episode provoked public outrage. The rules were enacted in an effort to prevent discrimination and the withholding of treatment merely on the basis of an infant's handicap. Although this objective is praiseworthy,

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223. See, e.g., *In re Quinlan*, 70 N.J. 10, 49, 355 A.2d 647, 668 (1975), cert. denied, 429 U.S. 922 (1976).

224. *Id.*

225. A federal district court in New York recently rejected the DHHS request for access to hospital records concerning "Baby Jane Doe." *Chicago Tribune*, Nov. 19, 1983, at 8, col. 4. The infant had been born with meningocele, hydrocephaly, and microcephaly. The parents and physicians agreed that corrective surgery would be withheld. The physicians predicted that without surgery the infant would live for six weeks to two years. With surgery, the infant would live into her twenties, however, she would be retarded, epileptic, paralyzed, bedridden and doomed to constant pain. *Complex Case of Baby Jane Doe*, *New York Times*, Oct. 23, 1983, § 4, at E6, col. 2. An attorney from Vermont heard of the decision and petitioned the New York courts to override the parents' decision. The New York Superior Court dismissed the suit and upheld the parents' decision. *Weber v. Stony Brook Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983).

the rules are poorly conceptualized. First, the rules effectively eliminate parents' rights to participate in the decision-making process. Second, the vague and confusing terms provide little guidance to the physician seeking to counsel the parents. Finally, the rules do little to assist those seeking well-reasoned approaches to the question of when treatment should be withheld.

The proper resolution of this issue, how decisions to withhold treatment from infants should be made, is a tremendous challenge to all those currently involved in the decision-making process. This challenge has not been met by the proposed rules. Instead, the rules only promote uncertainty. Although this Comment suggests an alternative to the DHHS rules, it is imperative that the DHHS re-examine its position and allow for the development of well-reasoned approaches to the problem. Perpetuating the current ill-conceived and ill-advised course of action will only generate confusion in an already complex area of health care.\*

*Denice Krez*

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\*Subsequent to the submission of this Comment for publication, the DHHS published Final Rules in the Federal Register. 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. pt. 84) (proposed Jan. 12, 1984). The DHHS indicated that the proposed rules were significantly modified in response to the 16,739 comments received during the notice and comment period. *Id.* at 1623.

Close examination of the final rules reveals, however, that the DHHS effectively made only four substantive modifications to the proposed rules. *Id.* at 1651-54. The first modification is that the final rules encourage, but do not require, recipient health care providers to establish Infant Care Review Committees. *Id.* at 1651. The DHHS recommends that these review committees assist health care providers in developing standards, policies, and procedures for providing care to handicapped infants and make decisions concerning treatment in specific cases. *Id.* The supplementary information section, however, indicates that the committees may not be given an exclusive role in reviewing decisions to withhold treatment from infants and are not a substitute for mechanisms to enforce § 504. *Id.* at 1624. Thus, the final rules continue the enforcement mechanisms of the proposed rules. Specifically, the DHHS's assertion of the authority for access to hospital records and ability to conduct on-site investigations in the health care setting remain in effect. In addition, health care providers continue to have an affirmative duty to take necessary steps to ensure compliance with the rules. *Id.* at 1654.

The second modification of the final rules continues the notice requirement of the proposed rules, but offers two alternative notices and changes the requirement for location, size and wording of the notice. If the care provider has policies and procedures concerning both withholding treatment and review of decisions to withhold treatment from handicapped infants, Notice A may be posted. *Id.* at 1651. On the other hand, if the hospital has no such procedures, the hospital must post Notice B. With the exception of the reference to hospital policies in Notice A, both notices are similar. Further, the final rules require only that the notice be posted in locations where members of the health care team would see the notice and need not be posted where parents of infant patients would see the notice. *Id.* In contrast, the proposed rules required that the notice be posted in each nurses' station responsible for the care of infants.

The size of the notice has been decreased from 8 ½ by 11 inches to 5 by 7 inches. In addition, the wording of the notice has been revised in order to describe the protection of the law given to handicapped infants in simple terms and convey information in a less negative manner than the wording of the notice in the proposed rules. *Id.* at 1626. To illustrate, the



notice required in the final rules carries the heading "PRINCIPLES OF TREATMENT OF DISABLED INFANTS" rather than the heading "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY LAW." *Id.* The content of the notice in the final rules is also meant to reflect deference to medical judgments. *Id.* The notice mandated by the final rules states that "nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of the present or anticipated medical or physical impairments." *Id.* at 1651. This language was not present in the notice required by the proposed rules. In addition, reference to the fact that failure to feed or care for infants may be violative of state criminal and civil laws has been deleted from the notice requirements. *Id.* Despite these changes, however, the major substantive element of the notice requirement of the proposed rules remains in effect. Specifically, the final rules mandate that the notice contain hotline numbers for reporting suspected cases of noncompliance to designated hospital officials, child protective services, or the DHHS. *Id.*

The third and most important modification of the proposed rules is contained in the appendix of the final rules. *Id.* at 1653-54. In this section, the DHHS set forth illustrative interpretative guidelines for applying the law relating to health care for handicapped infants. *Id.* at 1653. The guidelines appear to remedy some of the interpretative difficulties encountered with the proposed rules. The DHHS indicates that futile treatment, treatment which may cause harm to the infant, or treatment with a low probability of success may be withheld without violating § 504 so long as the decision to withhold treatment is based upon reasonable medical judgments and not solely on the infant's handicap. *Id.* at 1653-54. At the same time, however, the guidelines appear to supply an extremely broad definition of handicap which makes § 504 applicable to any infant who has a present or anticipated physical or mental impairment. This broad definition is coupled with the affirmative duty placed on health care providers to take all necessary steps to ensure compliance with the rules. These modifications make virtually all decisions to withhold treatment from infants subject to the mandate of § 504.

The most significant failing of the guidelines, however, is that they do not address whether or not decisions to withhold treatment will survive § 504 scrutiny in cases where the infant's present or anticipated physical or mental impairment is inextricably intertwined in the decision-making process. Thus, the impact of these guidelines is that the final rules will have precisely the same effect on decision-making indicated in the Comment.

The fourth and final modification concerns the new guidelines for the DHHS investigations set forth in the appendix to the final rules. *Id.* at 1654. Pursuant to the guidelines, upon receipt of a complaint alleging non-compliance with § 504, the DHHS officials will immediately conduct a preliminary inquiry into the matter. *Id.* The DHHS will first initiate telephone contact with hospital officials to obtain information concerning the condition of the infant and the treatment being offered. *Id.* If the hospital has an Infant Care Review Committee, the DHHS will also obtain information from the committee. *Id.* On the basis of the information obtained, the DHHS will determine whether or not on-site investigation is necessary. *Id.* Any doubts concerning compliance will be resolved by on-site investigation. *Id.* Unless impracticable, hospital personnel will be contacted prior to the on-site investigation. *Id.* The DHHS will make every effort to minimize disruption of patient care and coordinate its activities with those of state child protective service agencies. *Id.* In addition, the DHHS will obtain the assistance of qualified medical consultants to aid in evaluating medical records. When possible, the consultant will be a specialist with respect to the condition of the infant who is the subject of the investigation or inquiry. *Id.* The DHHS will inform the hospital of the results of the investigation and whether the matter will be referred to the Department of Justice following the investigation. *Id.* To the extent permitted by law, all information obtained will be confidential. Finally, the guidelines indicate that as a matter of policy, the DHHS will not make comments to the public or media regarding the substance of preliminary inquiries or investigations. Although these guidelines provide articulated procedural safeguards for parents and health care providers not present in the proposed ruled, the DHHS's assertion of the underlying right of access to conduct investigations has been effectively adopted without modification from the proposed rules.

Six weeks after publication of the final rules, the Court of Appeals for the Second Circuit

denied the DHHS the right of access to the medical records of a severely deformed newborn infant. *United States v. University Hosp., State Univ. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984). The infant, identified only as Baby Jane Doe, was born on October 11, 1983. *Id.* at 146. She had multiple birth defects, the most serious of which were myelomeningocele, microcephaly, and hydrocephalus. *Id.* As a result of the myelomeningocele, the baby had impaired rectal, bladder, leg, and sensory functions. Because of the microcephaly and hydrocephalus, she was also considered to be "at extremely high risk" for severe mental retardation. *Id.* In addition, she had a malformed brain stem, upper extremity spasticity, and an inability to close her eyes or make full sucking motions. *Id.* Physicians presented Baby Doe's parents with two treatment options. One option consisted of surgical treatment which would prolong the infant's life, but would not improve her handicapping conditions. *Id.* After careful consideration of the options, the Does' chose the conservative medical treatment for their infant. *Id.*

On October 16, 1983, a Vermont attorney, unrelated to the Does, initiated proceedings in the New York State Supreme Court seeking appointment of a guardian ad litem for the infant and an order directing that surgery be performed on the infant. *Id.* The court ordered surgery, however, one day later the Appellate Division of the New York Supreme Court reversed the decision and dismissed the proceeding. *Id.* at 147. The court determined "that the concededly concerned and loving parents [had] made an informed, intelligent, and reasonable determination based upon and supported by responsible medical authority." *Id.* Twelve days later, the New York Court of Appeals affirmed the decision, but relied on different grounds to support the decision. *Id.* Specifically, the court determined that because the Vermont attorney lacked any relationship to the parties and because the state agency responsible for such proceedings was not involved, there was "no precedent or authority" for the proceeding. *Id.*

While the state court proceedings were pending, the DHHS received a complaint that Baby Jane Doe was being discriminatorily denied medically indicated treatment because of her handicaps. The DHHS initially referred the complaint to the New York State Child Protection Services. Following an investigation, the state agency concluded that there was no ground for state intervention. *Id.* In the interim, the Surgeon General of the United States reviewed the record of the state court proceedings which included copies of the medical records of the first eight days of Baby Doe's life. *Id.* The DHHS subsequently requested that University Hospital make all of Baby Doe's medical records available for inspection by the DHHS officials. *Id.*

Due to the hospital's repeated refusals to comply with the DHHS's request for the infant's medical records, the DHHS brought an action alleging that the hospital violated § 504 and 45 C.F.R. § 80.6(c) by denying the DHHS access to information concerning Baby Doe. *Id.* at 148. The district court concluded that the decision not to perform surgery was the result of the Does' reasonable refusal of surgery and not because of any discrimination by the hospital. *Id.* at 148-49. As such, the court could not find the hospital liable for any violation of the Rehabilitation Act. *Id.*

The court of appeals affirmed the decision but found that neither the legislative history and case law interpreting § 504 nor the purposes of the Rehabilitation Act would support the DHHS's assertion of authority to obtain access to the infant's medical records. *Id.* at 153-59. Further, in the court's opinion, absent any clear congressional directive for federal intervention in the medical decision making process, "it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit." *Id.* at 159. In view of this decision, the continuing validity of the DHHS's rules is questionable.

