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# Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?

By ROBYN S. SHAPIRO\*  
and RICHARD BARTHEL\*\*

On April 15, 1985, after several years of debate between the federal government and the medical profession, the Department of Health and Human Services ("HHS") promulgated the final regulations<sup>1</sup> governing medical decision-making for impaired infants under the federal Child Abuse Amendments of 1984.<sup>2</sup> On the same day, HHS published a set of model guidelines for infant care review committees ("ICRCs") within health care facilities.<sup>3</sup> The long-running controversy over care for impaired infants that preceded the final regulations was inevitable because of the complexity of medical decision-making for newborns. The controversy over impaired infant care continues today despite these "Baby Doe regulations."

This Article begins by examining the complexity of medical decision-making for impaired newborns. It then discusses the implications of the new federal regulations imposed on the states, focusing on three procedural mechanisms that could satisfy the requirements set forth in the

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1. 50 Fed. Reg. 14,878 (1985) (codified at 45 C.F.R. § 1340 (1985)). This Article will refer to these provisions as "the Baby Doe regulations." The term "Baby Doe" has been associated with impaired infant treatment dilemmas since the Bloomington, Indiana "Infant Doe" decision. See *In re* Infant Doe, No. GU 8204-004A (Monroe County Cir. Ct., Ind. Apr. 12, 1982), *cert. denied sub nom.*, *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983). That case addressed the question of nontreatment for a baby known only as "Infant Doe," who was born with Down's Syndrome and tracheoesophageal fistula. Over the course of his six days of life, he became the focal point of an intensive medical, legal, and ethical debate. See *infra* notes 113-14 & accompanying text.

2. 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985).

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

regulations. The Article next discusses the HHS "Model Guidelines for Health Care Providers to Establish Infant Care Review Committees."<sup>4</sup> The Article reviews the experience of one hospital's ethics advisory committee, concluding that the committee provided an effective means of ensuring the provision of treatment when appropriate. Finally, the Article proposes a model statute for use in impaired infant medical decision-making situations. This model statute improves upon the procedural mandates of the federal regulations by (1) incorporating into the decision-making process the views of multidisciplinary experts and providing for their oversight; (2) decreasing the necessity for judicial intervention; (3) avoiding disruption of hospital care; and (4) offering an effective response to inappropriate treatment decisions.

## The Complexity of Infant Care Decision-Making

### Background—Medical Decision-Making for the Older Child

A competent adult has a right to refuse medical treatment, even if the ultimate result is death.<sup>5</sup> The incompetent adult has as much right as the competent adult to refuse medical treatment.<sup>6</sup> Because an incompetent person cannot express his wishes, however, others are entrusted with the responsibility for his treatment decisions. Theoretically, these decisions should conform to what the incompetent patient would choose if he could<sup>7</sup> or should advance the incompetent patient's best interests.<sup>8</sup> Greater complexities arise, however, in a decision to withhold treatment from a child because the decision also involves the rights and responsibilities of the child's parents. Parents generally have a right to make fundamental decisions about the upbringing of their children.<sup>9</sup> The United

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4. *Id.*

5. Roth & Wild, *When the Patient Refuses Treatment: Some Observations and Proposals for Handling the Difficult Case*, 23 ST. LOUIS U.L.J. 429, 432 (1979). In *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914), Judge Cardozo stated that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body." And in *Erickson v. Dilgard*, 44 Misc. 2d 27, 28, 252 N.Y.S.2d 705, 706 (N.Y. Sup. Ct. 1962), the court concluded that "it is the individual who is the subject of a medical decision who has the final say and that this must necessarily be so in a system of government which gives the greatest possible protection to the individual in the furtherance of his own desires." *Id.* at 28, 252 N.Y.S.2d at 706.

6. One court has found an exception to this right when the death of an incompetent adult would leave an orphan. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 745, 370 N.E.2d 417, 427 (1977).

7. *Id.* at 750-52, 370 N.E.2d at 430-31.

8. See *In re Quinlan*, 70 N.J. 10, 39, 355 A.2d 647, 663, *cert. denied*, 429 U.S. 922 (1976).

9. See, e.g., *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (right of Amish children to forego compulsory high school education); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (right to

States Supreme Court has said that "it is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder."<sup>10</sup>

If the parent abuses or fails to care for the child, however, the state will protect the child from the action or inaction of the parent.<sup>11</sup> With respect to children, most scholars agree that the appropriate legal standard to guide the state's action is the best interest of the child.<sup>12</sup> As one court explained:

While [the child] "belongs" to his parents, he belongs also to his state. . . . [T]he fact the child belongs to the state imposes upon the state many duties. Chief among them is the duty to protect his right to live and grow up with a sound mind in a sound body, and to brook no interference with that right by any person or organization.<sup>13</sup>

Thus, courts have ordered life-saving treatment in many cases in which it was clear that the child would benefit from medical care that the parents refused to provide. For example, in *Custody of a Minor*<sup>14</sup> Chad Green's parents stopped chemotherapy treatments which the hospital believed were necessary to fight the child's acute lymphocytic leukemia. The treating hospital sought a court order to resume the treatments. Evidence at the court hearing disclosed that, without the treatments, the boy would die within a few weeks, but with treatment he had a better than even chance of complete recovery. The uncontradicted medical testimony at the trial favored chemotherapy, and the court ordered resumption of the treatments.<sup>15</sup>

Similarly, in *Jehovah's Witnesses v. King County Hospital*,<sup>16</sup> *People ex rel. Wallace v. Labrenz*,<sup>17</sup> and *John F. Kennedy Memorial Hospital v. Heston*<sup>18</sup> the courts ordered life-saving blood transfusions when parents who were Jehovah's Witnesses refused to consent to transfusions for their

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choose parochial schools over public schools). See generally *United States v. Orito*, 413 U.S. 139 (1973) (prince to privacy extends to certain aspects of family relationship).

10. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

11. *Brant, Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 Mo. L. Rev. 337, 363 (1981).

12. See J. GOLDSTEIN, A. FREUD & A.J. SOLNIT, *BEFORE THE BEST INTERESTS OF THE CHILD* 92-93 (1979).

13. *In re Clark*, 21 Ohio Op. 2d 86, 90, 185 N.E.2d 128, 132 (1962).

14. 375 Mass. 733, 379 N.E.2d 1053 (1978). This was the first Chad Green case. For the second Chad Green case, see *infra* notes 21-23 & accompanying text.

15. *Id.* at 737-41, 379 N.E.2d at 1057-58.

16. 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968).

17. 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952).

18. 58 N.J. 576, 279 A.2d 670 (1971).

children. More recently, in the Tennessee case of *In re Hamilton*,<sup>19</sup> Pamela Hamilton's parents asked the court not to order radiation and chemotherapy treatments for their twelve-year-old daughter's bone cancer. Doctors testified that without treatment Pamela would die. Pamela's father testified that the family's fundamentalist sect did not permit its members to seek medical treatment, but rather counseled them to rely on the power of prayer. The court declared Pamela a neglected child, gave the state temporary custody, and ordered the medical treatment.<sup>20</sup>

Courts also have overruled parents' medical treatment decisions in cases in which the medical situation was not life-threatening, but the child's failure to receive medical care would have significantly harmed his future health. In the second case involving Chad Green,<sup>21</sup> for instance, instead of conventional care, Chad's parents administered laetrile, large doses of vitamins, enzyme enemas, and folic acid treatments to their son. These treatments caused low-grade chronic cyanide poisoning, hypervitaminosis that damaged his central nervous system and liver, and possible colon damage.<sup>22</sup> The court proscribed these treatments.<sup>23</sup> Similarly, ruling that a child's medical situation need not be immediately life-threatening to justify intervention, the court in *In re Karwath*<sup>24</sup> overruled a father's refusal to authorize removal of his children's tonsils and adenoids. Additionally, in *In re Gregory S*<sup>25</sup> the court overruled a mother's refusal to permit medical or dental care for her child who was suffering from umbilical hernia, cavities, and fractured teeth. Finally, in *In re Rotkowitz*<sup>26</sup> the court overruled a father's objection to surgical correction of his child's leg deformity.

Courts have upheld parents' decisions to reject treatment for their child contrary to doctors' advice when it was not clear that the parents' action would unduly harm the child. For instance, in *In re Hofbauer*<sup>27</sup> the parents did not want their seven-year-old who suffered from Hodgkins' disease to be treated with chemotherapy and radiation. Instead, the parents favored metabolic therapy.<sup>28</sup> In neglect proceedings, the court

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19. 657 S.W.2d 425 (Tenn. Ct. App. 1983).

20. *Id.* at 427-29.

21. Custody of a Minor, 378 Mass. 732, 393 N.E.2d 836 (1979); see *supra* notes 14-15 & accompanying text.

22. Custody of a Minor, 378 Mass. at 741-42, 393 N.E.2d at 842.

23. *Id.* at 746-47, 393 N.E.2d at 845.

24. 199 N.W.2d 147 (Iowa 1972).

25. 85 Misc. 2d 846, 380 N.Y.S.2d 620 (N.Y. Fam. Ct. 1976).

26. 175 Misc. 948, 25 N.Y.S.2d 624 (N.Y. Dom. Rel. Ct. 1941).

27. 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

28. *Id.* at 652, 393 N.E.2d at 1011, 419 N.Y.S.2d at 938.

found the parents innocent and allowed them to retain custody of their child because they justifiably feared the side effects of radiation and chemotherapy; metabolic therapy was controlling the disease; they were willing to have conventional therapy administered in the future, if necessary; and they were loving parents and genuinely concerned about their child's welfare.<sup>29</sup> Similarly, in *In re Seiferth*<sup>30</sup> the court refused to overrule the parents and order surgery for a fourteen-year-old with a cleft palate and harelip, stating that the child's condition was not an emergent threat to his health or life. The court refused to order the surgery despite evidence that the operation would improve the child's speech, appearance, and psychological maturation.<sup>31</sup>

Courts also have upheld parents' decisions not to treat their child when no known treatment would substantially prolong the child's life. For instance, in *In re Green*<sup>32</sup> the court refused to order a splenectomy over the objections of parents of a child afflicted with sickle-cell anemia. Because the child was certain to die of the disease, the court would not overrule the parents' decision to spare him the ordeal of surgery.<sup>33</sup> Similarly, in *Custody of a Minor*<sup>34</sup> the court refused to order treatment for a four-and-one-half-month-old abandoned child who was suffering from serious congenital malformations of the heart and associated blood vessels.<sup>35</sup> The court based its decision on the fact that patients with these conditions normally die within a year, with or without treatment.<sup>36</sup> More recently, in *In re Guardianship of Barry*<sup>37</sup> the parents of a terminally ill ten-month-old successfully petitioned for approval to remove the child's life-support system. The court said that because the child was wholly lacking in cognitive brain function and completely unaware of his surroundings with no hope of developing any awareness, the parents' right to refuse life support outweighed the state's interests in preserving life.<sup>38</sup>

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29. *Id.* at 656-57, 393 N.E.2d at 1014, 419 N.Y.S.2d at 941.

30. 309 N.Y. 80, 127 N.E.2d 820 (1955).

31. *Id.* at 85-86, 127 N.E.2d at 822-23. Parental objections in *Seiferth* were based on a "philosophy" that there were "forces in the universe" that would close the cleft. *Id.* at 84, 127 N.E.2d at 822. The child apparently agreed with that philosophy and did not want the surgery. *Id.*

32. Child Div., Milwaukee County Ct., Wis. Mar. 18, 1966, cited in 12 CRIME & DELINQUENCY 377.

33. *Id.* at 384-85.

34. 385 Mass. 697, 434 N.E.2d 601 (1982).

35. *Id.* at 701, 434 N.E.2d at 604.

36. *Id.* at 711, 434 N.E.2d at 608.

37. 445 So. 2d 365 (Fla. Dist. Ct. App. 1984).

38. *Id.* at 371.

In summary, courts tend to overrule parental refusal of consent for medical treatment for their children when the proposed therapy promises a clear medical benefit. Courts tend to uphold parental refusal when the benefits are marginal or substantially controversial.

Theoretically, the decision to extend treatment to the impaired infant should follow these guidelines, which incorporate a balancing of the risks, harms, and benefits of treatment. However, neonatal medical uncertainties and difficult psychosocial factors discussed in the following section render medical decision-making for the newborn more complex.

### Medical Decision-making for the Newborn

#### *Neonatal Conditions and Diseases*

Much publicity surrounded the medical decision-making process for Infant Doe<sup>39</sup> of Bloomington, Indiana, who suffered from Down's syndrome, and Baby Jane Doe,<sup>40</sup> of New York, who suffered from spina bifida. But ethical and legal dilemmas are not limited to publicized cases and in fact affect the care of many impaired newborns. In most cases, the legal and ethical dilemmas arise because of uncertainties regarding diagnosis, prognosis, and probable outcomes of treatment for these infants. The following sections describe some of these conditions.

#### Prematurity/Low Birth Weight

Each year, approximately 230,000 low birth weight infants are born in the United States; most are premature.<sup>41</sup> According to one expert, one quarter of these infants are "at risk for serious lifetime disability."<sup>42</sup> Medical problems, which may stem from the immaturity of these infants' body systems, include malnutrition, respiratory insufficiency, brain hemorrhage, life-threatening infection, and brain injury from biochemical imbalances.<sup>43</sup> Treatment for many of these conditions is risky. Respiratory insufficiency, for example, can lead to brain damage. On the other hand, mechanically inflating the lungs to supply needed oxygen could damage lung tissue and contribute to brain hemorrhage by impeding blood flow

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39. See *infra* note 62 & accompanying text.

40. See *Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 467 N.Y.S.2d 685, *aff'd*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (per curiam), *cert. denied*, 464 U.S. 1026 (1983); *infra* note 116.

41. See OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, THE COSTS AND EFFECTIVENESS OF NEONATAL INTENSIVE CARE (CASE STUDY #10), at 11 (1985).

42. NEONATAL-PERINATAL MEDICINE 1-2 (R. Behrman 2d ed. 1977).

43. See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 200 n.17 (1983) [hereinafter cited as PRESIDENT'S COMMISSION].

from the brain into the chest cavity. Furthermore, excessive oxygen supply may damage the infants' eyes and lungs.<sup>44</sup>

### Neural Tube Defects

Disorders related to malformations in central nervous system development include anencephaly (most or all of the brain is absent), hydranencephaly (most of the brain has not developed), encephaloceles (a portion of the skull has not closed normally, causing a protrusion of brain and other nervous tissue), and spina bifida cystica (a portion of the spinal cord or its covering fail to develop normally, leaving a sac of nervous tissue protruding from the back).<sup>45</sup> In the latter condition, the mortality rate is high, and survivors suffer a range of disabilities of varying severity, including paralysis below the lesion, incontinence, neurological dysfunctions of various sorts, and hydrocephalus.<sup>46</sup> With spina bifida, as with Down's syndrome,<sup>47</sup> it is not possible to predict accurately at birth the extent to which medical treatment early in life will prevent later medical problems.<sup>48</sup>

### Chromosomal Abnormalities

The most common chromosomal abnormality is Down's syndrome, or Trisomy 21, which occurs once in every 600 to 700 live births.<sup>49</sup> Infants with Down's syndrome may suffer from decreased muscle tone, mental retardation, abnormalities of the eyelids, hand and foot malformations, reproductive disorders, congenital heart defects, gastrointestinal abnormalities, and thyroid gland defects.<sup>50</sup> Ability to predict the degree of retardation is very poor.<sup>51</sup> Trisomy 18, which occurs once in 3000 to 3500 live births, involves profound retardation, malformation of the ears, jaw, hands, and feet, and possibly heart defects, cleft palate, maldeveloped diaphragm, abnormalities of the abdominal wall, and abnormal respiratory control.<sup>52</sup> Trisomy 13 occurs once in every 5000 live

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44. *Id.*

45. For further description of these disorders, see R. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS 279-84 (1984).

46. See Soare & Raimondi, *Quality of Survival in Treated Myelomeningocele Children*, in DECISION MAKING AND THE DEFECTIVE NEWBORN 68 (C. Swinyard ed. 1978).

47. See *infra* notes 49-54 & accompanying text.

48. R. WEIR, *supra* note 45, at 68.

49. D. SMITH, RECOGNIZABLE PATTERNS OF HUMAN MALFORMATION 10 (3d ed. 1982).

50. *Id.* at 10-11.

51. R. WEIR, *supra* note 45, at 44-45.

52. See D. SMITH, *supra* note 49, at 14.



births and entails defects in the formation of the brain, skull, and face.<sup>53</sup> Neurologic problems in these children include seizures, abnormal respiratory control, and severe mental retardation. Eighty percent also have congenital heart disease.<sup>54</sup>

#### Genetic disorders

Other genetic disorders, such as phenylketonuria ("PKU"), involve life-threatening or life-diminishing abnormalities of body chemistry and metabolism.<sup>55</sup> While therapy exists for some of these disorders, such as PKU, other metabolic defects, such as the self-mutilating Lesch-Nyhan syndrome,<sup>56</sup> cannot be treated.<sup>57</sup>

#### *Treatment vs. Nontreatment*

From a medical perspective, the decision to extend treatment to critically ill or severely impaired infants involves the same weighing of risks, harms, and benefits of treatment as with older children.<sup>58</sup> One factor that renders decision-making for newborns uniquely difficult, however, is the degree of uncertainty in neonatal medicine. As discussed above,<sup>59</sup> medical science has not yet adequately developed tools to predict the effect of many neonatal disorders or their treatments. For instance, consider the hypothetical case of Infant X:

A pediatrician is called to the delivery room to attend the premature birth of Infant X. The estimated gestational age from the date of the pregnancy is twenty-eight weeks. The baby's weight after delivery is 750 grams. The child has respiratory difficulty and, upon physical examination, appears younger than the presumed age. The pediatrician knows that in this setting the expected survival rate is thirty to forty percent. To enhance chances of survival, the physician must place a breathing tube in the child within seconds. The doctor also must conduct a further evaluation for other anomalies, but must make an immediate decision on intubation.

In this situation, the doctor must weigh several other questions. What other anomalies is this infant likely to be suffering from? How

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53. *Id.* at 18-19.

54. *Id.*

55. See TABER'S CYCLOPEDIA MEDICAL DICTIONARY 1285 (15th ed. 1985) [hereinafter cited as TABER].

56. Lesch-Nyhan is an inherited metabolic disease which entails mental retardation, aggressive behavior, self-mutilation, and renal failure. Biochemically there is excess uric acid production due to the virtual absence of an enzyme essential for purine metabolism. *Id.* at 945.

57. See R. WEIR, *supra* note 45, at 236-39.

58. See *supra* notes 5-38 & accompanying text for a discussion of the risks, harms, and benefits of treating the older child.

59. See *supra* notes 39-57 & accompanying text.

serious might they be? To what degree could they be treated successfully later? What will be the infant's quality of life if they cannot be treated? Is that potential quality of life worth an attempt to intubate, which carries a significant mortality risk? Uncertainties such as those faced by Infant X's pediatrician make it difficult for doctors to provide families, ethics committees, courts, or other policy-makers with the prognostic information necessary for informed decision-making regarding critically ill newborns.

In addition to medical uncertainties, various psychosocial factors render newborn health care decision-making difficult. One of these factors is the physician's own attitude. In advising the infant's family, some physicians feel that they must convey authority because the parents and other caretakers of the infant expect it. Some physicians will step beyond the boundaries of their authority, perhaps in an effort to fulfill these expectations or as a result of their own paternalism or bias.

Other psychosocial forces further complicate the decision-making process. Parents' distress at the birth of an impaired infant potentially distorts their expectations and beliefs, hinders their thinking, and may even encourage them to abrogate decision-making. Parents, too, have their own biases about disabled children, based on a complicated mix of knowledge, experience, religious belief, and cultural background. Several other influences on decision-making include the views of other caretakers, such as the infant's grandparents and nursing staff, the policies and procedures of the care-giving institution, and the social and legal climate.

Given the absence of clear-cut medical prognoses and the impact of psychosocial factors discussed above, it is not surprising that clear guidelines for the treatment of critically ill or disabled infants have not emerged and that nontreatment decisions have been haphazard and perhaps arbitrary. This is illustrated by a comparison of the following cases.

In 1972, a Maryland Down's syndrome infant with duodenal atresia<sup>60</sup> died of starvation over a fifteen-day period after his parents refused consent for corrective surgery.<sup>61</sup> In April 1982 in Bloomington, Indiana, a court refused to order life-saving surgery over parental objection for Infant Doe, who was born with Down's syndrome and tracheoesophageal fistula.<sup>62</sup> In both these cases, despite medical uncer-

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60. Duodenal atresia is congenital closure of a portion of the small intestine. See TABER, *supra* note 55, at 151.

61. See Rowe, *Infanticide: Who Makes the Decision?*, WIS. MED. J., May 1974, at 10.

62. *In re Infant Doe*, No. GU 8204-004A (Monroe County Cir. Ct., Ind. Apr. 12, 1982), *cert. denied sub nom.*, *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983). A tracheoesophageal fistula is a congenital abnormality involving an anormal communication between the windpipe and the gullet that prevents normal ingestion of food. R. WEIR, *supra*

tainty regarding the degree of the infant's mental retardation, the courts determined that nontreatment and death were in the infant's best interests.

Yet in *Maine Medical Center v. Houle*<sup>63</sup> the court ordered treatment, over parental objection, for a brain-damaged infant born with no left eye, a rudimentary left ear, a malformed thumb, several fused vertebrae, and a tracheoesophageal fistula that prevented his ingestion of food. The *Houle* court determined that it was in the infant's best interests to receive treatment and live, despite the fact that its impairments were probably more severe than those faced by the Downs syndrome infants discussed above. Similarly, the court overruled the parents and ordered surgery for a child born with spina bifida in *In re Cicero*.<sup>64</sup> Evidence in that case showed that, with the surgery, the child could probably walk with braces, but would have no bladder or bowel control and would be mentally retarded; without the surgery, she would not live more than six months.<sup>65</sup> In ordering the surgery, the court stated that when there is a chance to live a useful, fulfilled life, parental inaction may not deny that chance.<sup>66</sup> The court also ordered treatment over parental objection in the case of Karen Ann McNulty,<sup>67</sup> who suffered congenital rubella. She had cataracts on both eyes, congenital heart damage, coarctation of the aorta,<sup>68</sup> and respiratory problems. She also was mentally retarded and apparently deaf. In ordering the cardiac surgery, which had a fifty to sixty percent mortality rate, the court said: "If there is any lifesaving treatment available it must be given regardless of quality of life that will result."<sup>69</sup>

Thus, the uncertainty of neonatal medicine, the psychological and sociological complexities presented by doctors, parents, and other caregivers, and the unpredictability of the current legal climate all have combined to render medical decision-making for the impaired newborn extremely difficult. Pursuant to congressional mandate under the 1984

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note 45, at 43-44. This esophageal disorder is often corrected with a surgical procedure that succeeds about ninety percent of the time. *Id.*

63. No. 74-145 (Super. Ct., Cumberland County, Me. Feb. 14, 1974).

64. 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979).

65. *Id.* at 700-01, 421 N.Y.S.2d at 966-67.

66. *Id.* at 702, N.Y.S.2d at 968.

67. *In re McNulty*, No. 1960 (P. Ct., Essex County, Mass. Feb. 15, 1978), cited in Paris, *Terminating Treatment for Newborns: A Theological Perspective*, LAW MED. & HEALTH CARE, Feb. 15, 1978, at 121.

68. Coarctation of the aorta is a localized malformation resulting in the narrowing of the aorta. TABER, *supra* note 55, at 346.

69. *In re McNulty*, No. 1960 (P. Ct., Essex County, Mass. Feb. 15, 1978), cited in Paris, *supra* note 67, at 121.

Child Abuse Amendments,<sup>70</sup> the Department of Health and Human Services has responded to the arbitrary nature of nontreatment of disabled infants in two ways. First, it promulgated the "Baby Doe" regulations.<sup>71</sup> Second, it issued "Model Guidelines for Health Care Providers to Establish Infant Care Review Committees."<sup>72</sup> An analysis of both the regulations and the guidelines follows.<sup>73</sup>

### The Federal Government's Answers

On April 15, 1985, the Department of Health and Human Services published the final "Baby Doe" regulations under the Child Abuse Amendments.<sup>74</sup> These regulations provide for federal assistance to state child protective service systems dedicated to preventing "medical neglect." "Medical neglect," a new category of child abuse created by the legislation, is defined as "the withholding of medically indicated treatment from a disabled infant with a life-threatening condition."<sup>75</sup> Under the regulations, in order for a state child protective service system to qualify for federal grants, certain requirements must be satisfied. First, the agency must have a liaison in hospitals who can investigate possible medical neglect cases.<sup>76</sup> Second, state laws must allow the system to initiate legal action, if necessary.<sup>77</sup> Third, the system must be allowed access to medical records in cases of suspected neglect.<sup>78</sup> Finally, the system must be able to secure an independent medical examination of the infant in question.<sup>79</sup> In addition to these implementing regulations, HHS issued a companion set of regulations entitled "Model Guidelines for Health Care Providers to Establish Infant Care Review Committees."<sup>80</sup> The next sections analyze the implications of the regulations' delegation

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70. 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985).

71. 45 C.F.R. § 1340 (1985).

72. 50 Fed. Reg. 14,893 (1985). The regulations encourage, but do not require, hospitals to establish ICRCs.

73. For a discussion elsewhere in this symposium of the 1984 Child Abuse Amendments and the implementing regulations promulgated by HHS, see Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 HASTINGS L.J. 765 (1986).

74. 45 C.F.R. §§ 1340.1-.15 (1985). The regulations implement the 1984 Child Abuse Amendments, 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985). These regulations are supplemented by an appendix containing interpretive guidelines, although these guidelines are not meant as binding rules of law. 45 C.F.R. § 1340.20 (1985).

75. 45 C.F.R. § 1340.15(b) (1985).

76. *Id.* § 1340.15(c)(2)(i).

77. *Id.* § 1340.15(c)(2)(iii).

78. *Id.* § 1340.15(c)(4)(i).

79. *Id.* § 1340.15(c)(4)(ii).

80. 50 Fed. Reg. 14,893 (1985).

to the states of child abuse prevention responsibility<sup>81</sup> and the guidelines' endorsement of infant care review committees.<sup>82</sup>

### "Baby Doe" Regulations—The Procedural Requirements

#### *The Alternatives*

A significant portion of the Baby Doe regulations describes a set of minimum requirements that a state child protection service ("CPS") system must fulfill in order to qualify for federal grants under the Child Abuse Prevention and Treatment Act.<sup>83</sup> In brief, a state CPS system must have a procedure to designate one or more persons in health care facilities who will identify and pursue cases of suspected medical neglect,<sup>84</sup> to ensure that state law authorizes the CPS system to go to court to intervene in cases as necessary,<sup>85</sup> to obtain medical records or other information relevant to an investigation of medical neglect,<sup>86</sup> and to obtain an independent medical examination as part of the investigation.<sup>87</sup> A state may meet these requirements by adopting any of the following procedural mechanisms: 1) those which now accompany existing state child abuse statutes; 2) procedural provisions modeled after the regulations<sup>88</sup> promulgated under section 504 of the 1973 Rehabilitation Act;<sup>89</sup> or 3) procedural provisions based upon the ABA's *Model Procedures for Child Protection Service Agencies*.<sup>90</sup>

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81. See *infra* notes 83-136 & accompanying text.

82. See *infra* notes 138-71 & accompanying text.

83. (codified as amended at 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985)).

84. 45 C.F.R. § 1340.15(c)(2)(i) (1985). The procedures must specify that the CPS will promptly contact each health care facility to obtain the name, title, and telephone number of individuals designated by such facilities for the purposes of coordination, consultation, and notification of activities, and will at least annually recontact each facility to obtain any changes in the designations. *Id.* § 1340.15(c)(3).

85. *Id.* § 1340.15(c)(2)(iii). In every case which results in a judicial proceeding, the state must ensure the appointment of a guardian ad litem to represent and protect the rights of the infant. *Id.* § 1340.14(g).

86. *Id.* § 1340.15(c)(4)(i).

87. *Id.* § 1340.15(c)(4)(ii).

88. 49 Fed. Reg. 1622, 45 C.F.R. 84.55 (1984).

89. 29 U.S.C. § 794 (1982).

90. AMERICAN BAR ASSOCIATION LEGAL PROCEDURES FOR HANDICAPPED INFANT CARE PROJECT, MODEL PROCEDURES FOR CHILD PROTECTIVE SERVICE AGENCIES RESPONDING TO REPORTS OF WITHHOLDING MEDICALLY INDICATED TREATMENT FROM DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS (Oct. 24, 1985) [hereinafter cited as ABA PROCEDURES].

## State Child Abuse Statutes

As discussed, parents' rights to make medical decisions for their infants are not absolute.<sup>91</sup> The state has an interest in the welfare of all its citizens, including infants.<sup>92</sup> Thus, in many cases in which it has been clear that a child would benefit from medical care and the parents have refused to provide it,<sup>93</sup> courts have ordered the needed treatment. All states now have statutes which impose upon parents the legal duty to provide necessary medical assistance to children,<sup>94</sup> and it is often these statutes that courts rely on in allowing the state to intervene. These statutes take varying forms, ranging from requirements of child support and provision of necessities<sup>95</sup> to prohibition of cruelty, maltreatment, or endangering the life or health of a minor.<sup>96</sup> Several state statutes specifically punish the failure to furnish medical assistance.<sup>97</sup> Even when the duty to provide medical care is not expressly mentioned, courts have interpreted general terms prohibiting neglect, cruelty, maltreatment, or endangering health to include the provision of needed medical aid.<sup>98</sup>

Courts in several cases have applied these neglect statutes when a parent's refusal to provide medical care caused or could have caused death or serious injury. *In re Jerry M.*,<sup>99</sup> for instance, involved a mother who waited several hours before taking her child to the hospital for treatment of head injuries. Relying on New York's child neglect statute, the court held that the mother's action constituted neglect and awarded custody of the child to his paternal grandparent. Similarly, in *W.H. v. Moore*<sup>100</sup> the court found that a mother had knowingly endangered her

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91. See *supra* notes 11-26 & accompanying text.

92. The doctrine of *parens patriae* imposes upon the state the duty to protect children. See *In re Phillip B.*, 92 Cal. App. 3d 796, 801, 156 Cal. Rptr. 48, 51 (1979), *cert. denied*, 445 U.S. 949 (1980): "*Parens patriae* . . . refers traditionally to the role of the state as sovereign and guardian of persons under a legal disability to act for themselves such as juveniles, the insane, or the unknown." *West Virginia v. Chas. Pfizer & Co.*, 440 F.2d 1079, 1089 (2d Cir. 1971).

93. This parental refusal of medical care is defined as child abuse in the 1984 amendments. See 42 U.S.C.A. § 5102 (West Supp. 1985).

94. See Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 218 (1975) (citing, CAL. PENAL CODE § 270 (West 1970); N.J. STAT. ANN. § 9:6-1 (West 1960)).

95. See, e.g., N.Y. PENAL LAW § 260.05 (McKinney 1985).

96. See, e.g., CONN. GEN. STAT. ANN. tit. 53, ch. 939, § 53-21 (West 1985); ILL. ANN. STAT. ch. 23, § 2354 (Smith-Hurd 1985); N.Y. PENAL LAW § 260.10 (McKinney 1980); PA. CONS. STAT. ANN. tit. 18, § 4304 (Purdon 1983).

97. See, e.g., N.J. STAT. ANN. §§ 9:6-1, -3 (West 1960).

98. See, e.g., *State v. Clark*, 5 Conn. Cir. Ct. 699, 705, 261 A.2d 294, 298 (1969).

99. 78 Misc. 2d 407, 408-09, 357 N.Y.S.2d 354, 355-56 (N.Y. Fam. Ct. 1974).

100. 591 S.W.2d 645 (Tex. Civ. App. 1979).

children, causing them to suffer burns, bone fractures, bruises, and lesions. The injuries should have been promptly treated by medical personnel, but were not. The court terminated the mother's rights because she had had control of her children and refused to do anything to prevent injury.<sup>101</sup> Again, in *State v. Fabritz*<sup>102</sup> a mother was convicted under the state's child abuse law, which obligates parents to provide necessary medical treatment for their children.<sup>103</sup> In that case, the mother found her child in a listless state after being in the custody of others, yet delayed eight hours before taking her to the hospital. In upholding the mother's conviction, the court stated that her failure to act caused bodily injuries beyond those sustained in the original assault.<sup>104</sup> And in *Maine Medical Center v. Houle*<sup>105</sup> the court held that the refusal of parents to correct a tracheoesophageal fistula that prevented normal feeding and breathing in their impaired infant constituted neglect.<sup>106</sup>

Furthermore, state liability for neglect may be imposed even in non-life-threatening situations in which ameliorative care has been recommended and refused. In *re Sampson*,<sup>107</sup> for instance, involved a fifteen-year-old boy suffering from neurofibromatosis. The disease caused a massive deformity on the right side of his face and neck, giving him a grotesque, repulsive appearance which, the court observed, "must inevitably exert a most negative effect upon his personality development, his opportunity for education and later employment, and upon every phase of his relationship with peers and others."<sup>108</sup> The court found that he was "neglected," even in the absence of an immediate threat to his health from the condition, when his mother, a Jehovah's Witness, refused to consent to blood transfusions necessary for corrective surgery.<sup>109</sup>

These cases demonstrate that state child abuse legislation has been construed to allow court intervention in cases of withholding medical treatment from impaired newborns. In states with such statutes, no

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101. *Id.* at 646.

102. 276 Md. 416, 348 A.2d 275 (1975), *cert. denied*, 425 U.S. 942 (1976).

103. *Id.* at 424-25, 348 A.2d at 280.

104. *Id.* at 425, 348 A.2d at 280-81.

105. No. 74-145 (Super. Ct., Cumberland County, Me. Feb. 14, 1974).

106. *See also* *State v. Scott*, 400 So. 2d 627 (La. 1981) (father convicted under state child abuse statute for failure to seek medical assistance for his son burned by hot grease); *Matthews v. State*, 240 Miss. 189, 126 So. 2d 245 (1961) (parents prosecuted for neglecting to provide digitalis for a child left in care of nursery); *State v. Perricone*, 35 N.J. 463, 181 A.2d 751 (1962) (parents prosecuted for refusing blood transfusion).

107. 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970), *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).

108. *Id.* at 661, 317 N.Y.S.2d at 644.

109. *Id.* at 671, 317 N.Y.S.2d at 654.

more may be needed to comply with the Baby Doe regulations than a CPS system liaison in hospitals. Existing laws already satisfy the other requirements in the federal regulations designed to protect against withholding of medically indicated treatment.<sup>110</sup>

#### Section 504 of the 1973 Rehabilitation Act

On the other end of the spectrum, a state might wish to take an activist approach to suspected cases of infant medical neglect. Instead of relying on its child neglect and abuse statutes to cover instances of medical neglect, such a state could pattern its child protection system after the regulations issued in 1983<sup>111</sup> under section 504 of the 1973 Rehabilitation Act.<sup>112</sup> In response to the *Bloomington Infant Doe* case,<sup>113</sup> President Reagan sent a memorandum to then Secretary of Health and Human Services Richard Schweiker, instructing him to notify health care providers that section 504 of the 1973 Rehabilitation Act "forbids recipients of Federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps."<sup>114</sup> The Secretary responded on March 7, 1983, with an interim final rule under section 504

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110. State child neglect and abuse statutes are typically accompanied by procedural mechanisms that enable the CPS system to obtain medical records and other pertinent information, obtain an independent medical examination, and initiate court action in cases of suspected medical neglect, as required by the federal regulations. For example, in Wisconsin a court is assigned jurisdiction over children alleged to be in need of protection or services, including children whose "parent, guardian, or legal custodian neglects, refuses or is unable for reasons other than poverty to provide necessary care, food, clothing, medical or dental care or shelter so as to seriously endanger the physical health of the child . . . ." WIS. STAT. § 48.13(10) (West 1979). Any person with information about such a child is empowered to consult with an intake worker, who conducts an inquiry on behalf of the court to determine the best interests of the child and of the public. *Id.* § 48.243(1). If the intake worker determines that the child should be referred to the court, he requests the district attorney or other responsible official to file a petition to declare the child to be in need of protection or services. *Id.* § 48.243(3). Once the petition is filed, the court must appoint counsel or a guardian ad litem for the child, *id.* § 48.23(3m), who has full right of access to the child's medical records and other pertinent information which would otherwise be confidential. The filing of the petition also empowers the court, upon a showing of reasonable cause, to order the child to undergo an outpatient examination by a physician, psychiatrist, or licensed psychologist. *Id.* § 48.295(1).

111. 49 Fed. Reg. 1622 (1984) (codified at 45 C.F.R. § 84.55 (1985)).

112. Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (1973) (codified as amended at 29 U.S.C. § 794 (1982)).

113. *In re Infant Doe*, No. GU 8204-004A (Monroe County Cir. Ct., Ind. Apr. 12, 1982), cert. denied sub nom. *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

114. 49 Fed. Reg. 1622 (1984). Section 504 of the Rehabilitation Act states in part: "No otherwise qualified handicapped individual . . . 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." 29 U.S.C. § 794 (1982).



that required hospitals receiving federal funds to post in pediatric wards, nurseries, delivery rooms, and neonatal intensive care units warning signs regarding discriminatory failure to care for disabled infants.<sup>115</sup>

HHS also attempted to establish a twenty-four-hour toll-free telephone line for the reporting of parents, physicians, and hospitals that fail to comply with the regulations. A call to HHS would activate an investigative team to review the care of the infant.<sup>116</sup> Various medical groups

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115. 48 Fed. Reg. 9630, 9631-32 (1983).

116. *Id.* at 9631. On March 18, 1983, the American Academy of Pediatrics, joined by several other medical associations, brought suit in U.S. District Court against HHS and Secretary Margaret Heckler to prevent the implementation of the regulations. On April 14, 1983, a few weeks after the rule took effect, Judge Gerhard Gesell struck it down. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Judge Gesell cited numerous failings in the rule, including the observation that the hot-line was "ill considered" and could be seriously misused, that the investigative squads might jeopardize the quality of care in neonatal intensive-care units, and that the rule was "arbitrary and capricious" and virtually without meaning, beyond its "in terrorem" effect. *Id.* at 399-403; see Administrative Procedure Act, 5 U.S.C. § 706(2)(A) (1982) (extending the scope of judicial review to holding unlawful and setting aside agency action that is "arbitrary or capricious"). In July 1983, HHS issued a virtually identical "revised" set of section 504 regulations, intended to become effective after the mandatory 60-day comment period. 48 Fed. Reg. 30,846 (1983). The final rule that emerged from the comment process, which continued the use of the hot-line and the warning notices in hospitals, took effect on February 13, 1984. 49 Fed. Reg. 1622 (1984) (codified at 45 C.F.R. § 84.55 (1985)). The final regulations provided that: (1) Infant Care Review Committees ("ICRCs") in recipient health care institutions were to be encouraged; (2) informational notices regarding proscribed discrimination under section 504 and the telephone numbers of the HHS 24-hour hot-line and of the appropriate child protection agency were to be posted where health professionals could see them; (3) state child protective service agencies were to use full authority to protect unlawful neglect, including on-site investigations and timely applications for court-ordered treatment; (4) access to records was to be expedited and not limited to business hours. *Id.*

Subsequently, in what became known as the "Baby Jane Doe Lawsuit," the Second Circuit affirmed that section 504 of the Rehabilitation Act does not apply to treatment of seriously ill newborns. *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984), *aff'g* 575 F. Supp. 607 (E.D.N.Y. 1983). The Second Circuit relied extensively on strongly worded dicta in Judge Gesell's opinion:

The legislative history [on this subject] focuses on discrimination against adults and other children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever suggested that Section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life.

*Id.* at 158 (quoting *American Academy of Pediatrics*, 561 F. Supp. at 401).

On March 23, 1984, several medical groups challenged the "Baby Doe II Rule" on the theory that the Second Circuit's decision in the Baby Jane Doe case rendered the rule invalid. On June 11, 1984, the district court in New York issued a nationwide injunction prohibiting HHS from implementing the "Baby Doe II Rule." The Second Circuit affirmed. *American Hosp. Ass'n v. Heckler*, 585 F. Supp. 541 (S.D.N.Y.), *aff'd*, Nos. 84-6211, 84-6213 (2d Cir. Dec. 27, 1984).

On June 9, 1986, the United State Supreme Court affirmed the Second Circuit's decision. *Bowen v. American Hospital Assn.*, 106 S. Ct. 2101 (1986). The Supreme Court held that the

have successfully challenged the implementation of these procedures in federal court. The hot-line and investigation squad approach, if established on a local basis, may nevertheless provide a second possible route for state child protective systems to fulfill the requirements under the Baby Doe regulations of investigation and intervention in suspected cases of withholding medically indicated treatment.

#### The ABA Model Procedures for Child Protective Service Agencies

An approach to suspected cases of infant medical neglect that is neither as passive as relying on present state child abuse and neglect laws nor as aggressive as mimicking the section 504 regulations' approach might be to adopt the procedures suggested by the American Bar Association. In October 1985 the American Bar Association published a final draft of its *Model Procedures for Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment From Disabled Infants with Life-Threatening Conditions*.<sup>117</sup> Under this model, the state child protective service ("CPS") agency would have a CPS specialist available to investigate promptly reports of suspected withholding of medically indicated treatment.<sup>118</sup> In the course of the investigation, the CPS specialist would contact the designated hospital/CPS liaison, the hospital's ethics committee (if one exists), the CPS medical consultant, and the CPS supervisor.<sup>119</sup> After investigation, the CPS specialist could decide to seek additional information by an on-site investigation, independent medical evaluation, informal resolution of the matter, or court action, or the specialist could close the investigation.<sup>120</sup> Additionally, the CPS specialist would monitor any treatment ordered by the court or agreed to by the parents.<sup>121</sup>

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regulations were "totally foreign to the authority conferred on [the Secretary] by Section 504" to prevent discrimination, *id.* at 2121, and that the Secretary could not "dispense with the [Act's] focus on discrimination and instead . . . employ federal resources to save the lives of handicapped newborns. . . ." *Id.* at 2123. The court continued, "the legislative history of the Rehabilitation Act does not support the notion that Congress intended intervention by federal officials into treatment decisions traditionally left by state law to concerned parents and the attending physicians or, in exceptional cases, to state agencies charged with protecting the welfare of the infant." *Id.* at 2122 n.33.

Since the Supreme Court's decision only addresses the question of the applicability of Section 504 to treatment of impaired infants,, it does not affect a state's ability to fulfill the requirements of the 1984 Child Abuse regulations by mimicking the section 504 approach.

117. ABA PROCEDURES, *supra* note 90.

118. *Id.* pt. III, § 3.1.

119. *Id.* pt. IV, §§ 4.2, 4.4, 4.7.

120. *Id.* pt. VI. The on-site investigation would involve interviews with medical personnel or ICRC members and review of medical records.

121. *Id.* pt. VII, § 7.1.

*Analysis of the Alternatives*

As the following analysis demonstrates, these three possibilities for complying with the Baby Doe regulations contain numerous drawbacks that warrant consideration of a different approach to the Baby Doe dilemma. Reliance on present state child abuse statutes may allow many inappropriate nontreatment decisions to escape review; the section 504 approach is too heavy-handed and may inhibit decision-making; and the ABA approach entails the possibility of unproductive hospital disruption and, in addition, suffers from an inappropriate remedy that may harm legitimate state child abuse prevention efforts.

## State Child Abuse Statutes

While it is conceivable that only slight modifications in existing laws could satisfy the federal procedural requirements, experience and the professional commentary that prompted initial federal intervention into infant treatment decision-making in 1982 indicate that, in practice, such laws may not be adequate. First, as discussed above,<sup>122</sup> court decisions to date regarding infant treatment have been haphazard and arbitrary and have failed to establish clear guidelines for appropriate nontreatment. In addition, while judicial and administrative machinery may be in place to prevent inappropriate denial of care, that machinery may not always be put to use.<sup>123</sup> For instance, a 1977 article,<sup>124</sup> which reported results of a survey of pediatric surgeons and pediatricians, indicated that 76.8% of the pediatric surgeons and 59.5% of the pediatricians said they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down's syndrome;"<sup>125</sup> and 3.4% of the pediatric surgeons said that they would seek a court order if parents refused consent in such situations.<sup>126</sup> Although it is quite likely that a child protective service system would refer such a case to court and that a court would then order surgery over parental objection, this study suggests that nontreatment in such situations may occur without ever coming to the attention of the CPS system or the court.

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122. See *supra* notes 60-69 & accompanying text.

123. See, e.g., Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (1977); Todres, *Pediatrician: Attitudes Affecting Decisionmaking in Defective Newborns*, 60 PEDIATRICS 197 (1977); *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, HASTINGS CENTER REP., Apr. 1976, at 2.

124. Shaw, Randolph & Manard, *supra* note 123.

125. *Id.* at 590.

126. *Id.* at 590-91.

## Section 504 of the 1973 Rehabilitation Act

There are several difficulties in satisfying the Child Abuse Act's procedural requirements by requiring warning notices in hospital nurseries and instituting anonymous hot-lines to the state CPS system, which would then activate investigation. First, this approach could inhibit decision-making by parents and physicians. An ever-present, anonymously activated surveillance mechanism could well leave patients, visitors, and professionals with the impression that health care providers are naturally prone to abuse their patients. This impression could lead parents and physicians to overreact and make inappropriate medical treatment decisions.

Furthermore, this procedure could disrupt hospital functioning unnecessarily. Experience under the interim section 504 regulations demonstrated that the hot-line initiated several unfounded accusations. For example, on March 23, 1983, within one day of posting its section 504 notices, Vanderbilt Hospital was accused of denying care to ten infants.<sup>127</sup> Two federal investigators and a neonatologist flew to the hospital. During the next two days, the team met with all ten infants' physicians, the chief of pediatrics, the chief pediatric resident, and the associate director for nursing, and visited each child and examined medical records. Afterward, the team determined that the care being given the children was "exemplary in all respects."<sup>128</sup> Strong Memorial Hospital in Rochester, New York, was another target of federal investigation.<sup>129</sup> A caller from another city had read a newspaper article quoting a father as saying that no surgery was planned for his Siamese twins. The caller reported that physicians were denying care to the infants. The federal investigation revealed no wrongdoing, but caused anguish to the parents of the twins and to parents of other children at the hospital as well.<sup>130</sup>

In fact, an attorney for the hospital was quoted as saying, "[t]he parents of one critically ill patient signed the child out of the hospital against medical advice for fear their child was not being well cared for . . . ."<sup>131</sup> Indeed, in striking down the section 504 regulations, the District of Columbia federal district court said of emergency investigation teams: "their sudden descent . . . monopolizing physician and nurse time and making hospital charts and records unavailable during treat-

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127. Strain, *The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 NEW ENG. J. MED. 443, 444 (1983).

128. *Id.*

129. *Id.*

130. *Id.*

131. Culliton, *Baby Doe Reg. Thrown Out by Court*, 220 SCIENCE 479, 480 (1983).

ment can hardly be presumed to produce higher quality care for the infant."<sup>132</sup> In summary, if a state CPS system satisfies the federal Baby Doe requirements by mimicking the section 504 approach and instituting anonymous hot-lines and investigative teams, it may provoke paranoia and inappropriate decision-making, unfounded accusations, and unnecessary hospital disruption.

#### The ABA Model Procedures for Child Abuse Protective Service Agencies

Although the ABA Model Procedures<sup>133</sup> decrease the likelihood of unfounded accusations by incorporating roles for specialists with appropriate qualifications for investigating infant medical neglect, several of the model's provisions, such as on-site investigations, medical record review, independent medical evaluations and treatment monitoring, entail possible disruption of hospital activities. Furthermore, in the absence of clear-cut legal and medical criteria for impaired infant nontreatment, the distinction between CPS-endorsed and CPS-prohibited nontreatment would depend, to a large extent, on the biases of the CPS specialist.

More importantly, the ABA proposal—and any other proposal that is directed to implementing the federal regulations—is flawed by the context of the Federal Child Abuse Prevention and Treatment Act.<sup>134</sup> Classifying allegedly inappropriate medical treatment decisions as “child abuse,” which the Act’s regulations do,<sup>135</sup> creates an impression that parents and physicians must be policed to prevent them from neglecting infants born with disabilities. Second, because the penalty for “child abuse” under the 1984 Child Abuse Amendments and implementing regulations is a state’s loss of federal anti-child abuse funds,<sup>136</sup> redress for a medical treatment decision that violates the federal law, as implemented by the state’s procedures, will not be better medical care for the impaired infant. Rather, the result will be fewer federal funds for the state to fight child-beating, sexual abuse, and other behavior that is more appropriately classified as “child abuse.” It is inappropriate to place the impaired infant medical treatment dilemma within the federal child abuse legislation because federal child abuse remedies do not adequately address the problem.

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132. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 399 (D.D.C. 1983).

133. ABA PROCEDURES, *supra* note 90.

134. 42 U.S.C.A. §§ 5101-5106, 5111-5113, 5115 (West Supp. 1985).

135. *Id.* § 5102(1).

136. 42 U.S.C.A. § 5116e (West Supp. 1985)..

### Model Guidelines for Health Care Providers to Establish Infant Care Review Committees

In light of the deficiencies inherent in each of the foregoing approaches to satisfying the Baby Doe regulations' procedural requirements, the concept of increased reliance upon infant care review committees—the subject of companion regulations<sup>137</sup> issued under the 1984 Child Abuse Amendments—deserves serious consideration.

#### *The Model Guidelines*

Section 124 of the Child Abuse Amendments of 1984 required the Secretary of HHS to publish interim and final model guidelines to encourage Infant Care Review Committees.<sup>138</sup> The resulting Model Guidelines encourage health care facilities to establish committees for the purposes of "educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment . . . from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions."<sup>139</sup> The thrust of these guidelines was well articulated in the March 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. . . . Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone.

Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision . . . if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate.<sup>140</sup>

Since the Commission's report, "a broad range of medical and health associations endorsed the concept of hospital review committees to deal

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137. 50 Fed. Reg. 14,893 (1985).

138. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 124, 98 Stat. 1749, (1984).

139. 50 Fed. Reg. 14,893 (1985).

140. PRESIDENT'S COMMISSION, *supra* note 43, at 227.

with issues relating to medical care for disabled infants."<sup>141</sup>

The Model Guidelines recommend that ICRC membership be multidisciplinary and include, at a minimum, a practicing physician, a practicing nurse, a hospital administrator, a social worker, a representative of a disabled group, a lay community member, and a member of the facility's organized medical staff as chair.<sup>142</sup> Procedures should exist to inform both hospital personnel and patients' families of the existence and functions of the ICRC and its availability on a twenty-four-hour basis.<sup>143</sup> Further, the guidelines provide that the ICRC should develop policies to "facilitate effective coordination and cooperation between the hospital and the state child protective services system."<sup>144</sup>

### *The Advantages*

Consultations with infant care review committees can help to ensure that treatment decisions are made in as careful and informed a manner as possible. The complexity of impaired infant treatment cases often makes it impossible to define clear clinical criteria for withholding treatment, and an attending physician may not have access to all facts necessary to make the treatment decision that would further the infant's best interests. Proper diagnosis, prognosis, and treatment alternatives often require updated information that may be available through ethics committee consultation.

In addition, the attending physician's judgment may be distorted by pressures from parents or others, by social and political presuppositions, by legal mandates, as well as by personal biases. Parents may press for nontreatment simply because they are overwhelmed with negative feelings toward the child or because they see the child's continued life as a threat to their own well-being.<sup>145</sup> The physician may feel pressured by the federal government's recent involvement in promulgating guidelines for research and for the care of disabled newborns, or because government authorities are now involved in executing prospective payment poli-

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141. 50 Fed. Reg. 14,893 (1985). These associations include the American Academy of Pediatrics, the Neonatal Association of Children's Hospitals and Related Institutions, the American Hospital Association, the American Medical Association, the Catholic Health Association, the Federation of American Hospitals, the American College of Hospital Administrators, the American College of Physicians, and the American Nurses Association. *Id.*

142. *Id.* at 14,894.

143. *Id.*

144. *Id.* at 14,895.

145. *Cf. Ellis, Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 414 (1982) (cautioning that "[p]arent-child bonding may not yet be complete [in the perinatal period] and the parental love assumed by society to exist in other contexts may not yet have developed").

cies that may cause some persons to forego medical care. Insurance companies are now involved in medical decision-making, especially through preferred provider organizations and health maintenance organizations that reward physicians who keep their patients away from expensive care.<sup>146</sup> Hospital administrators are involved in determining who will receive nonreimbursed expensive care. Medical consultants likewise are involved in day to day decisions to which they bring their own moral and professional standards. Thus, the complexity and the importance of these decisions can benefit from consultation with an ethics committee composed of individuals with medical, legal, ethical, and social expertise.

Furthermore, additional advantages are gained if ICRC consultation improves review of infant treatment decisions and decreases the necessity for judicial intervention. Using the judicial process for infant care decision-making is burdensome, time consuming, and sometimes inappropriate. First, it is difficult for many parents of impaired infants to afford effective counsel to represent their interests. Second, the judicial process is too complicated and time-consuming to deal effectively with many life and death treatment decisions that must be made immediately after birth. In some cases courts eventually have ordered treatment for impaired newborns only to have the child die before the treatment could be administered. In *Maine Medical Center v. Houle*,<sup>147</sup> for instance, the impaired infant's doctors obtained a court order authorizing treatment over parental objections, but the child died before surgery could be performed. Perhaps emergency court sessions could be instituted; however, manipulating the process so that it works more quickly could jeopardize the quality of decision-making.

Finally, the judicial process can be inappropriate for some infant medical decision-making dilemmas. Consider the situation in which a trial court refuses to order life-sustaining surgery for an infant over parental objection. Should the losing party be able to obtain an emergency order from the appellate court ordering the treatment so that the infant will survive until appellate review can be performed? What should happen if the order were granted, the treatment were administered, and the appellate court subsequently affirmed the trial court's holding? Should the appellate court then order active euthanasia for the child?

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146. See Luft, *Health Maintenance Organizations and the Rationing of Medical Care*, in 3 PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SECURING ACCESS TO HEALTH CARE 313, 315 (1983).

147. No. 74-145 (Super. Ct., Cumberland County, Me. Feb. 14, 1974).



*Disadvantages*

Evaluation of ethics committees must include discussion of several potential problems. First, some fear that although the committee is supposed to be multidisciplinary and representative of diverse views and interests, it may come to be dominated by one individual, discipline, or point of view. Clearly, in order to be effective, the committee must remain open to all perspectives and must guard against such domination—whether by paternalistic physicians or by attorneys concerned only with protecting the institution from liability and adverse publicity. Self-education may serve as a valuable tool in helping individual committee members to arrive at their own reasoned decisions rather than succumbing to the will of more forceful committee members. If committee members better learn how to think through ethical dilemmas, they will rely less on emotion, intuition, or the beliefs of powerful authority figures.

Second, while most committees are not officially empowered to make medical decisions, there is danger that a committee's recommendation will carry such weight. Attending physicians might well feel very reluctant to disregard the committee's advice. This is especially so in cases where the committee's effect on physicians is to decrease their sense of responsibility for the health-care decisions they make. The committee needs to be sensitive to this potential problem so that it does not have this effect.

Third, review of a patient's history and situation by people other than the patient's care-givers raises privacy concerns. These concerns are alleviated when the patient consents to the committee consultation. Even in cases in which the patient has not been asked for consent, committee consideration of the case should be seen as any other consultation engaged in for the patient's benefit, for which consent is implied. In addition, however, committee review raises concerns regarding confidentiality because it is uncertain whether the minutes of committee meetings are discoverable. The question of protecting such minutes from discovery has not yet been litigated and the answer will most likely vary from state to state.

Fourth, committee review may increase legal liability exposure for all involved. For instance, if the committee had recommended that Infant Doe should not be treated, the physician had followed that advice, and the baby had died, it is possible that the attending physician and all committee members would be susceptible to indictment for conspiracy to commit murder. In less extreme circumstances, if a negligently conducted committee review led to patient injury and physician civil liabil-

ity, the result could be institutional ethics committee liability.<sup>148</sup> It is more likely, however, that diligent committees would have the opposite effect on liability exposure and would actually protect physicians, nurses, institutions, and patients. By making physicians aware of legal liability issues in individual cases, an ethics committee may forestall the initiation of lawsuits or disciplinary action. And in cases where a suit is brought, the fact that the physician had consulted an ethics committee for advice would tend to show that the physician had acted in good faith.

Because physicians are unlikely to be found criminally liable for withholding care if they have acted on a "good faith" judgment that is not "grievously unreasonable" by medical standards, resort to an ethics committee should decrease the risk of adverse legal consequences in the criminal arena.<sup>149</sup> And in the civil arena, a physician who seeks and follows ethics committee advice probably would gain protection in a later malpractice action because the committee's consensus would be evidence that the physician acted reasonably in the case. Furthermore, a physician who does not follow the ethics committee's advice does not necessarily increase his civil liability exposure because failure to follow the committee's advice would not in itself show that his actions were negligent.<sup>150</sup>

The major problem with ethics committees may be that they might not be consulted on the full range of cases in which their advice is needed. Achieving the goals and functions of an ethics committee requires that cases be brought to it. Data about existing ethics committees indicate that even where ethics committees exist, they are seldom used. A survey for the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research indicated that even in hospitals where an institutional ethics committee existed, it was used on an average of once a year.<sup>151</sup> The American Academy of Pediatrics 1985 survey on infant ethics committees reported that 56.2% of the respondent hospitals with committees considered no cases during 1985; 10.2% considered one case; 13.2% considered two

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148. Such liability might be avoided in states that have statutes that give hospital or medical staff review committees immunity from liability. See, e.g., N.Y. EDUC. LAW § 6527(3) (McKinney 1972).

149. See *In re Spring*, 405 N.E.2d 115, 122 (Mass. 1980); Robertson, *Committees as Decision Makers: Alternative Structures and Responsibilities*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING 88 (R. Cranford & A. Doudera eds. 1984).

150. See *Panel Discussion: Implementing and Utilizing an Institutional Ethics Committee*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING 229 (R. Cranford & A. Doudera eds. 1984) (comments of John Robertson, J.D.).

151. Youngner, *A National Survey of Hospital Ethics Committees*, in PRESIDENT'S COMMISSION, *supra* note 43, at 446-47.

cases; and 7% considered three cases.<sup>152</sup> Perhaps this low rate of utilization can be explained by such factors as the relative newness of the committee as a resource, ignorance on the part of the medical staff concerning its utility, and the ideological bias toward independence and self-reliance in clinical decision-making.<sup>153</sup> Short of *requiring* committee review in certain cases, if a committee is to penetrate the hospital, it must confront and overcome these hindering factors. One important step toward this end is educating staff physicians as to the availability of the committee for *consultation*, as opposed to decision-making.

### *The Experience*

Interest in infant care review committees has greatly increased over the past two years. Alexandra Gekas, director of the National Society for Patient Representatives, attributes much of this heightened interest to the Baby Doe regulations.<sup>154</sup>

The Research Department of the American Academy of Pediatrics reports that in 1985 nearly 66% of hospitals surveyed had a committee that would consider ethical issues concerning the care of infants, compared to 56% of hospitals surveyed in 1984, and that 54% of those currently without committees are considering establishing one.<sup>155</sup> More than 40% of hospitals without ICRCs in 1984 now have them, including 42% of those that had decided against an ICRC in 1984.<sup>156</sup> Of the presently functioning committees, 45.6% meet regularly, 32.6% meet whenever necessary, and 21.7% hold both regular meetings and ad hoc meetings. Forty percent of the surveyed committees will meet on an emergency basis, if necessary.<sup>157</sup>

Although the general functions, membership, legal status, goals, and activities of infant care review committees are summarized in the Model Guidelines<sup>158</sup> and have been well discussed in the literature,<sup>159</sup> studies

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152. AMERICAN ACADEMY OF PEDIATRICS DEPARTMENT OF RESEARCH, FOLLOW-UP SURVEY ON IBRCs 3 (1985) (referring to ICRCs as Infant *Bioethics* Review Committees) [hereinafter cited as AMERICAN ACADEMY OF PEDIATRICS].

153. See Robertson, *supra* note 149, at 91.

154. *Ethics Committees Double Since '83 Survey*, HOSPITALS, Nov. 1, 1985, at 60, 64.

155. AMERICAN ACADEMY OF PEDIATRICS, *supra* note 152, at 1.

156. *Id.*

157. *Id.* at 2.

158. See *supra* notes 138-44 & accompanying text.

159. See, e.g., INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISIONMAKING (R. Cranford & A. Doudera eds. 1984). In general, the literature indicates that the intended roles of ICRCs are the following: 1) consultation—advising physicians, patients, and families on individual treatment decisions; 2) policy formulation—recommending policy to the hospital governing body or medical staff; 3) education—educating hospital staff about issues in

regarding actual ICRC case consultations are not currently available.<sup>160</sup> The data discussed below address the experience of an ICRC at a large children's hospital over its three-and-one-half years of existence prior to the passage of the Child Abuse Regulations and during the six months following the law's implementation.<sup>161</sup>

*Children's Hospital of Wisconsin Ethics Advisory Committee*

The Children's Hospital of Wisconsin Ethics Advisory Committee ("EAC") was originally formed as an ad hoc committee of the medical staff in the spring of 1982. From the beginning, physicians could, but were not required to, seek or follow the EAC's advice. All EAC consultations became part of the infant's medical record. Initially, EAC consultations were available only at the request of the attending physician, but in the fall of 1984, when the committee became a regular committee of the medical staff, it was empowered to accept inquiries and requests for consultation from anyone. The EAC always has been a multidisciplinary group, including nonprofessional members of the community. Current

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ethical decision-making and about how to use the ICRC; 4) multidisciplinary discussion—providing a locus for interdisciplinary participation in value decisions; 5) emotional support—providing, through in-depth discussions among concerned individuals, a kind of cathartic experience for those involved in difficult cases. See generally Griffin & Thomasma, *Health Care Distribution and Hospital Impartial Panels*, 1 BIOETHICS REP. 124 (Commentary) (1984); Ozar, *The Challenge of Multiple Professional Perspectives in Institutional Ethics Committees*, 1 BIOETHICS REP. 153 (Commentary) (1984); Robertson, *Ethics Committees in Hospitals: Alternative Structures and Responsibilities*, 10 QUALITY REV. BULL. 6, 6-10 (1984); American Academy of Pediatrics, *American Academy of Pediatrics Guidelines for Infant Bioethics Committees*, 3 BIOETHICS REP. 940 (Literature) (1984). This Article focuses on the advantages and disadvantages of the ICRC in its consultative role. Other commentators have analyzed the ICRC in its other functions. For instance, in Thomasma, *Hospital Ethics Committees and Hospital Policy*, 11 QUALITY REV. BULL. 204, 205 (1985), the author advocates a more active policy-making role for ethics committees. He notes that, to date, little attention has been given to policies regarding the significant ethical problems that challenge daily practice in the hospital—resource allocation, stop-treatment orders for terminally ill patients, interprofessional conflicts, informed consent, and decision-making for incompetent patients. *Id.* at 205. Resistance to policies governing such ethical dilemmas stems from inertia, concerns about disrupting the physician/patient relationship, and the misperception that the guidelines would take decision-making power out of the hands of responsible parties and invest it in a "cookbook" of decisions formulated ahead of time. *Id.* at 205-06. The author argues, however, that because policies for resolving ethical conflicts are based principally on past experience or traditional commitment, they need not take decision-making power away from patients and their families, but can make these decisions more manageable during times of grief. *Id.* at 206.

160. This lack of information probably stems, in part, from an institution's concerns about confidentiality and from the uncertain legal status of ICRCs and their members.

161. These data were collected from the medical records of the infants whose cases came before the Children's Hospital of Wisconsin Ethics Advisory Committee and from the recollection of Dr. Richard Barthel, who is Chairman of the Committee and who was present at all of the consultations discussed below.

membership consists of seven physicians and six laypersons.<sup>162</sup> An on-call team of four members is available twenty-four hours a day, seven days a week for urgent consultations.

Case consultation may be requested by contacting the chairperson, who sets an appropriate meeting time for all nonfrivolous consultation requests. All caretakers of the infant are invited to attend the EAC meeting. They initiate the discussion by explaining the infant's situation. Thereafter, committee members and invited guests exchange questions, comments, and information. The major focus of this exchange is determination of the *medical* best interests of the infant. Legal implications of treatment alternatives also are important in the committee's discussion, but the committee considers them only after it completes the medical evaluation. Similarly, the committee explores ethical components of case consultation after it discusses the medical facts involved. Although the committee takes no votes, it attempts to reach consensus in each case consultation. When the EAC does not reach consensus, members may file minority reports. If the EAC cannot reach consensus on withdrawing or withholding treatment, the infant is treated in conformance with the presumption in favor of preserving human life.

In four years the EAC responded to twenty-two requests for consultations. Fifteen of these requests concerned patients less than one year old.<sup>163</sup> Of this group, thirteen were less than six months old and, of the thirteen, seven were less than one month old at the time of consultation. The analysis below focuses on the group of thirteen patients less than six months old.

Three general situations calling for consultation may be identified in the patient group under six months of age: First, life-threatening conditions in which the parents and physician agreed that treatment was futile and should be withheld; second, life-threatening conditions in which the parents requested no further treatment, but the physicians favored continued treatment; and third, non-life-threatening conditions in which the

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162. The seven physicians include two full time Medical College of Wisconsin faculty members based at the hospital, three private practicing physicians, one neonatologist from another hospital, and one pediatric resident in the third year of training. The six nonphysicians include one registered nurse, two social workers, one attorney, one ethicist, and one parent.

163. Of the seven cases in which patients were more than one year old, two concerned children between 12 and 18 months and involved care that related to congenital problems or birth injuries. The five remaining cases all involved children who were more than nine years old at the time of consultation; three of the five were children who were dying and for whom intervention was generally considered to be experimental and only possibly helpful.

parents, the physician, or other caregivers questioned whether the child's quality of life merited continued support or treatment.

**Life-Threatening Conditions in Which the Parents and Physicians Agreed that Treatment was Futile and Should be Withheld**

All of these infants were severely impaired; five had severe brain injuries and one had a severe heart lesion. In each case the physician advised the committee that either initiation of treatment or further treatment would be futile. The parents agreed in each case. In four of these cases the EAC also agreed, believing that all possible reversible medical diagnoses had been considered and rejected and that prognoses for the known conditions were reasonably secure. In each case, the committee determined that the treatment either was futile, only prolonged the dying process, or was inhumane and not in the best interests of the child.<sup>164</sup> All four children died shortly after support was discontinued.

In two cases, one of unexplained coma in a three-and-one-half month old and one of severe brain infection in a three-month old, the EAC reached consensus that treatment or diagnostic studies should be continued. In these cases, the Committee's physicians were not satisfied that all appropriate diagnostic tests had been pursued. Although the EAC recognized that the possible diagnostic studies were relatively invasive to the child with coma and that the results would not affect the irreversible problems, the committee felt that the test results would be useful to the parents in better understanding why the child died and in future genetic counseling. The EAC recommended that the child with the brain infection receive a longer course of antibiotic treatment, although it recognized that treatments probably could not fully reverse the damage that had already occurred. Both of these children died despite continued care.

**Life-Threatening Conditions in Which the Parents Requested no Further Treatment, but the Physician Favored Continued Treatment**

All three children in this category had severe abnormalities or significant retardation. In each case, the EAC sided with the physician and advised continued treatment. Committee members sensed that the parents were experiencing conflict between their own interests and those of

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164. In making many of these determinations, the EAC was guided by the Baby Doe regulations, which direct physicians to treat impaired infants unless the infant is irreversibly comatose; treatment would merely prolong dying; or treatment would be virtually futile in terms of the survival of the infant and, under the circumstances, inhumane. 45 C.F.R. § 1340.15(b)(2)(i)-(iii) (1985).

the child. The members determined that the child's interest in sustained, though impaired, life should prevail. In these cases, the EAC hoped that further information, counseling, and support for the parents would allow them to accept these recommendations. The parents in all three cases transferred care to a different physician or hospital, or both. One child died within six months of the consultation. The parents of this child had made a reasonable adjustment to the new physician's recommendations for the child's care. A second child continues to be impaired after more than twenty surgical procedures. Its parents are reportedly bitter and angry. No information is available about the third child.

Non-Life-Threatening Conditions in Which Either the Parents, the Physician, or Other Caretakers Questioned Whether the Child's Quality of Life Merited Continued Support or Treatment

Child *A* was congenitally paralyzed and unable to breathe or move. The physician felt that it was not in the child's best interest to be mechanically ventilated indefinitely and asked the committee if it would be ethical to stop ventilation. The EAC split strongly on the answer to this question because of the members' differing perspectives on the child's quality of life. Some felt that the child's inability to move and to communicate rendered the quality of his life negligible. Others felt unable to make such a judgment given the infant's age and the unpredictability of treatment outcome. Because the EAC could not reach a consensus, it advised continued ventilator support.<sup>165</sup> The child continued on mechanical ventilation in the hospital until home ventilation was technologically possible. The child has been discharged and continues on mechanical ventilation at home with twenty-four hour nursing care.

Child *B* was a one-month old child in foster care, who suffered from a severe, rare syndrome of skull, heart, and extremity abnormalities. The child was blind and probably deaf, and was not able to feed adequately to stabilize its weight, much less grow. The child's foster mother felt it was best to feed orally only. The physician requested consultation from the EAC as to whether there was an ethical obligation for more vigorous care, including non-oral feeding and surgery. The EAC felt strongly that mandatory "routine"<sup>166</sup> care included non-oral feeding. Surgery, how-

165. As indicated earlier, if the EAC cannot reach consensus on the question of withdrawing or withholding treatment, treatment will be administered in conformance with the presumption in favor of preserving human life. This presumption reflects the laws and customs of this country as well as the various religious beliefs of many citizens. See Fost, *Ethical Issues in the Treatment of Critically Ill Newborns*, 10 PEDIATRIC ANNALS 383 (1981).

166. The EAC has reached a base-line consensus that no child will die of starvation at the hospital if methods are available to prevent it.

ever, could be delayed because it was not "routine," was not required to prevent deterioration of the child's condition, and probably would not significantly improve the quality of the child's life. In addition, delaying surgery would allow for further assessment and clarification of the child's guardianship status. The child was discharged with a feeding tube placed into the stomach and no further information is available.

Child *C* had complications from total parenteral nutrition ("TPN"),<sup>167</sup> including liver dysfunction. The child required this method of non-oral feeding because her entire bowel had been destroyed following an intrauterine accident. The physician felt that the child could probably survive without TPN, but that lack of weight gain and diarrhea could weaken the child and perhaps lead to death, and the child's development would probably stop. If TPN continued, there probably would be further liver damage with increased bleeding, jaundice, and eventual coma and death. It was doubtful that the parents could provide home TPN care because of several family problems. The physician asked the EAC if TPN was ethically obligatory. In the context of this case, the EAC advised a trial treatment of oral feedings and then TPN if problems developed.<sup>168</sup> After a week of oral feeding, physicians inserted a TPN tube. The child continues on home TPN with extensive home nursing care.

Child *D* was born with hydrancephaly, a brain malformation that usually portends severe impairment and shortened lifespan. The damage to this infant's brain and skull was particularly severe. All of the child's medical consultants agreed that the prognosis included blindness, deafness, seizures, and negligible developmental potential. The parents refused to accept this assessment. They wanted physicians to do everything possible to sustain their child's life. Psychiatric assessment of the mother indicated that she was under stress but competent, well informed but unable to accept the medical information.

As the child began to deteriorate, the mother pushed for further medical and surgical care. Two consultants and the majority of the nursing staff felt that further treatment imperiled the child's best interests. A neurological consultant requested an EAC consultation. The committee reached a consensus that further care was not ethically mandatory. There was a strong minority opinion that further care violated the child's best interests and that the mother's "abusive" stance should be reported and the case should be "taken to court." The committee's recommenda-

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167. Parenteral nutrition is the intravenous administration of a greater than normal amount of nutrients. See R. WEIR, *supra* note 45, at 281.

168. See *supra* note 166.



tions were entered into the child's chart, but there was no change in care.<sup>169</sup>

### Summary of Committee Actions

Governmental intervention in impaired infant medical decision-making has resulted from concern about inappropriate nontreatment.<sup>170</sup> In considering whether the infant care review committee is another option for addressing those concerns, the experience of existing ethics committees is useful. The Wisconsin Children's Hospital ethics committee discussed above has functioned to prevent decisions to stop or withhold treatment from impaired infants under the age of six months in a significant proportion of the cases that have come before it. In each of the three cases in which the parents favored withdrawal or withholding of treatment, but in which their physicians favored continuation or initiation of treatment, the Committee refused to support withdrawal or withholding of treatment. In three other cases in which the infant's life was not threatened, but continuing or initiating treatment was of questionable value, the committee recommended some form of treatment and support in each case. Perhaps most significant, in two of six cases in which the parents and physicians agreed that further treatment or support would be futile, the committee departed from that agreement and recommended continued treatment. Obviously, this particular ICRC has not served merely as a rubber stamp of nontreatment decisions, but rather has taken an active role to ensure the provision of support and treatment that it considered appropriate—even in some cases in which the physician and parents agreed to the contrary. It is all but certain that the ICRC consultation in these cases provided a speedier and more manageable forum for ensuring treatment than would have been possible through a state child protective service system or a state court.<sup>171</sup>

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169. The Model Guidelines for ICRCs indicate that in cases of disagreement between a physician and an infant's family, and the family wishes to continue life-sustaining treatment, the ICRC should counsel that "the family's wishes be carried out, for as long as the family wishes, unless such treatment is medically contraindicated." Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893, 14,895-96 (1985). "Medically contraindicated" is the key concept, and one made more poignant in the situation described above.

170. For a fuller discussion of the reasons for governmental intervention, see Legislative History, Child Abuse Amendments of 1985, P.L. 98-457, reprinted in 1985 U.S. Code Cong. & Ad. News 2918, 2925-27.

171. Of course, there is no way of predicting whether the experience of the Wisconsin Children's Hospital EAC is representative of ICRCs generally in the area of treatment decisions for impaired newborns. While the data from Children's Hospital is intriguing, it serves to illustrate the need for a much broader empirical database from which to evaluate the performance of ethics committees generally.

## A Better Approach to the Baby Doe Dilemma

The model statute that follows is a better approach to answering the Baby Doe dilemma than the alternatives conceivable under the 1984 Child Abuse Amendments. The proposed statute would build on the advantages of the infant care review committee consultation (which is suggested but not mandated in the Model Guidelines),<sup>172</sup> avoid potential hospital care disruption in the ABA<sup>173</sup> and section 504 approaches to satisfying the 1984 Child Abuse Regulations,<sup>174</sup> improve the ad hoc system that existed prior to the Child Abuse Amendments<sup>175</sup> by subjecting difficult nontreatment decisions to outside expert scrutiny, and incorporate an effective response for inappropriate withholding of treatment decisions.<sup>176</sup>

### *A Model State Statute*<sup>177</sup>

(1) A "severely impaired newborn" is one who allegedly has substantial physical and/or mental deficiencies that cannot be significantly cured or alleviated by surgery or other medical treatment.

(2) In all cases in which a severely impaired newborn needs life-prolonging medical treatment and the parent(s) or guardian(s) of the child refuse(s) to consent to that treatment, if all of the treating physicians and the hospital "Ethics Committee" or similar institutional body concur with the decision of the parent(s) or guardian(s), then treatment shall not be administered. In all such cases, this action or inaction shall be without any civil or criminal liability on the part of any participants, whether parent, guardian, hospital, or others.

(3) In all cases in which a severely impaired infant needs life-prolonging medical treatment and the parent(s) or guardian(s) of such child refuse(s) to consent to that treatment, if any of the treating physicians and/or the hospital "Ethics Committee" or similar institutional body favor treatment, then the matter shall be set for an immediate hearing by the state court appointed Medical Treatment Panel. At the Panel hearing, the Panel shall appoint a guardian ad litem to represent the interests of the newborn. The guardian ad litem shall then marshal all available arguments in favor of the treatment that the parent(s) or guardian(s) are seeking to terminate or withhold. Within one week, or

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172. See *supra* notes 138-47 & accompanying text.

173. See *supra* notes 117-21, 133-36 & accompanying text.

174. See *supra* notes 111-16, 127-32 & accompanying text.

175. See *supra* notes 60-69, 122-26 & accompanying text.

176. See *supra* notes 134-36 & accompanying text.

177. The Model State Statute is based largely upon the model statute that appears in Shapiro, *Medical Treatment of Defective Newborns: An Answer to the "Baby Doe" Dilemma*, 29 HARV. J. ON LEGIS. 137 (1983). The statute here broadens the definition of the "severely impaired newborn" who is subject to the State Statute, and thus provides for a greater number of nontreatment decisions to be subjected to outside scrutiny by ethics committees, treatment panels, or courts. In addition, this revised model statute removes possible restrictions on the discretion of the Medical Treatment Panel in determining whether withholding of treatment is in the infant's best interests by omitting a list of specific factors that the Panel is to consider.

such shorter time as the Panel may order, the Panel shall meet and hear arguments regarding medical treatment for the newborn. Within two days after this hearing, the Panel shall render a decision. The Panel shall order that treatment be withheld if it can be proved by clear and convincing evidence that withholding of treatment is in the patient's best interest. A majority vote of the Panel shall be sufficient on which to base findings and an order.

(4) Any party to the Panel hearing may within three (3) days after the date of an order made by the Panel, commence an action for a trial. The judgment or order of the trial court shall supersede any order made by a Panel in a hearing under this chapter. The findings and order of any Panel shall be admissible in any action in the trial court. If no action for trial is commenced within three (3) days of the Panel order, any party may file a certified copy of the Panel order with the trial court and the court shall then render judgment in accordance with the order.

(5) Four Medical Treatment Panels shall be established by the State Court Administrator to hear controversies presented under this chapter. Each Panel shall consist of five members:

(a) One physician licensed to practice medicine in the state appointed by the State Supreme Court Administrator for a six-month term, or for the duration of any case pending at the expiration of such term, from a list submitted by an appropriate statewide organization of physicians as designated by the administrator.

(b) One person employed in the hospital administration department of a hospital in the state, appointed by the administrator.

(c) One attorney licensed to practice law in the state, appointed by the administrator.

(d) Two persons who are not attorneys and who, at the time of their appointment, are not engaged in or licensed to practice medicine, appointed by the governor for two-year staggered terms.

Persons appointed to a Panel by the administrator under paragraphs (a), (b), or (c) are encouraged to serve on a panel and to decline only for good cause. No person shall serve on a Panel if the person has a professional or personal interest in a case under consideration.

As discussed earlier, one advantage of ICRC consultation is that the importance and complexity of many impaired infant care decisions require more thorough review than a single physician can provide.<sup>178</sup> That advantage is even more important when the alternative is decision-making by a judge who is not necessarily equipped to deal with changing or uncertain clinical facts, and who understandably may be reluctant to make value judgments concerning, for example, the quality of life faced by a disabled newborn. Thus, section two of the Model Statute attempts to minimize judicial intervention. It does so by establishing an initial ethics committee consultation for making nontreatment decisions. The

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178. See *supra* text following note 144.

requirement in section two of concurrence of the newborn's parents, his treating physician, and the hospital's ethics committee on the decision to withhold treatment offers protection against inappropriate decision-making. The proposed statute ensures the suitability of a nontreatment decision by the convergence of the parents' role in protecting their child's best interests; the physician's role in medically evaluating the infant's condition, prognosis, and proposed treatment; and the Ethics Committee's role in more objectively analyzing difficult moral dilemmas.<sup>179</sup>

Section three calls for a mandatory review of nontreatment questions by a Medical Treatment Panel when there is disagreement among the newborn's parents, the treating physicians, or the hospital's ethics committee. Panel hearings would provide an intermediate level of decision-making that would avoid lengthy and cumbersome court procedures. In addition, a panel decision, which incorporates the collective guidance of those in health care, hospital administration, law, and other disciplines, is most appropriate for this type of morally and ethically complex decision.

Section four entrusts the ultimate resolution of the nontreatment decision to the judiciary in cases in which either the parents, the physicians, or the ethics committee disagrees with the Panel order. It is appropriate for the court to resolve the controversy because of the role courts traditionally have played as the final arbiter of otherwise insoluble conflicts.<sup>180</sup>

## Conclusion

There are limitations to all approaches addressing the Baby Doe dilemma. From the family's viewpoint, the stress of the birth of an im-

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179. See Thomasma, *supra* note 159, in which the author states:

Although the supreme courts of a number of states have recommended hospital ethics committees or their analogs, what is needed is legislation requiring an appeals review by a hospital ethics committee (with an attempt at resolution) prior to consideration by the judicial system. Although its purpose is entirely different, the model for prejudicial review exists in legislation to control the number of frivolous malpractice lawsuits.

*Id.* at 205. See, e.g., WIS. STAT. §§ 655.002-25 (1980). In this statutory scheme, malpractice claims must be heard by a panel before suit is filed. The panel is appointed by an agency of the state supreme court.

180. Precedent for this type of hierarchy was set by the eventual resolution of the case of Rudolfo Torres in Minnesota. In that case, a 57-year-old patient went into a coma after open-heart surgery, possibly because of negligence by the treating hospital. *In re Conservatorship of Torres*, 357 N.W.2d 332, 334 (Minn. 1984). He had no documented wishes regarding medical care and no family to speak for him. Because of the possibility of a negligence action on his behalf, the request to terminate life-support systems went to the courts even after it was routed through both the hospital's own ethics committee and a second, extramural hospital ethics committee that consulted on the case. The court endorsed this procedure. *Id.* at 340-41.

paired infant is intense and long-term. It is difficult to assess the impact on the family of the birth of a disabled newborn, with all that it entails—loss of privacy, strained decision-making capabilities, and necessarily changed lifestyles.

From the physician's perspective, any answer to the dilemma that entails outside intrusion into medical decisions could provoke responses of abandonment or passive-aggressive compliance, which would fracture cooperation between family and physician. On the other hand, physician bias or fear of legal liability could result in excessive treatment, which would not be in the best interest of either the infant or the parents.

This Article has examined current state child abuse statutes, the HHS Baby Doe regulations, and the ABA Model Guidelines as possible solutions to the Baby Doe dilemma, and has found that their disadvantages warrant consideration of an alternative. The Article suggests a model state statute that builds upon the HHS Model Guidelines for ICRCs and takes into account the experiences of ethics advisory committees, such as the one operating at Children's Hospital in Wisconsin.

The Model Statute proposed in this Article is an approach that minimizes the deleterious impact of outside intervention in such decision-making dilemmas and maximally accommodates pursuit of the infant's best interests. Any method of societal intervention, however, must ultimately be judged in terms of its benefits and human and economic costs. Careful choices and excellent processes notwithstanding, the results of society's answer to the Baby Doe dilemma for society, family, physician, and child may not be known for years.