

Summer 1984

## The Legislative Response to Infant Doe

Abigail Lawlis Kuzma

Follow this and additional works at: <https://www.repository.law.indiana.edu/ilj>



Part of the [Family Law Commons](#), [Legislation Commons](#), and the [Medical Jurisprudence Commons](#)

---

### Recommended Citation

Kuzma, Abigail Lawlis (1984) "The Legislative Response to Infant Doe," *Indiana Law Journal*: Vol. 59: Iss. 3, Article 3.

Available at: <https://www.repository.law.indiana.edu/ilj/vol59/iss3/3>

This Article is brought to you for free and open access by the Maurer Law Journals at Digital Repository @ Maurer Law. It has been accepted for inclusion in Indiana Law Journal by an authorized editor of Digital Repository @ Maurer Law. For more information, please contact [kdcogswe@indiana.edu](mailto:kdcogswe@indiana.edu).



**JEROME HALL LAW LIBRARY**

INDIANA UNIVERSITY  
Maurer School of Law  
Bloomington

# The Legislative Response to Infant Doe

ABIGAIL LAWLIS KUZMA\*

## INTRODUCTION

Infant Doe was born in Bloomington, Indiana, on April 9, 1982<sup>1</sup> with two congenital anomalies,<sup>2</sup> Down's syndrome<sup>3</sup> and esophageal atresia with tracheoesophageal fistula.<sup>4</sup> His parents refused to consent to the surgery necessary to correct the esophageal atresia with tracheoesophageal fistula and the baby was given no nutrition or fluids.<sup>5</sup> The Monroe County Circuit Court<sup>6</sup> and the Indiana Supreme Court<sup>7</sup> sanctioned the parents' decision and Infant

---

\* B.A. 1978 Honors Philosophy, University of Wisconsin; J.D. 1981, Indiana University.

1. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment at 1).

2. The coroner who performed the autopsy after Infant Doe's death explained in an article, published in the *New England Journal of Medicine*, that chest X-ray films taken shortly after Infant Doe's birth indicated a slightly enlarged heart. However, the autopsy proved that no heart defect was present. See generally Pless, *The Story of Baby Doe*, 309 NEW ENG. J. MED. 664 (1983) (letter to the editor). Much confusion regarding the physical condition of Infant Doe was generated by the repeated misreporting of the facts of the case by newspapers such as the *Indianapolis Star*. According to the *Indianapolis Star*, Infant Doe not only had Down's syndrome and a tracheoesophageal fistula but also intestinal problems and a heart condition, necessitating repeated and perhaps unsuccessful operations. See, e.g., *Indianapolis Star*, Apr. 16, 1982, at 1, col. 4. Evidently, the slightly enlarged heart was not a factor in the Monroe County Circuit Court's declaratory judgment since that anomaly is not mentioned in the court's account of the facts of the case. Interestingly, when Senate Bill 418 (hereinafter referred to as the Indiana Statute, see *infra* text accompanying notes 220-32) was heard in the House Human Affairs Committee of the Indiana General Assembly on March 9, 1983, a lengthy discussion centered on the public's confusion of the facts of the case due to newspapers reporting the case incorrectly. Nevertheless, the *Indianapolis Star* again reported the facts of the case incorrectly on March 10, 1983, while reporting on the House Human Affairs Committee meeting. See *Indianapolis Star*, Mar. 10, 1983 at 18, col. 1.

3. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment at 1); Pless, *supra* note 2, at 664. Down's syndrome (Mongolism), or Trisomy 21, is the most common significant malformation syndrome in man. It occurs because of faulty inclusion of a third chromosome 21 at conception, and includes, in addition to the well known constellation of facial abnormalities, a mild to severe mental impairment. In a minority of infants born with Down's syndrome, heart defects are present, sometimes severe. Also there is an increased incidence of tracheoesophageal malformations. See generally R. BEHRMAN & V. VAUGHAN, *NELSON TEXTBOOK OF PEDIATRICS* 295-97 (12th ed. 1983).

4. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment at 1); Pless, *supra* note 2, at 664. For an explanation of esophageal atresia with tracheoesophageal fistula see *infra* text at note 15.

5. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment at 2); *Bloomington Herald-Telephone*, Apr. 16, 1982, at 1, col. 1.

6. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982).

7. On April 19, 1982 the Indiana Supreme Court declined to overturn the lower court's rulings. *Bloomington Sunday Herald-Times*, Apr. 10, 1983, at 1, col. 1. The case actually in-

Doe died six days later, April 15, 1982 "as a result of multiple congenital abnormalities."<sup>8</sup> This was not the first case in which parents of a handicapped infant refused corrective treatment that resulted in the death of their child.<sup>9</sup> However, this case received national attention,<sup>10</sup> and resulted in the adoption of a Health and Human Services (HHS) proposed regulation<sup>11</sup> and three state statutes<sup>12</sup> reacting against the outcome of the case. This Article discusses the complex background from which legislation emerges, analyzes and criticizes the federal regulation and the state statutes enacted, and examines alternative legislative solutions.

### THE INFANT DOE CASE

The Infant Doe case involved a child who was born with Down's syndrome and reparable<sup>13</sup> esophageal atresia with tracheoesophageal fistula. Down's syndrome or "Mongolism" is an incurable chromosomal disorder that involves a certain amount of physical deformity and an unpredictable degree of mental retardation.<sup>14</sup> Esophageal atresia with tracheoesophageal fistula indicates that the esophageal passage from the mouth to the stomach ends in a pouch, with an abnormal connection between the trachea and the esophagus such that substances taken orally pass to the lungs instead of the stomach, eventually resulting in suffocation unless surgery is performed to correct the malformation.<sup>15</sup> Corrective surgery to correct esophageal atresia with tracheoesophageal fistula is routinely performed with success,<sup>16</sup> but the Bloom-

---

volved two separate actions, the second action was filed under the juvenile court docket, *In re Infant Doe*, No. JV8204-038A, by the prosecuting attorney as a petition for emergency detention under IND. CODE § 31-6-4-4 (1982). The court denied the petition because it did not find Infant Doe a child in need of services under IND. CODE § 31-6-4-3 (1982). The Indiana Supreme Court refused to overturn the lower court's rulings in either of the actions.

8. Bloomington Herald-Telephone, Apr. 20, 1982, at 1, col. 5.

9. See, e.g., Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973); Shaw, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (1977); Smith, *On Letting Some Babies Die*, 2 HASTINGS CENTER STUD. 37 (May, 1974).

10. *Saving Newborns*, MacNeil-Lehrer Report (May 18, 1982).

11. 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

12. ARIZ. REV. STAT. ANN. § 36-2281 (West Supp. 1983); IND. CODE ANN. § 31-6-4-3 (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36 (West Supp. 1983).

13. Pless, *supra* note 2, at 664.

14.

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

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

15. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 893-94.

16. See generally M. RAVITCH & K. WELCH, PEDIATRIC SURGERY 464-65 (3d ed. 1979).

ington Hospital is not equipped to handle the operation.<sup>17</sup> However, the parents of Infant Doe refused to transfer their baby to Riley Hospital, a referral hospital in Indianapolis, Indiana, for corrective surgery.<sup>18</sup> Approximately twenty-six hours after Infant Doe was born, a hearing was held at Bloomington Hospital to determine whether the parents had a right to choose a course of treatment for their child that consisted of allowing the child to die.<sup>19</sup> An attorney was present at the hearing to represent the child's parents.<sup>20</sup> No attorney was present to represent Infant Doe's interests.<sup>21</sup> Six physicians attended the hearing, three of whom had obstetric privileges and three of whom had pediatric privileges at Bloomington Hospital.<sup>22</sup> The obstetricians "recommended that the child remain at Bloomington Hospital with full knowledge that surgery to correct tracheoesophageal fistula was not possible at Bloomington Hospital and that within a short period of time the child would succumb due to inability to receive nutriment and/or pneumonia."<sup>23</sup> The obstetrician who attended Mrs. Doe at the birth of her child "testified that, even if surgery were successful, the possibility of minimally adequate quality of life was non-existent due to the child's severe and irreversible mental retardation."<sup>24</sup> The three physicians with pediatric privileges who attended the hearing stated that the appropriate treatment was to transfer the infant to Riley Hospital immediately for corrective surgery, and one of the pediatricians testified that Down's Syndrome children may have a reasonable quality of life.<sup>25</sup>

In its declaratory judgment, the court concluded that the parents of Infant Doe had the right to choose the course of treatment recommended by the obstetricians in the case, that of refusing corrective surgery and allowing the child to die.<sup>26</sup> The case was unsuccessfully brought before the Indiana Supreme Court on an Emergency Appeal,<sup>27</sup> and the child died on the sixth day after he was born while the guardian ad litem was on his way to Washington, D.C., to appeal the case to the United States Supreme Court.<sup>28</sup>

#### LEGISLATIVE BACKGROUND

Infant Doe had but two of several thousand possible congenital

---

17. *In re Infant Doe*, No. GU8204-004A (Monroe County Cir. Ct. Apr. 12, 1982) (declaratory judgment at 2).

18. *Id.*

19. *See generally id.* at 3.

20. *Id.* at 1.

21. *Id.*

22. *Id.*

23. *Id.* at 2.

24. *Id.*

25. *Id.*

26. *See generally id.* at 2-3.

27. *No Decisions Yet on Possible Prosecution*, Bloomington Sunday Herald-Times, Apr. 10, 1983, at 1, col. 3.

28. *Id.* at col. 3.

malformations.<sup>29</sup> It is estimated that five percent of newborn infants have a major congenital malformation.<sup>30</sup> A number of these congenital anomalies are likely to give rise to questions regarding the appropriateness of treatment and the possibility of nontreatment. These anomalies include: spina bifida with meningocele,<sup>31</sup> trisomy 13,<sup>32</sup> trisomy 18,<sup>33</sup> anencephaly,<sup>34</sup> holoprosencephaly,<sup>35</sup> DiGeorge's syndrome,<sup>36</sup> hydranencephaly,<sup>37</sup> and Potter's syndrome.<sup>38</sup> There are also a number of inherited metabolic diseases<sup>39</sup> and certain congenital infections<sup>40</sup> which may occur in conjunction with a congenital anomaly.<sup>41</sup> Many of these congenital malformations must be surgically

---

29. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 311.

30. *Id.* "Of the approximately 3.2 million babies born in the U.S. each year, an estimated 30,000 are so severely deformed that they can't be expected to live more than a vegetative life, if they survive at all." Wall St. J., July 21, 1982, at 1, col. 1.

31. Spina bifida with meningocele is one of the most common malformations of the nervous system. It is evident at birth as a defect of the lower vertebral column consisting of a protruding sac of neural tissue. Typically, bladder and bowel control is defective and the lower extremities may be spastic or paralyzed. Additionally, other associated malformations may cause hydrocephalus, an abnormally large fluid collection in the brain that can cause mental impairment. Untreated, an infant with meningocele may survive only a few days. However, surgical procedures for hydrocephalus and bladder drainage are possible, allowing in many cases a lifestyle not unlike that of the paraplegic. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 1561-62.

32. Trisomy 13 and Trisomy 18 are rare chromosomal aberrations characterized by severe mental retardation, complex heart and kidney malformations, as well as facial, hand and foot abnormalities. Most infants with Trisomy 13 die within the first year of life and those with Trisomy 18 die within the first three months of life. See generally *id.* at 299-300.

33. See *supra* note 32.

34. Anencephaly is recognized by the absence of skull and brain at birth. Death is imminent for anencephalic infants and many are stillborn. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 1560.

35. Holoprosencephaly is a developmental defect of the brain that results in only a rudimentary, undeveloped bud of cerebrum, the higher portion of the brain where sensory processing and logical thinking takes place. However, because the vital lower brain stem is present, the portion of the brain that controls breathing and other bodily functions, a vegetative state can be maintained. See generally *id.* at 1563.

36. DiGeorge's syndrome is a rare disease characterized by the lack of thymic and parathyroid glands. The absence of parathyroid glands causes tetany, readily treated by widely available therapeutics. However, the absent thymus causes a severe immunodeficient state similar to AIDS (Acquired Immune Deficiency Syndrome). Experimental thymic transplants have been performed and may become more common in the future. See generally *id.* at 507-08. Nevertheless, early death is expected due to the chronic serious infections that begin early in infancy. R. HOEKELMAN & S. BLATMAN, *PRINCIPLES OF PEDIATRICS HEALTH CARE OF THE YOUNG* 1067 (1978).

37. Hydranencephaly is a developmental abnormality resulting in the absence of the cerebrum. This portion of the brain is replaced by a large fluid filled cavity. Affected infants generally die within one year. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 1565.

38. Potter's Syndrome consists of the total lack of kidneys as well as characteristic facial anomalies. Lung development is usually severely retarded. Almost half of affected infants are stillborn. Those liveborn invariably die of kidney failure or pulmonary problems within a few weeks of birth. See generally *id.* at 1373.

39. Such as Tay Sachs disease and Congenital Adrenal Hyperplasia. See generally *id.* at 478-79, 1482-88.

40. Two examples of these congenital infections are Toxoplasmosis and Herpes. See generally *id.* at 847-79, 414-15.

41. See generally *id.* at 423.

corrected within a few days following birth,<sup>42</sup> and it is this need for immediate life-preserving surgery that gives rise to the opportunity to withhold treatment and nutrition. For example, if a Down's syndrome infant does not have an additional anomaly, such as a tracheoesophageal fistula, the decision of whether surgery or nutrition will be withheld does not arise since a typical Down's Syndrome infant will survive without surgical intervention or extraordinary medical care.<sup>43</sup>

That life-preserving surgery is not performed on some of these defective infants and that nutrition and fluids are withheld, is easily documented.<sup>44</sup> A number of articles in medical journals describe specific instances of decisions involving parents and physicians who debate the question of allowing a defective infant to die.<sup>45</sup> One leading article<sup>46</sup> asserted that fourteen percent of the 299 deaths occurring in the special-care nursery of the Yale New Haven Hospital, in New Haven, Connecticut, or their timing was associated with discontinuance or withdrawal of treatment.<sup>47</sup> Another article<sup>48</sup> showed that 76.8% of the pediatric surgeons polled stated that they would acquiesce in the parents' decisions not to treat an infant born with intestinal atresia and Down's syndrome.<sup>49</sup> Numerous newspaper articles and other sources also depict instances of nontreatment decisions involving defective newborns.<sup>50</sup>

Many are concerned that these nontreatment decisions are made unwisely,

---

42. One example of such a malformation is intestinal malrotation where the twisted bowel must be untangled to prevent bowel perforation and death. *See generally id.* at 908-09.

43. *See generally id.* at 295-97. It should be noted that there is no logical distinction from a nontreatment perspective between a typical Down's syndrome infant and one who has a correctable congenital malformation. If the condition is correctable, then the infant's prospects in life medically and socially are virtually identical to those of a typical Down's syndrome infant. In other words, the presence of a correctable life threatening anomaly may be used as an excuse to terminate the life of the infant. Logically, if it is not acceptable to terminate the life of a typical Down's syndrome infant, then it should not be acceptable to terminate the life of a Down's syndrome infant with a correctable congenital malformation.

A second example is the infant with spina bifida with meningocele, for whom a nontreatment decision means almost certain death. *See id.* at 1562. Without immediate surgery to enclose the sac protruding from the infant's back the child will be consumed by infection. *See id.* Over 90% of these infants will die within their first year if the operation to enclose the protruding sac is not performed. *Id.*

44. *See infra* notes 45-50 and accompanying text.

45. *See supra* note 9.

46. Duff & Campbell, *supra* note 9.

47. *Id.* at 891.

48. Shaw, *supra* note 9.

49. *Id.* at 590. *But see* Strain, *The Decision to Forego Life-Sustaining Treatment for Seriously Ill Newborns*, 72 PEDIATRICS 572, 572 (1983).

50. *See, e.g.,* N.Y. Times, Nov. 6, 1983, at 21, col. 5; Chicago Tribune, May 24, 1982, at 10, col. 1; Hartford Courant, June 15, 1981, at 1, col. 1; 48 Fed. Reg. 30,846, 30,847-48 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983). Despite the apparent frequency of nontreatment decisions for defective newborns, both physicians and parents may be criminally prosecuted and civilly liable for deciding to withhold treatment. *See generally* Ellis, *Letting Defective Babies Die: Who Decides?* 7 AM. J.L. & MED. 393, 401-11 (1982); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 217-44 (1975).

hastily or without appropriate review.<sup>51</sup> Except in a few instances, nontreatment decisions are made privately, the sole participants being the parents and the physician and perhaps some of the parents' personal advisors and friends.<sup>52</sup> However, the parents are not ideal decisionmakers. After the birth of a defective child "[t]here is almost always an initial phase of severe *shock* lasting days to months. During this time the parents are typically incapable of assimilating information."<sup>53</sup> The parents "are overwhelmed by feelings of shock, fear, guilt, horror and shame."<sup>54</sup> Some physicians believe that informed consent has no meaning under these circumstances because parents who are "suddenly confronted with an uncertain future of financial and psychological hardship, with potentially devastating effects on their marriage, family, and personal aspirations,"<sup>55</sup> are often too upset to understand the nature of the options presented to them. Another problem with parental decisionmaking is that, due to lack of information, "[l]ay parents may seriously underestimate the potential of a retarded child for pleasure, employment, or even self-sufficiency."<sup>56</sup> Or they may "believe the multiple hospitalizations and ultimate handicap will result in a life of chronic sorrow or depression, unaware of data that the majority of survivors do not appear to differ markedly from normal controls in these aspects."<sup>57</sup> Finally, many have challenged whether parents make treatment decisions based on the defective infant's best interests. "When the child is seen as presenting a great burden to the parent, there is an obvious conflict of interest which may make the parent unable to put the child's interests first."<sup>58</sup> It may also be argued that parents should not be disinterested in their decisionmaking when they have other children at home who would be adversely affected by the financial and psychological strain involved in raising a defective child. Therefore, it cannot be assumed that a parent will be able to make an informed decision regarding the treatment of a defective child based on the best interests of the defective child.<sup>59</sup>

Nor can it be assumed that the physician is the best decisionmaker. While

---

51. See Berseth, *A Neonatologist Looks at the Baby Doe Rule: Ethical Decisions by Edict*, 72 PEDIATRICS 428, 428 (1983); PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 207-14 (1983) [hereinafter cited as PRESIDENT'S COMMISSION].

52. See PRESIDENT'S COMMISSION, *supra* note 51, at 207. In our legal system strong presumptions exist in favor of parental autonomy and family privacy and against coercive state intervention. Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645, 648 (1977).

53. Fost, *Counseling Families Who Have a Child With a Severe Congenital Anomaly*, 67 PEDIATRICS 321, 321 (1981).

54. Shaw, *Dilemmas of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 885, 886 (1973).

55. Robertson, *supra* note 50, at 215.

56. Fost, *supra* note 53, at 322.

57. *Id.* at 322-23.

58. *Id.* at 323.

59. As one author noted, "[a] reasonable patient would not choose as a proxy someone who is of the opinion that the patient's continued existence constitutes a threat to the decisionmaker." *Id.*

physicians are generally thought to be much more informed than the parents regarding alternative treatments, possible prognoses, and social services available for the care and treatment of defective newborns, not all physicians keep abreast of new information.<sup>60</sup> In any case, "nothing in their training or background qualifies [physicians] to identify, assess, and balance all interests involved—in short to 'play judge.'" <sup>61</sup> Furthermore, a physician's personal feelings may influence the advice he gives to the parents. For example, the physician who delivers a handicapped baby "may feel a sense of having failed the family with whom he has a relationship—and his own emotions come into play . . . . His recommendations may be influenced unconsciously by his discomfort with the situation and his strong desire to 'save' the family."<sup>62</sup> "The physician also may feel that his expertise and training are misused when employed to maintain the life of an infant whose chances for a productive existence are so diminished. By neglecting other patients he may feel that he is prolonging rather than alleviating suffering."<sup>63</sup>

Dissatisfaction with the parents and physician as decisionmakers has prompted legislative attempts to control the decisionmaking process involved in withholding treatment from defective newborns.<sup>64</sup> It is difficult, however, to draft legislation in this area. Neonatology is such a highly specialized, complex field of medicine that it is nearly impossible to prescribe a workable method of decisionmaking other than one that analyzes each situation on a case by case basis. One can isolate the black and white decisions such as allowing an infant to die who has a terminal, incurable defect,<sup>65</sup> for whom prolonging life constitutes a cruel and pointless prolonging of suffering; or requiring treatment for an otherwise normal infant who has a surgically correctable but life threatening anomaly.<sup>66</sup> The grey areas in between, however, do not lend themselves to clear "right" and "wrong" answers, even for those who feel strongly that parents must be allowed to make treatment decisions for their defective newborns or who feel strongly that all infants should have a "right to life."<sup>67</sup> Many find legislation inappropriate or harmful in an area of such complexity and moral disagreement.<sup>68</sup>

Moreover, neonatology changes so rapidly, due to vast strides in technology,

---

60. See, e.g., *Am. Med. News*, June 3, 1983, at 26, col. 2.

61. Robertson, *supra* note 50, at 264.

62. Robertson, *supra* note 50, at 260 n.248, citing Giannini & Goodman, *Counseling Families During the Crisis Reaction to Mongolism*, 67 *AM. J. MENTAL DEFICIENCY* 740, 740-41 (1962).

63. Robertson, *supra* note 50, at 260.

64. 48 Fed. Reg. 30846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983); ARIZ. REV. STAT. § 36-2281 (West Supp. 1983); IND. CODE ANN. § 31-6-4-3 (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36 (West Supp. 1983). In addition, Tennessee passed Senate Joint Resolution No. 17 (1983) and California passed Senate Concurrent Resolution No. 75 (1982) to express dissatisfaction with nontreatment decisions.

65. Anencephaly, for example.

66. Esophageal atresia, for example.

67. See, e.g., *infra* text accompanying notes 124-28.

68. One *New England Journal of Medicine* editorial asks, "[a]nd is it proper for the state to substitute its judgment on such a matter for that of parents and physicians?" Angell, *Handi-*



that concepts of treatment soundly based on current medical research may become obsolete, irrelevant, or even wrong in a few years.<sup>69</sup> Furthermore, it should be noted that it is not always possible to make an accurate prognosis regarding the development of a defective newborn; there is always an unknown element in this sort of diagnostic projection. For example, a physician cannot always predict with accuracy which premature infant will thrive<sup>70</sup> or how retarded, if at all, an infant with hydrocephalus will be.<sup>71</sup> In contrast, legislation tends to anticipate a clear, unchanging situation in that it sets in concrete particular values and rules, responding badly, if at all, to complexity and change. Therefore, legislation that assumes a static, simplistic arena for nontreatment decisions is bound to be problematic.

Given these considerations, proposed legislation affecting nontreatment decisions has taken one of two routes. One route prescribes a method whereby parents or others may determine the appropriate treatment for defective newborns. This position can be legislated in various ways,<sup>72</sup> but the justification for allowing the parents or another to decide is generally based on a belief that some infants may not have a "life worth living," that the "quality of life" of some individuals is so lacking that life-sustaining treatment is not in the best interest of the infant.<sup>73</sup> For example, in his article concerning infants who have spina bifida with meningomyelocele,<sup>74</sup> John Lorber rejects any special treatment beyond custodial nursing care for all patients whose prognosis is for an "unacceptable" quality of life.<sup>75</sup> Lorber contends that such a view avoids suffering and hardships for the patient, such as repeated operations and hospitalization, as well as excessive cost.<sup>76</sup> This line of reasoning assumes that if the patient were fully informed and able to communicate, he would agree that nontreatment is in his best interest.<sup>77</sup>

A qualify of life analysis may include not only considerations of the future "personhood" of the defective newborn,<sup>78</sup> but also the impact of the defec-

---

*capped Children: Baby Doe and Uncle Sam*, 309 NEW ENG. J. MED. 659, 659-60 (1983). See also, Weir, *The Government and Selective Nontreatment of Handicapped Infants*, 309 NEW ENG. J. MED. 661, 663 (1983).

69. Cf. Strain, *supra* note 49, at 572 for a discussion of a recent shift in the attitude of the medical profession.

70. See generally R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 351-52. See also, 2 W. REICH, *ENCYCLOPEDIA OF BIOETHICS* 720 (1978).

71. Hydrocephalus may be treated with shunt operations but even with good neurosurgical and medical management about 60% will have significant intellectual and motor handicaps and 40% will have normal intellect. R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 1568-69.

72. See, e.g., *infra* text accompanying notes 235-70.

73. Robertson, *supra* note 50, at 252. See also W. REICH, *supra* note 70, at 724-26.

74. See discussions of three of Lorber's works in W. REICH, *supra* note 70, at 725.

75. *Id.*

76. *Id.*

77. Robertson, *supra* note 50, at 252; see also Note, *Birth Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599, 605-19 (1978) for a thorough discussion of the use of "the best interests of the child" as a standard for decisionmaking.

78. See generally W. REICH, *supra* note 70, at 726-34. See also Robertson, *supra* note 50, at 246-51.

tive infant's survival on his family and on society as a whole.<sup>79</sup>

[O]ne who argues that the harm of treatment justifies violation of the defective infant's right to life usually relies on the psychological, social, and economic costs of maintaining his existence to family and society. In their view the minimal benefit of treatment to persons incapable of full social and physical development does not justify the burdens that care of the defective infant imposes on parents, siblings, health professionals, and other patients.<sup>80</sup>

The burden that raising a defective infant imposes on parents and siblings is obvious. Recently, however, more articles have been appearing in medical journals and elsewhere concerning the burden on society of maintaining defective newborns. For example, one article noted that the share of the gross national product devoted to health care has risen to 9.4% in 1980 from 4% in 1940 and "targeted" neonatal intensive care units as one of the most costly high technology areas of medicine benefiting relatively few people at extraordinarily high expense, thus contributing to the increase of federal spending on health care.<sup>81</sup> Another article, published in the *New England Journal of Medicine*,<sup>82</sup> concluded that for low-birth-weight infants weighing from 500 to 1499 grams, "the provision of neonatal intensive care resulted in an increase in cost that was greater than the increase in projected earnings."<sup>83</sup> The author also pointed out that a program treating the lower-birthweight infants "represents a net drain on society's resources—that is, the program consumes more resources than it saves or creates. Then the question (from a social perspective) is, 'How much is society willing to pay for improved health outcomes?'"<sup>84</sup> Given the fact that medical technology continues to advance at a costly rate, economic considerations are likely to become increasingly important.

The second route proposed legislation has taken is to consciously reject a "quality of life" type of analysis. This route, which some have labeled the "sanctity of human life analysis,"<sup>85</sup> attempts to prohibit health care profes-

---

79. W. REICH, *supra* note 70, at 728.

80. Robertson, *supra* note 50, at 255-56. Robertson points out that this type of quality of life analysis breaks down into utilitarianism with all of its problems of extension.

First, this judgment . . . requires a coherent way of measuring and comparing interpersonal utilities, a logical-practical problem that utilitarianism has never surmounted. But even if such comparisons could reliably show a net loss from treatment, the fact remains that the child must sacrifice his life to benefit others. If the life of one individual, however useless, may be sacrificed for the benefit of any person, however useful, or for the benefit of any number of persons, then we have acknowledged the principle that rational utility may justify any outcome.

*Id.* at 256.

81. N.Y. Times, Mar. 30, 1982, at 21, col. 4.

82. Boyle, *Economic Evaluation of Neonatal Intensive Care of Very-Low-Birth-Weight Infants*, 308 NEW ENG. J. MED. 1330 (1983).

83. *Id.* at 1333.

84. *Id.* at 1335.

85. See, e.g., Singer, *Sanctity of Life or Quality of Life?*, 72 PEDIATRICS 128 (1983).

sionals or parents from making decisions to withhold treatment for defective infants on grounds that the quality of life of the infant is inadequate:

The arguments supporting care in all circumstances are based on the view that all living creatures are sacred, contain a spark of the divine, and should be so regarded. Moreover, identifying those human offspring unworthy of care is a difficult task and will inevitably take a toll on those whose humanity cannot seriously be questioned.<sup>86</sup>

Persons who advocate this position question the premise that defective children suffer so terribly that they are better off dead. These persons may point out that

one who has never known the pleasures of mental operation, ambulation, and social interaction surely does not suffer from their loss as much as one who has. While one who has known these capacities may prefer death to a life without them, we have no assurance that the handicapped person, with no point of comparison, would agree. Life, and life alone, whatever its limitations might be of sufficient worth to him.<sup>87</sup>

Proponents of the second legislative route argue that those who would allow defective infants to die because they have an inadequate quality of life are not looking out for the interests of the defective newborn but instead the selfish interests of others, such as the family. Moreover, they may question the relevance of the interests of others, such as the families' or health professionals' pain or inconvenience due to the presence of a defective newborn in their lives.<sup>88</sup> They point out that the law does not ordinarily view human life in cost-effective terms,<sup>89</sup> and they fear that allowing defective newborns to die is but one step down a slippery slope of allowing others to die, such as the senile or those who do not have an adequate quality of life and represent great expense to their families and society as a whole.<sup>90</sup>

#### THE HHS PROPOSED REGULATION

Thus far, the only legislation or rules that have been passed have taken the second route. In response to the *Infant Doe* case, on April 30, 1982, President Reagan directed Health and Human Services' then Secretary Schweiker "to notify health care providers of the applicability of Section 504 of the Federal Rehabilitation Act of 1973 to the treatment of handicapped patients."<sup>91</sup> According to the President's memorandum, "that law [section 504] forbids recipients of federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefits or service that would ordinarily be provided to persons without handicaps."<sup>92</sup>

---

86. Robertson, *supra* note 50, at 248.

87. *Id.* at 254.

88. *See id.* at 255-61.

89. *See Note, supra* note 77, at 607.

90. Singer, *supra* note 85, at 128.

91. Letter from President Ronald Reagan to Secretary Schweiker (Apr. 30, 1982).

92. *Id.*

On May 18, 1982, HHS issued a "Notice to Health Care Providers"<sup>93</sup> stating, in part:

Under Section 504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

(1) the withholding is based on the fact that the infant is handicapped; and

(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.<sup>94</sup>

On March 7, 1983, HHS issued a regulation<sup>95</sup> that established a Handicapped Infant Hotline whereby "[a]ny person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact" the hotline or the respective state child protective agency.<sup>96</sup> Furthermore, the regulation required a notice stating: "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW"<sup>97</sup> to be posted "in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery."<sup>98</sup> The regulation also authorized immediate intervention by an HHS investigation squad to protect "the life or health of a handicapped individual."<sup>99</sup> HHS based its authority to issue the regulation on section 504 of the Rehabilitation Act of 1973,<sup>100</sup> which states: "No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."<sup>101</sup> HHS issued the regulation as an interim final rule, effective March 22, 1983.<sup>102</sup>

Physician and hospital organizations immediately protested the regulation<sup>103</sup> and the American Academy of Pediatrics, the National Association of Children's Hospitals, the Children's Hospital National Medical Center and related institutions brought an action challenging the validity of the regulation.<sup>104</sup> On April 14, 1983, the District of Columbia district court ruled

---

93. Notice from Betty Lou Dotson, Director, Office of Civil Rights for HHS to "Health Care Providers" (May 18, 1982).

94. *Id.* at 1.

95. 48 Fed. Reg. 9,630 (1983) (to be codified at 45 C.F.R. pt. 84) (interim final rule, Mar. 7, 1983).

96. *Id.* at 9,631.

97. *Id.*

98. *Id.*

99. *Id.* at 9,632.

100. *Id.* at 9,630.

101. Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (1976).

102. 48 Fed. Reg. 9630 (1983).

103. See Weir, *supra* note 68, at 662.

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

that the interim final rule was invalid as an arbitrary and capricious agency action, promulgated outside the procedural requirements of the Administrative Procedure Act.<sup>105</sup> The court's decision was based on several grounds. The court found no evidence in the record that consideration was given to the disruptive effects of a twenty-four hour, toll-free hotline, noting that "[t]he sudden descent of 'Baby Doe' squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce a higher quality of [neonatal] care."<sup>106</sup> HHS also failed to address the possible ill effects of forcibly removing an infant from a hospital if a parent refused to allow medical care or of terminating federal assistance to the hospital as an enforcement measure for noncompliance with the regulation.<sup>107</sup> The court noted that HHS did not consider the malpractice and disciplinary risks physicians and hospitals might face if "caught between the requirements of the regulation and established legal and ethical guidelines."<sup>108</sup> Nor did HHS address the issue of appropriate treatment when an infant has a fatal prognosis,<sup>109</sup> the means of funding the extensive care mandated by the regulation,<sup>110</sup> or the problem of allocating scarce medical resources between defective newborns and other patients.<sup>111</sup>

In addition, the court struck down the rule on the ground that it failed to comply with either the public notice or the thirty day, delay-of-effective-date requirements of the Administrative Procedure Act.<sup>112</sup> The court rejected Secretary Heckler's argument that the rule was either "procedural" or "interpretative" and therefore fell outside the requirements of the APA.<sup>113</sup> Therefore, since the rule was issued March 7, 1983, as an interim final rule, to be effective March 22, 1983, it clearly violated the notice requirements of the APA.<sup>114</sup> The court ordered HHS to place a notice in the *Federal Register* advising that the interim rule had been declared invalid.<sup>115</sup>

On July 5, 1983, HHS issued a new proposed regulation which was identical to the March 7 regulation except that the instructions for posting the notice were more specific, and provisions affecting recipient state child protective services agencies have been added.<sup>116</sup> Nearly 17,000 comments were submitted to HHS concerning the July 5 proposed regulation during the com-

---

105. *Id.* at 404. For the procedural requirements of the Administrative Procedure Act, hereinafter referred to as the "APA" see 5 U.S.C. § 553(b)(B), (d) (1982).

106. 561 F. Supp. at 399.

107. *Id.*

108. *Id.* at 400.

109. *Id.*

110. *Id.*

111. *Id.*

112. *Id.*; see also *supra* note 105.

113. 561 F. Supp. at 401.

114. See the 30-day delay of effective date requirements, 5 U.S.C. § 553(d)(1)-(3).

115. 561 F. Supp. at 404; see 48 Fed. Reg. 17,588 (1983) (to be codified at 45 C.F.R. pt. 84) (notice of court order declaring rule invalid, Apr. 25, 1983).

116. 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

ment period provided under the regulation. On the basis of their analysis of these comments, HHS made modifications to the July 5 proposed rule in promulgating the final rule published January 12, 1984.<sup>117</sup> Although the final rule differs from the original regulation,<sup>118</sup> the criticisms raised by the district court are still pertinent. The supplementary information and appendix portions of the July 5 proposed regulation and the January 12 final rule attempt to deal with some of the objections which led the District of Columbia district court to find the first rule invalid.

In response to the criticism that the former regulation did not give any guidance for the treatment of infants with a fatal prognosis, HHS explained in the July 5 proposed regulation that section 504 of the Rehabilitation Act of 1973 protects only those infants who are able to benefit from treatment:

Section 504 would hold that where an infant would not benefit medically from a particular treatment, the infant would not be "qualified" to receive the treatment . . . . Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies . . . which merely temporarily prolong the process of dying.<sup>119</sup>

HHS further explains that "not all judgments made by a health care provider . . . are medical judgments,"<sup>120</sup> and gives examples such as withholding treatment from a Down's syndrome, blind, deaf or paralyzed child as being decisions which may not be "medically" indicated.<sup>121</sup>

Much of the concern on the part of the medical community regarding this regulation centers on their perception that the regulation forseees an "oversimplified picture of the considerations that go into many selective nontreatment decisions."<sup>122</sup> The medical community fears that it will not be clear when the physician's judgment is discriminatorily based.<sup>123</sup> For instance, as one of the daily medical judgments that would not ordinarily give rise to concerns about compliance with section 504, HHS cites the example of premature or low birth weight infants, "even though these infants may be seriously ill and require intensive medical care."<sup>124</sup> In fact, premature infants are prone to numerous medical disorders that result in just the sort of handicap that might lead to a discriminatory decision of the type that the regulation is intended to prohibit. A premature infant may develop blindness or severe visual im-

---

117. 49 Fed. Reg. 1,622, 1,622 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

118. The final rule "encourages" the establishment of Infant Care Review Committees and sets out a suggested framework for those committees. The final rule also changes the posted notice requirement so that hospitals have a choice between two postings and the size of the posting is reduced to 5 by 7 inches. *See generally, id.* at 1650-51.

119. 48 Fed. Reg. 30,846, 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

120. *Id.* at 30,847.

121. *Id.* at 30,852.

122. Weir, *supra* note 68, at 663.

123. *Id.*

124. 48 Fed. Reg. 30,846, 30,847 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

pairment because of retrolental fibroplasia<sup>125</sup> if, during his treatment, he requires the prolonged use of high oxygen concentrations because of immature lung development.<sup>126</sup> In addition, it is not uncommon for premature infants to develop extensive gangrenous infections of the intestine requiring repeated surgical procedures and complex means of artificial nutrition.<sup>127</sup> Or, the premature infant may develop a chronic lung impairment called bronchopulmonary dysplasia from prolonged mechanical ventilation,<sup>128</sup> or be afflicted with retrolental fibroplasia, extensive infections, bronchopulmonary dysplasia, and intracranial bleeding. It is conceivable that a parent or physician may desire to withhold corrective surgery from the infant because even if the surgery is successful, the infant will remain impaired. When premature infants develop numerous medical disorders, it becomes increasingly difficult to determine whether the physician's decision is discriminatory if eventually the infant's condition deteriorates to a point at which it is unclear whether the infant will survive.

Even the cases HHS considers "clear" under the July 5 proposed regulation may not be self evident upon a closer examination. HHS mentions the treatment of intracranial bleeding or anencephaly as "futile therapy" merely temporarily prolonging the process of dying and therefore outside the scope of section 504.<sup>129</sup> It is now known, however, that intracranial bleeding may be quite treatable and does not necessarily indicate a permanent handicap, much less imminent death.<sup>130</sup> A failure to treat anencephaly may also be problematic under the regulation. All infants who die do so because of some physical disorder, and these disorders are likely to qualify the infant as handicapped under the Rehabilitation Act of 1973 which defines a "handicapped individual" as "any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities . . . or (C) is regarded as having such an impairment."<sup>131</sup> The presence of anencephaly clearly renders an infant handicapped since an anencephalic infant has both physical and mental impairments that substantially limit all of his major life activities.<sup>132</sup> The July 5 proposed regulation reads "Discriminatory failure to feed and care for handicapped infants . . . is prohibited by Federal law"<sup>133</sup> and HHS defines a discriminatory decision as "any decision to withhold treatment which is based on the infant's handicap rather than on a medical judgment . . ."<sup>134</sup> A physician who allows an anencephalic

---

125. See R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 1761-62.

126. *Id.*

127. *Id.* at 351.

128. *Id.* at 371.

129. 48 Fed. Reg. 30,846, 30,846-47 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

130. R. BEHRMAN & V. VAUGHAN, *supra* note 3, at 357-58.

131. 29 U.S.C. § 706(7) (1976).

132. See *supra* note 34.

133. 48 Fed. Reg. 30,846, 30,851 (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

134. *Id.* at 30,852 (1983). This problem is alleviated in the May 18, 1982 Notice to Health

infant to die makes his decision "based on the infant's handicap;" but for the presence of the handicap, anencephaly, a nontreatment decision would not arise. Therefore, even a decision not to treat anencephaly could be logically interpreted as discriminatory. Another ambiguity in the meaning of the word "discrimination" is found in the appendix of the July 5 proposed regulation. According to the proposed regulation: "Even if a handicapped infant faces imminent and unavoidable death, no health care provider should take upon itself to cause death by starvation or dehydration."<sup>135</sup> And yet the regulation reads "*discriminatory* failure to feed," leading to the assumption that failure to treat or feed that is not discriminatory falls outside the scope of section 504.<sup>136</sup>

Further confusion exists regarding the words "qualified to receive medical care or treatment."<sup>137</sup> HHS has distinguished patients who are not able to benefit medically from treatment as being unqualified infants.<sup>138</sup> However, the appendix to the July 5 proposed rule defined services that a "qualified" infant is to receive as "services that are (1) generally provided by the program or activity, and (2) are appropriate, in the exercise of reasonable medical judgment, to the circumstances of the particular handicapped infant."<sup>139</sup> This definition is replete with problems. Consider the situation of an infant, like Infant Doe, who is born with Down's syndrome, with intestinal atresia, and with tracheoesophageal fistula. If correcting the esophageal blockage is not among the "services generally provided by the program" at Bloomington Hospital, then HHS evidently does not require corrective surgery. In addition, to speak of treatment that is "appropriate, in the exercise of reasonable medical judgment" is begging the question since the perceived need for the HHS regulation itself arises out of a recognition that some physicians find corrective surgery "inappropriate" for a Down's syndrome infant. Similarly, the use of the phrase "customary medical care"<sup>140</sup> is problematic since "it is impossible to identify a consensus on which infants or children within this broad range should be treated."<sup>141</sup> Unfortunately the summary of information and an appendix of the July 5 proposed regulation are neither thoroughly considered nor clearly stated and therefore do not adequately describe the circumstances under which the regulation is intended to apply.

The January 12 final rule acknowledges many of these ambiguities found in the July 5 proposed regulation. The supplementary information section of

---

Care Providers that qualifies violations of section 504 to situations where the "existence of the handicap does not render the treatment medically contraindicated." Notice from Betty Lou Dotson to "Health Care Providers" (May 18, 1982).

135. 48 Fed. Reg. 30,846, 30,852 (1983).

136. *Id.* at 30,851 (emphasis added).

137. *Id.* at 30,846.

138. *See generally id.* at 30,846.

139. *Id.* at 30,852.

140. *Id.* at 30,847.

141. Committee on Bioethics, *Treatment of Critically Ill Newborns*, 72 PEDIATRICS 565, 565 (1983).



the January 12 final rule notes the ambiguity of phrases such as "futile therapies," "services generally provided," and "dubious medical benefit."<sup>142</sup> Moreover, that section admits that "[t]he characterization of the infants with intracranial hemorrhage as analogous to anencephaly is incorrect."<sup>143</sup> However, HHS's response to this problem of interpreting when section 504 is applicable to a given situation gives little aid. HHS simply explains that the application of constitutional and statutory civil rights protections in many contexts is difficult, and concludes that it would be imprudent to speculate on the outcome of applying section 504 in a wide variety of specific factual circumstances.<sup>144</sup> However, the January 12 final rule greatly improves upon the explanation of "discriminatory" nontreatment. The January 12 final rule requires that the following statement<sup>145</sup> be posted "in appropriate places":

Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and *medically beneficial* treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.<sup>146</sup>

The addition of the words "medically beneficial" is substantially clearer because it injects an objective criteria into the analysis of whether nontreatment is discriminatory. HHS explains that "[i]f the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is 'otherwise qualified' to receive that treatment or service, and it may not be denied solely on the basis of the handicap."<sup>147</sup> HHS uses the example of an infant born with myelomeningocele and explains that if the surgery necessary to enclose the protruding sac would not medically benefit the patient because the patient is riddled with infection, respiratory problems or other fatal complications such that surgery would be futile, then nontreatment is not discriminatory. However, if the surgery is likely to effect the intended result of avoiding infection or other fatal consequences, then the surgery is medically beneficial and nontreatment is discriminatory.<sup>148</sup> Physicians' "reasonable medical judgment" may still differ as to whether treatment is medically beneficial in cases where the patient has multiple complications and the prognosis is uncertain. However, the addition of the words "medically beneficial" clarify that the standard for analysis is the objective physical condition of the patient, not subjective speculations of future intelligence or family inconvenience. HHS indicates that "in a 'close case' it may be prudent to preserve the status quo" and err on the side of preserving life until further consideration indicates otherwise.<sup>149</sup>

---

142. 49 Fed. Reg. 1,622, 1,631 (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

143. *Id.*

144. *Id.* at 1,632.

145. Actually, the hospital has a choice between two alternative statements. *Id.* at 1,651.

146. *Id.* (emphasis added).

147. *Id.* at 1,636.

148. *Id.* at 1,637.

149. *Id.* at 1,643.

In its summary of information of both the proposed rule and the final rule, HHS acknowledges the district court's concern for the "malpractice and disciplinary risks that may be imposed on physicians and hospitals caught between the requirements of the regulation and established legal and ethical guidelines."<sup>150</sup> The July 5 summary reads "recipients may be restricted in their provision of treatment by the lack of parental consent."<sup>151</sup> HHS expects the regulation to force hospitals receiving federal financial assistance into developing a policy against nontreatment decisions in order to avoid having medicare and medicaid funding cut off as a reprisal for noncompliance.<sup>152</sup> This concept poses various problems. Given the nature of tort and criminal law, it is illogical to threaten hospitals for the acts of physicians practicing within the hospital because ordinarily, a hospital is not legally responsible for the actions of physicians unless the physicians are employees of the hospital.<sup>153</sup> In general, obstetricians, pediatricians and family practitioners, the doctors who would be involved in this sort of nontreatment decision, are independent contractors, not employees of the hospital.<sup>154</sup> Hospitals can make policies that will influence the type of treatment performed within the hospital. The sort of policy advocated by the HHS regulation, however, is much more complicated than the type of policy commonly developed by hospitals such as prohibiting the performance of abortions within a particular hospital. Enforcement of HHS's mandate against discriminatory nontreatment decisions for defective newborns would require a case-by-case analysis of the circumstances surrounding the treatment decisions—in other words, it would require that hospitals make medical determinations.<sup>155</sup>

Furthermore, the regulation puts the physician in a legally precarious position. If the parents make a discriminatory decision to refuse treatment, the physician may face a charge of battery if he treats the infant without parental consent.<sup>156</sup> Treatment administered to a child without the consent of the ap-

---

150. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983).

151. 48 Fed. Reg. 30,846, 30,848 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

152. 49 Fed. Reg. 1,622, 1,641-42 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).  
153.

Although a hospital may certainly be liable if a physician who is known to be generally incompetent or deficient in knowledge or skill retains staff privileges and negligently harms a patient, the legal rule has been that hospitals cannot be held liable for competent nonemployee physician decisions (e.g. for a physician's failure to obtain informed consent from a patient) because it has no right to control or prescribe medical practice.

Holder, *Parents, Courts, and Refusal of Treatment*, 103 PEDIATRICS 515, 517 (1983).

154. This is not true if the nontreatment decision involved a pediatrician employed by a health maintenance organization (HMO). Ordinarily physicians who practice with an HMO are employees of the HMO so that the HMO could be found liable under a theory of respondeat superior. See generally *Brown v. More*, 247 F.2d 711 (3d Cir.), cert. denied, 355 U.S. 882 (1957); Annot., 69 A.L.R.2d 305 (1960).

155. HHS argues unconvincingly that in fact it will not be making medical determinations. 49 Fed. Reg. 1,622, 1,630 (1984).

156. See generally Note, *Hospice: The Legal Ramifications of a Place to Die*, 56 IND. L.J. 673, 679 (1981).

propriate party is "viewed as an intentional interference with the person—a battery."<sup>157</sup> On the other hand, if the physician dismisses the case knowing that the infant still requires his services, and insists that the parents remove their child to another hospital and contract with another physician, he, and possibly the hospital, may be liable under a theory of abandonment.<sup>158</sup> A physician who has contracted with the parents to treat their newborn infant has assumed an obligation to act on the infant's behalf; once the physician-patient contract has been established, the physician is obligated to provide treatment "so long as the case requires."<sup>159</sup> A theory of abandonment is all the more probable given that the rejecting physician and hospital are aware that other hospitals and physicians may be reluctant to accept the infant as a patient because to treat him in accordance with the parent's wishes would be a violation of the regulation and could lead to a withdrawal of federal funding to their hospital as well.

In the summary of information of the January 12 final rule, HHS tries to refute this criticism by stating that under the law of most states, a physician is required to report cases of parental refusal of treatment since such action falls under the realm of child abuse reporting statutes. Therefore, while a physician cannot treat without consent of the parent and cannot transfer when to transfer would constitute abandonment, physicians are required to seek judicial review of the parent's nontreatment decision or trigger a child-protection investigation provided under state law.<sup>160</sup> Moreover, HHS suggests that a hospital can manipulate a physician's compliance with HHS standards by conditioning "a physician's staff membership or renewal or membership on an agreement to abide by the hospital's policy of nondiscrimination."<sup>161</sup>

In addition, as the district court pointed out "[n]or are the interests of the child served by a regulation that contemplates . . . termination of any federal assistance to the hospital as a whole."<sup>162</sup> To cut off federal funding for the hospital would be much more likely to affect patients in the hospital than the physicians making treatment decisions. In addition, if the regulation is successful at influencing treatment decisions by inducing hospitals to adopt strict policies regarding termination of treatment for handicapped infants, the regulation is likely to

lead pediatricians already anxious about the law to practice increasingly defensive medicine. The result is that pediatricians practicing defensive medicine will, to save their careers, be persuaded to give aggressive treatment to virtually all handicapped neonates—regardless of the handicap, the effectiveness of the treatment, or the harm done to the relatively few

---

157. *Id.*

158. *Id.* at 682-83; see also Robertson, *supra* note 50, at 225-26.

159. Note, *supra* note 156, at 683; see also Holder, *supra* note 153, at 517.

160. 49 Fed. Reg. 1,622, 1,631 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

161. *Id.* at 1637.

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

neonates who would be better off without life prolonging treatment.<sup>163</sup>

The summary of information of the final rule also discusses the district court's criticism that HHS failed to consider the "disruptive effects of a twenty-four hour, toll-free 'hotline' upon ongoing treatment of newborns."<sup>164</sup> The final rule summary and Surgeon General C. Everett Koop, M.D. examined instances in which the regulation has been applied and concluded that the Handicapped Infant Hotline and followup HHS investigations were successful in influencing hospitals to see that defective infants were treated when they had formerly been denied needed treatment.<sup>165</sup> The American Academy of Pediatrics, however, is critical of the operation of the regulation, noting: "[t]he solution of the [Department of Health and Human Services] intends to provide what might be far more detrimental to the health and safety of infants than the problems giving rise to the investigation."<sup>166</sup> The American Academy of Pediatrics listed several specific problems that occurred during the investigations performed by HHS in response to Handicapped Infant Hotline calls. During one investigation in Rochester, New York at Strong Memorial Hospital where conjoined (siamese) twins had been born, the HHS investigators had arranged for a neonatologist to be flown in from Norfolk, Virginia, for an evening consultation. The neonatologist discovered that investigators failed to obtain the parents' consent for him to examine the children and he left the next morning.<sup>167</sup> Evidently,<sup>168</sup> the neonatologist expressed "full support for the medical decisionmaking, level of parental involvement in that decisionmaking, and overall management of the case."<sup>169</sup> Nevertheless, the investigators would give no comment regarding when a final report would be issued.<sup>170</sup>

Similarly, in the Vanderbilt University Hospital case, in which a Handicapped Infant Hotline caller charged that ten children at the hospital were not being fed or given proper treatment, the neonatologist called in by the investigators reported that "the medical care being given the children at Vanderbilt was exemplary in all respects."<sup>171</sup> However, the investigators stated it would

---

163. Weir, *supra* note 68, at 663.

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

165. American Medical News, Aug. 19, 1983, at 1, col. 2.

166. Strain, *The American Academy of Pediatrics Comments on the "Baby Doe" Regulations*, 309 NEW ENG. J. MED. 443, 443-44 (1983).

167. *Id.* at 444.

168. The article does not explain how the neopathologist could have given his "full support" if he was not able to examine the patient.

169. Strain, *supra* note 166, at 444.

170. *Id.*

171. *Id.* Another article reacting to the disruptive effects of the Handicapped Infant Hotline, concluded that "[e]ither there are no instances of withholding care inappropriately or the hotline is an ineffective means of identifying them." Annas, *Disconnecting the Baby Doe Hotline*, 13 HASTINGS CENTER REP. 14, 16 (June 1983). The author explains that in a period of nearly one month the hotline received about 600 calls, of which only 16 calls made a specific allegation. *Id.* Of the 16 calls, only five allegations were perceived as warranting an investigation and none of the investigations were found to warrant further action. *Id.*

take thirty to ninety days before the final report could be issued.<sup>172</sup> Other problems were also noted in these two situations. In the Strong Memorial case, the negative publicity of the investigation led parents of other critically ill children in the facility to question the adequacy of care provided in the hospital and one family actually removed their infant from the hospital before his treatment was completed.<sup>173</sup> The Vanderbilt University Hospital investigation caused delay and confusion in the hospital routine while physicians and hospital staff were being interviewed and medical records reviewed by the investigators.<sup>174</sup> HHS hotly contests these allegations and sets forth a detailed summary of events connected with the Strong Memorial and Vanderbilt University Hospital investigations.<sup>175</sup>

In addition to these criticisms, it should be noted that the bureaucratic intrusion accompanying an HHS investigation could be tripled. HHS states in the summary of information portion of the regulation that it

intends to contact state child protective agencies whenever a complaint [from the Handicapped Infant Hotline] is received . . . in order to give states an opportunity to make their own investigation and to take appropriate action . . . . For those complaints that are expeditiously and effectively investigated and pursued by state agencies, the Secretary anticipates that additional federal efforts will *often* be unnecessary.<sup>176</sup>

This statement leads to the inevitable conclusion that HHS may decide that two separate investigations may be necessary if HHS does not approve of the state's handling of the case, thus duplicating the delay, confusion and intrusion accompanying such an investigation.

Moreover, the January 12 final rule interjects yet a third potential layer of bureaucracy. The January 12 rule "encourages" each hospital to establish an infant care review committee (ICRC)<sup>177</sup> and suggests a format of composition and activity that such a committee should follow.<sup>178</sup> The addition of an internal review committee had been suggested by many who commented on the July 5 proposed regulation.<sup>179</sup> Certainly this sort of review could serve as an important check of parents and physicians nontreatment decisions. However, under the final rule, HHS "will give careful consideration to the analysis and recommendations of the ICRC,"<sup>180</sup> when one exists within a hospital under investigation, but HHS makes clear that "review committees cannot be given an exclusive role in reviewing medical decisions concerning the withholding or withdrawal of medical or surgical treatments from han-

---

172. Strain, *supra* note 166, at 444.

173. *Id.*

174. *Id.*

175. 49 Fed. Reg. 1,622, 1,642-43 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

176. 48 Fed. Reg. 30,846, 30,849 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983) (emphasis added).

177. 49 Fed. Reg. 1,622, 1,651 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

178. *Id.* at 1,652.

179. *Id.* at 1,623-25.

180. *Id.* at 1,633.

dicapped infants."<sup>181</sup> Therefore, hospitals and parents could be forced to endure an internal hospital review of their decision, a state child protection investigation, in addition to a federal HHS investigation.

In addition to these issues, on which the district court based its decision, the court briefly discussed whether HHS exceeded its statutory authority in promulgating the regulation, and whether the regulation could be challenged constitutionally. As the court pointed out, the legislative and regulatory history of section 504 gives no indication that the section was anticipated as applying to decisionmaking with regard to defective newborns.<sup>182</sup> In fact, section 504 was initially directed toward eliminating discrimination against handicapped individuals in employment, and Congress originally defined the term "handicapped individual" in terms of employment.<sup>183</sup> As part of the Rehabilitation Act Amendments of 1974, however, Congress specifically expanded that definition to encompass impairments to "major life activities."<sup>184</sup> The Senate Report accompanying the amendment explained that the definition of "handicapped" was not to be limited to employment: "Section 504 was enacted to prevent discrimination against all handicapped individuals, regardless of their need for, or ability to benefit from, vocational rehabilitation services, in relation to Federal assistance in employment, housing, transportation, education, health services, or any other Federally-aided programs."<sup>185</sup> Given the present broad definition, it would appear that discrimination against handicapped infants with regard to treatment decisionmaking would fall under the purview of section 504.<sup>186</sup>

---

181. *Id.* at 1,624.

182. American Academy of Pediatrics v. Heckler, 561 F. Supp. at 401 (D.D.C. 1983).

183. 119 CONG. REC. 24,587 (1973) (remarks of Sen. Taft); Rehabilitation Act of 1973, Pub. L. No. 93-112, § 7(6), 87 Stat. 355, 361 (1973).

184. Rehabilitation Act Amendments of 1974, Pub. L. No. 93-516, § 111(a), 88 Stat. 1,617, 1,619 (1974).

185. S. REP. NO. 1297, 93d Cong., 2d Sess. 38, reprinted in 1974 U.S. CODE CONG. & AD. NEWS 6373, 6388.

186. Despite the 1974 amendment to expand the definition of handicapped persons, Angela R. Holder questions the jurisdiction of the statute beyond discrimination in employment:

[I]n at least one United States Circuit Court decision [United States v. Cabrini Medical Center, 639 F.2d 908 (2d Cir. (1981))] the court held in 1981 that receipt of Medicare and Medicaid funds by a private hospital did not constitute "receipt of financial assistance within the purview of the Rehabilitation Act." The case involved a laundry employee in the defendant hospital who "lost his temper" with a faucet and clubbed the faucet with a cane until it broke. He was fired. He argued that he was discharged because of a mental disability, and sought investigation by the Office of Civil Rights under the Authority of the Rehabilitation Act. The government argued that it had a right to investigate. The court held that "... the provisions of Title VI, as incorporated by § 505(a)(2), make it clear that the federal agencies are to concern themselves with investigation and enforcement only where 'the primary objective of the Federal financial assistance is to provide employment.' " Thus the applicability of the Rehabilitation Act in the nursery setting is subject to question.

Holder, *supra* note 153, at 517. HHS argues that two recent circuit courts have held that the reference to title VI procedures in section 505 did not intend to incorporate the employment restriction. Moreover, HHS argues that no case has held "that section 504 applies only to a

In addition, the court noted

that to the extent the regulation is read to eliminate the role of the infant's parents in choosing an appropriate course of medical treatment, its application may in some cases infringe upon the interests outlined in cases such as *Cary v. Population Services International* . . . *Roe v. Wade* . . . and *Griswold v. Connecticut*.<sup>187</sup>

While the Constitution does not explicitly mention a right of privacy, Supreme Court decisions have recognized that a right of privacy exists in the area involving decisionmaking in certain family matters.<sup>188</sup>

In *Griswold v. Connecticut*,<sup>189</sup> the Supreme Court found that an unwritten right of privacy exists in the penumbra of specific guarantees of the Bill of Rights,<sup>190</sup> and interdicted state intrusion into the area of personal decision-making with regard to contraception and its relation to family life.<sup>191</sup> In *Roe v. Wade*<sup>192</sup> the Supreme Court found that the state's intrusion into the area of a woman's decision to terminate her pregnancy is significant and that the right of privacy extends into this personal decisionmaking.<sup>193</sup> Nevertheless, the Court in *Roe* acknowledged that the right of privacy "is not unqualified and must be considered against important state interests;"<sup>194</sup> one must balance the right of privacy against the state's interest in preserving life.<sup>195</sup> In *Roe*, the Court found that the state's interest in restricting a woman's decision to terminate her pregnancy becomes increasingly compelling as the pregnancy progresses.<sup>196</sup> It held that prior to the end of the first trimester, the decision to abort the pregnancy is free from state intervention,<sup>197</sup> while in the second trimester the state may regulate abortions "in ways that are reasonably related to maternal health,"<sup>198</sup> and in the third trimester, the state may regulate or proscribe abortions entirely,<sup>199</sup> pursuant to its interest in "the potentiality of

---

very narrow segment of employment practices, and has no applicability to the provision of services and benefits under programs and activities receiving Federal financial assistance." 49 Fed. Reg. 1,622, 1,641 (1984) (to be codified at 45 C.F.R. pt. 84) (final Jan. 12, 1984).

187. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 403 (D.D.C. 1983). The court also mentioned that the regulation could be criticized as being overbroad. In the court's words, "[t]here is some merit to the view that a physician attending a severely defective newborn may well be unable to determine what type of conduct the rule purports to require or prohibit." *Id.* at 402. For a discussion of ambiguity in the language of the proposed federal regulation, see *supra* text accompanying notes 122-41.

188. *Poe v. Bolton*, 410 U.S. 179 (1973); *Eisenstadt v. Baird*, 405 U.S. 438 (1972).

189. 381 U.S. 479 (1965).

190. *Id.* at 484.

191. *Id.* at 485-86; *accord* *Roe v. Wade*, 410 U.S. 113 (1973) (woman's decision to terminate her pregnancy under certain conditions falls within right of privacy).

192. 410 U.S. 113 (1973).

193. *Id.* at 153.

194. *Id.* at 154.

195. *Id.* at 152-55. In *Roe*, the Court extended the state's interest in preserving life to preserving prenatal life as well. *Id.* at 150.

196. *Id.* at 162-63.

197. *Id.* at 163.

198. *Id.* at 164.

199. *Id.* at 164-65. The state may not endanger the mother's health, however, in regulating or proscribing abortions.

human life”<sup>200</sup> represented by a viable fetus. If the Court finds a compelling interest in preserving the life of a fetus, surely this compelling interest would not diminish at birth, and the Court would find a compelling interest in preserving the life of a newborn infant. Therefore, it is reasonable to suppose that the Supreme Court would override the parents’ decision to withhold life-preserving treatment for their defective newborn, despite the intrusion this would mean into the parents’ private decisionmaking.

It has been argued, however, that “the state’s interest in preserving life becomes increasingly compelling as the possibility of preserving life becomes greater, but as the prognosis dims this interest becomes less and less compelling.”<sup>201</sup> Thus, while the state’s interest in preserving the life of a defective newborn is ordinarily compelling, when the defective newborn’s condition is so hopeless that medical treatment is futile and preserving life merely postpones death and prolongs suffering, the state’s interest may be overridden by the parents’ right to privacy in deciding to terminate treatment. Given this analysis, the HHS regulation would only infringe on the parents’ right to privacy if the regulation were interpreted to prohibit parents from deciding to withhold treatment when the prognosis for the infant is dim. In the case of a hopeless infant, the bodily intrusion of the state’s interest could be perceived as great while the interest in preserving life is lessened. With the clarification of the HHS final rule by the addition of the words “medically beneficial,” it is unlikely that the regulation could be found to infringe on the parents’ right of privacy. This is because if the infant’s condition is hopeless, treatment is not “medically beneficial” and therefore treatment would not be required under the rule.

The final rule, with its improvements, provides a workable standard for nontreatment decisionmaking. Moreover, the rule’s enforcement procedures provide a mechanism to ensure consistent decisionmaking and certainly in the law. The impact of the rule on physicians and parents, however, could be described as a bureaucratic nightmare. Pressures are placed on hospitals and physicians to comply with the rule despite parental objections, and parents, physicians, and hospitals alike may be forced to endure three separate investigations. To some extent the bureaucracy accompanying the rule is inevitable. On a federal level no mechanism exists to enforce consistent employment of the HHS standard (“medically beneficial”) for nontreatment decisionmaking other than to provide for review on a national scale. One wonders, however, why an additional federal investigation would ever be necessary if an ICRC or a state child protection agency is operating in the hospital in

---

200. *Id.* at 164.

201. Note, *supra* note 156, at 694. An analysis of state court decisions finding a right to privacy and their impact on nontreatment decisions involving handicapped newborns may be found in Ellis, *supra* note 50, at 405-08. Ellis notes that the state court privacy decisions emphasized the elderly, vegetative or otherwise hopeless conditions of the patients involved and concludes that “it is unlikely that courts will extend the *Quinlan* constitutional right to refuse life sustaining treatment . . . beyond the terminally ill elderly patient and the patient in a vegetative condition.” *Id.* at 408.



question in compliance with the specifications and standards outlined by HHS. Nevertheless, for all its shortcomings, the HHS rule achieves its goal of providing a standard and an enforcement mechanism that checks nontreatment decisionmaking based on the parents' or physicians' subjective view of the handicapped infants' quality of life.

### STATE STATUTES

In addition to the proposed HHS regulation, three states have reacted to the Infant Doe case by enacting legislation designed to prohibit the occurrence of a similar situation.<sup>202</sup> Louisiana passed a statute in 1982, and Arizona and Indiana passed statutes in 1983.<sup>203</sup>

The Louisiana and Arizona statutes are similar and can be criticized as having many of the same problems as the HHS July 5 proposed regulation. While the language of the Arizona statute is clearer than that of the Louisiana statute, neither has anticipated the complexities of neonatology in that they do not distinguish between the enormous variations in the types and severity of handicaps in newborns.<sup>204</sup>

The Louisiana and Arizona statutes prohibit any person from depriving a newborn of "food or nutrients, water, or oxygen . . . with the intent to cause or allow the death of the child for any reason . . . ."<sup>205</sup> Both list discrimination against a handicapped child as included within the prohibited reasons for allowing the death of a child.<sup>206</sup> In addition, both statutes prohibit any person from depriving a "minor child" of "necessary" life-saving medical treatment or surgical care.<sup>207</sup>

It should be noted that because of the inconsistent use of the words "infant" and "child," ambiguity exists within the Louisiana statute regarding which children are protected against the deprivation of "food or nutrients, water, or oxygen" and which against the deprivation of necessary life-saving medical treatment or surgical care. The Louisiana statute uses the words "infant born alive" in subsection A concerning the deprivation of "food or nutrients, water or oxygen,"<sup>208</sup> and the words "minor child, from the moment of live birth" in subsection B concerning the deprivation of medical

---

202. ARIZ. REV. STAT. ANN. § 36-2281 (West Supp. 1983); IND. CODE ANN. § 31-6-4-3 (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36 (West Supp. 1983).

203. *Id.*

204. Angell, *supra* note 68, at 660.

205. ARIZ. REV. STAT. ANN. § 36-2281.A (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36.1.A (West Supp. 1983). The Arizona statute's language differs slightly from that of the Louisiana statute in that Arizona does not include the word "or" between the words "food" and "nutrients."

206. ARIZ. REV. STAT. ANN. § 36-2281.A (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36.1.A (West Supp. 1983).

207. ARIZ. REV. STAT. ANN. § 36-2281.B; LA. REV. STAT. ANN. § 40:1299.36.1.B (West Supp. 1983).

208. LA. REV. STAT. ANN. § 40:1299.36.1.A (West Supp. 1983).

or surgical care.<sup>209</sup> Clearly, an infant cannot be deprived of either "food, nutrients, water or oxygen" or necessary "medical or surgical care," but it is not clear whether under some circumstances an older, non-infant child may be allowed to starve or dehydrate, or be disconnected from a respirator. The confusion is compounded in subsection C of the statute which reads: "Nothing in this section shall be interpreted to prevent a *child's* parents and physician from discontinuing the use of life support systems or other medical treatment for a child in a continual profound comatose state."<sup>210</sup> Again, the question arises whether "infant" is included within the meaning of "child." In subsection C, unlike subsection B, the word "child" is not modified by the words "from the moment of live birth."<sup>211</sup> Furthermore, subsection C allows the discontinuance of "life support systems or other medical treatment,"<sup>212</sup> which presumably includes respirators and perhaps intravenous fluids and other forms of maintenance; and therefore if subsection C does include infants it could be interpreted to conflict with subsection A which prohibits the discontinuance of "food or nutrients, water or oxygen."

According to principles of statutory interpretation, "each part or section should be construed in connection with every other part or section so as to produce a harmonious whole."<sup>213</sup> Therefore, subsection C probably should be interpreted as an exception to subsections A and B that applies to infants and older children. The language, however, is extremely unclear, thus leaving any interpretation open to challenge.

Both Arizona and Louisiana (by implication) allow parents to refuse medical treatment or surgical care that is not necessary to save the life of the child,<sup>214</sup> and both statutes have an exception allowing parents to refuse potentially life-preserving treatment if the treatment itself imposes risks that outweigh the benefits of the treatment.<sup>215</sup> Neither statute, however, deals adequately with the problem of determining treatment for a child who is so defective that his prognosis is hopeless and for whom life-prolonging treatment merely

---

209. *Id.* § 40:1299.36.1.B.

210. *Id.* § 40:1299.36.1.C (emphasis added). It should be noted that this standard is more liberal than the "braindeath" criteria. One could be "profoundly comatose" under the Louisiana statute and not be braindead. For example, Karen Quinlan is in a state of continued profound comatose but is not braindead.

The *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* notes that the alternative of discontinuing not only respirators (as in Karen Quinlan's case) but also discontinuing nutrition by withdrawing intravenous fluids is presented. PRESIDENT'S COMMISSION, *supra* note 51, at 190. However the Commission states, "[m]ost of these patients (comatose) . . . are probably given such measures as basic hygiene and artificial nutrition." *Id.* at 187.

211. LA. REV. STAT. ANN. § 40:1299.36.1.C (West Supp. 1983).

212. *Id.*

213. SANDS, SUTHERLAND STATUTES AND STATUTORY CONSTRUCTION § 46.05, at 56 (1973).

214. ARIZ. REV. STAT. ANN. § 36-2281.C.1 (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36.1.B (West Supp. 1983).

215. ARIZ. REV. STAT. ANN. § 36-2281.C.2 (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36.1.C (West Supp. 1983).

prolongs suffering. The exception permitting parents to refuse treatment when the treatment itself imposes risks that outweigh the benefits of treatment does not apply to termination of treatment for a terminally ill, or hopelessly defective infant. When the child is hopeless, one cannot conclude that the "risks" of treatment are significant; if the goal is preserving the life, risky efforts may be resorted to in cases of terminal illness where the child will certainly die without the efforts and such efforts are the last hope for survival.<sup>216</sup>

Both the Louisiana and Arizona statutes could also be criticized as totally ignoring the psychological and economic costs to the family and society in that they do not attempt to weigh considerations of the infant's potential burden to others. But while Louisiana does not allow the parents of a defective child to allow their defective infant to die, the statute does allow them to give custody of the child to the state or to a licensed adoption agency,<sup>217</sup> thereby perhaps lessening the psychological burden of raising a defective infant. This statute, however, requires nonindigent parents to reimburse the state for expenses incurred for the infant's care.<sup>218</sup> Similarly, while the Arizona statute does not allow the parents any flexibility with regard to nontreatment decisionmaking, it does require the hospital to provide the parents with information regarding public or private agencies that provide "assistance, information or support pertaining to the care of the child."<sup>219</sup>

The Indiana Statute differs substantially from the Louisiana and Arizona statutes and poses its own set of problems. The statute consists of an amendment to the Indiana child protection procedures that clarifies the definition of a "child in need of services."<sup>220</sup> Instead of prohibiting the withholding of nutrition or medical treatment for a child, it triggers an investigation by the local child protection services when a case of deprivation of nutrition or medical treatment is reported.<sup>221</sup> The intent of the amendment is to clarify

216. ARIZ. REV. STAT. ANN. § 36-2281.A (West Supp. 1983); LA. REV. STAT. ANN. § 40:1299.36.1.A (West Supp. 1983). For example, while treating an infant with DiGeorge's syndrome for infections or attempting to dialyze an infant with Potter's syndrome does not pose substantial "risks" for the infant, such efforts are futile and therefore serve only to prolong suffering.

217. LA. REV. STAT. ANN. § 40:1299.36.2A (West Supp. 1983).

218. *Id.*

219. ARIZ. REV. STAT. ANN. § 36-2283 (West Supp. 1983).

220. The amendment reads in pertinent part:

Sec. 3(a) A child is a child in need of services if before his eighteenth birthday:

(1) his physical or mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parent, guardian, or custodian to supply the child with necessary food, clothing, shelter, medical care, education, or supervision . . . .

. . . .

(f) A child in need of services under subsection (a) includes a handicapped child who is deprived of nutrition that is necessary to sustain life, or who is deprived of medical or surgical intervention that is necessary to remedy or ameliorate a life threatening medical condition, if the nutrition or medical or surgical intervention is generally provided to similarly situated handicapped or non handicapped children.

IND. CODE ANN. § 31-6-4-3(a), (f) (West Supp. 1983).

221. See generally *id.* § 31-6-11.

that a handicapped newborn deprived of life-preserving nutrition or medical care may be a victim of child abuse or neglect and, therefore, a report of such a deprivation should initiate the child abuse procedures.<sup>222</sup>

The Indiana amendment cannot be criticized as requiring the suffering of hopelessly ill newborns in that the application of the amendment is limited to situations where "the nutrition or medical or surgical intervention is generally provided."<sup>223</sup> Since medical or surgical intervention is not generally provided when the child's condition is hopeless, such as when the child has anencephaly, the amendment does not mandate that life be prolonged under these circumstances.

Like other legislative efforts, however, the Indiana amendment anticipates an oversimplified picture of decisionmaking in neonatology. In reaction against the Infant Doe incident, the amendment describes a specific fact situation, anticipating discrimination against a mentally or physically handicapped infant who also has an additional life threatening anomaly. Unfortunately, without specific knowledge of the Baby Doe case and the goal of the amendment, a court could have difficulty interpreting the language of the statute as a whole. It is possible that a court would interpret subsection (f) as a limitation rather than a clarification of subsection (a).

Ordinarily, subsection (f) would be interpreted as merely one fact situation that would trigger the child protection investigation procedure, since it contains the word "includes." According to principles of statutory construction, "[a] term whose statutory definition declares what it 'includes' is more susceptible to extension of meaning by construction than where the definition declares what a term 'means.' Thus, it has been said that the word 'includes' is usually a term of enlargement and not of limitation."<sup>224</sup> When section 3 is taken as a whole, however, the legislative intent with regard to the addition of subsection (f) could be unclear since subsection (a) covered the fact situation described in subsection (f) before the addition of subsection (f). Under subsection (a), a defective infant for whom life preserving treatment has been withheld is a "child . . . before his eighteenth birthday . . . [who] is seriously endangered as a result of the . . . refusal . . . of his parent . . . to supply the child with necessary food . . . [or] medical care . . . ."<sup>225</sup> Statutory parts should be interpreted, when possible, to avoid internal inconsistencies.<sup>226</sup> Given that subsection (f) restates more specifically a fact situation that was already covered under subsection (a), a court in ignorance of the Infant Doe case, might interpret the addition of subsection (f) narrowly, as an act of the legislature to proscribe in what circumstances it intends the definition of a "child in need of services" to apply.<sup>227</sup> This interpretation is all the more plausible given

---

222. See *Bloomington Herald-Telephone*, Apr. 7, 1983, at 1, col. 1.

223. IND. CODE ANN. § 31-6-4-3(f) (West Supp. 1983).

224. SANDS, *supra* note 213, § 47.07, at 82.

225. IND. CODE ANN. § 31-6-4-3(a)(1) (West Supp. 1983).

226. SANDS, *supra* note 213, § 46.05, at 56.

227. For example, a court could apply the following rules of statutory construction: "Where

the maxim of statutory interpretation, “the law favors a rational and sensible construction”<sup>228</sup> and “[a] statute is a solemn enactment of the state acting through its legislature and it must be assumed that this process achieves an effective and operative result. It cannot be presumed that the legislature would do a futile thing.”<sup>229</sup> To interpret the amendment adding subsection (f) other than as a limitation of subsection (a), and still construe the subsections rationally and as a whole, one would have to allow that subsection (f) is simply a restatement of subsection (a) and therefore redundant and futile.

Interpreting subsection (f) as a limitation of subsection (a), a court could conclude that the statute applies to handicapped children only in the specific circumstances enumerated in subsection (f). For example, a court may conclude that because a parent's failure to give her handicapped daughter antibiotics for an ear infection is not a “life threatening medical condition,” the statute is not intended to apply.<sup>230</sup> But if a handicapped child may now be deprived of necessary but not life-threatening medical care, the statute would offer handicapped children less protection than they enjoyed before the 1983 amendment was added.

More importantly, the phrase “if the nutrition or medical or surgical intervention is generally provided to similarly situated handicapped or non-handicapped children,”<sup>231</sup> renders a result inconsistent with the one intended. First, with regard to the phrase “similarly situated handicapped . . . children,” presumably the author of the amendment envisioned a case similar to the Infant Doe case, in which the child is mentally or physically handicapped and also has a life-threatening disorder such as a tracheoesophageal fistula. The amendment anticipates that a parent might discriminatorily refuse life-

---

there is an inescapable conflict between general terms or provisions of a statute and other terms or provisions therein of a specific nature, the specific will prevail and be given effect over the general.” *Id.* § 46.05, at 57. Moreover, in describing the principle “*expressio unis est exclusio alterius*,” Sands explains:

As the maxim is applied to statutory interpretation, where a form of conduct, the manner of its performance and operation, and the persons and things to which it refers are designated, there is an inference that all commissions should be understood as exclusions. . . . “Exceptions strengthen the force of the general law and enumeration weakens it as to things not expressed.”

*Id.* § 47.23, at 123.

228. *Id.* § 45.12, at 37. “It has been called a golden rule of statutory interpretation that unreasonableness of the result produced by one among alternative possible interpretations of a statute is reason for rejecting that interpretation in favor of another which would produce a reasonable result.” *Id.*

229. *Id.* § 45.12, at 37. “The presumption is that the lawmaker has a definite purpose in every enactment and has adapted and formulated the subsidiary provisions in harmony with that purpose; that these are needful to accomplish it; and that, if that is the intended effect, they will at least conduce to effectuate it.” *Id.* § 46.05, at 57.

230. This interpretation is even more convincing when one applies Indiana Code § 31-6-4-3(f) in conjunction with Indiana Code § 31-6-4-3(d). Section 3(d) states that if the parent or guardian fails to provide medical care for religious reasons when the life or health of the child is not in serious danger, a presumption arises that the child is *not* in need of services. Unless subsection (f) is interpreted narrowly, so that it only applies to life-threatening medical conditions, it could conflict with subsection (d) if the parents' reason for withholding treatment is due to their religious beliefs.

231. *Id.* § 3(f).

preserving medical or surgical intervention because the child is otherwise irreversibly handicapped. However, even though the child's prognosis is not hopeless, the amendment will not trigger an investigation if the nutrition or medical intervention would not "generally" be provided to infants with two congenital anomalies. In other words, if at Bloomington Hospital (where Infant Doe was born) a policy or trend exists whereby infants with these two handicapping disorders are allowed to die, then Infant Doe would still be allowed to die. The statute does not provide us with a definition of "generally provided." Does it mean generally provided in a particular hospital, in the state, in the geographic region? Given that there is no consensus among physicians regarding appropriate treatment in these cases, it could be meaningless to interpret "generally provided" to mean other than within the immediate hospital. Unfortunately, the amendment has the effect of reducing the protection granted to infants such as Infant Doe under the original Indiana law in hospitals where a policy exists against providing life-preserving therapy for a handicapped infant with a "life threatening medical condition."

It is also unclear from the statute what degree of similarity is necessary for two infants to be "similarly situated." Consider, for example, a premature infant afflicted with intracranial bleeding. To be workable, the phrase would have to be applied literally so that one is comparing an infant with intracranial bleeding with another infant with the same or a similar level of intracranial bleeding. One could not obtain appropriate guidance for a treatment decision by comparing an infant with mild intracranial bleeding with an infant with fatal intracranial bleeding or with an infant who had DiGeorge's syndrome. Moreover, the phrase "generally provided" indicates that the infant is to be treated according to the policy followed in that locality.

Finally, the Indiana statute, as well as the Louisiana and Arizona statutes could be vulnerable to a constitutional challenge. As was noted with regard to the HHS regulation, if these statutes are interpreted to prohibit parents from choosing the appropriate medical treatment for their infant in a situation where the bodily invasion is significant and the state's interest in preserving life is outweighed by the parents' right to privacy, they might be struck down as denying parents their right of privacy to make medical treatment decisions for their severely defective newborns.<sup>232</sup>

#### ALTERNATIVE LEGISLATIVE APPROACHES

Aside from the approaches taken by the proposed federal rule and the Louisiana, Arizona and Indiana statutes, a number of legislative alternatives have been proposed. The approach recommended by the *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research*<sup>233</sup> and by many members of the medical profession<sup>234</sup> is legislation

---

232. See *supra* text accompanying notes 187-201.

233. PRESIDENT'S COMMISSION, *supra* note 51, at 227.

234. See, e.g., Committee on Bioethics, *supra* note 141, at 566; Weir, *supra* note 68, at 663.

that would require hospitals to set up an "ethics committee" to review different treatment decisions involving defective newborns.

A hospital ethics committee could be structured in a variety of ways. First, the composition of the committee must be determined. It may be desirable to have persons from various professions, each representing a particular viewpoint, such as social workers, nurses, clergy, philosophers, as well as physicians and presumably the parents of the defective newborn. It has been suggested that a hospital ethics committee should have representatives from the community as part of its membership.<sup>235</sup> An ethics committee composed entirely of hospital personnel may fall prey to hospital politics and bureaucracy,<sup>236</sup> thereby reducing its effectiveness as an impartial decisionmaking body. Community involvement adds a lay person's perspective, making the decision more representative of a societal viewpoint.

Practical problems must be raised concerning the composition of the ethics committee. Certainly, the fewer persons sitting on such a committee, the easier it would be for the committee to meet on short notice without undue disruption of normal hospital routine. At least one physician must be present since much of the review will involve an analysis of the medical circumstances surrounding the case. As a practical matter, however, it may be difficult for a hospital to recruit physicians (and others for that matter) to donate their time to serve on such a committee since many physicians are extremely busy and have little free time. Moreover, few physicians have enough expertise in neonatology to render skilled judgments; for physicians other than pediatricians and family practitioners their latest experience with diagnosing and treating diseases of newborn infants may be early in their medical training, perhaps decades past. In addition, meeting on short notice, as would be required of a committee member, may be problematic for many medical professionals and others.<sup>237</sup>

Second, the committee's function must be determined. At least three separate functions are possible for an ethics committee: it could advise parents; it could be the final arbiter of the case; or it could simply review nontreatment decisions previously rendered by parents and physicians. It should be noted that the composition of the ethics committee would be affected by the function of the committee. For example, if the committee were created to be solely advisory in nature, it may not be necessary for the parents of the defective child to be members since the committee's function would be to gather information and make an impartial, expert conclusion based on the facts of the particular case. Presumably, after the committee reaches its conclusion, it

---

235. Strain, *supra* note 49, at 473.

236. See Robertson, *supra* note 50, at 265.

237. Many developmental abnormalities constitute neonatal emergencies. For these conditions "[t]he best prognosis depends on early diagnosis, speedy transport to a hospital where appropriate skills and equipment are available, and effective surgical management." P. JONES, CLINICAL PEDIATRIC SURGERY DIAGNOSIS AND MANAGEMENT 17 (2d ed. 1976). For example, the optimal age of the infant to repair esophageal atresia is one day old. *Id.* at 18.

would then assist the parents with their decisionmaking by presenting the parents with expert advice. If, however, the committee's function is to be the final arbiter of the case, it is logical for the parents to participate actively in the committee's deliberations since it is the parents who must eventually consent to or refuse life-preserving treatment.<sup>238</sup>

For the committee to be the "final arbiter" in this sense means that the decision of the committee represents the course of treatment or nontreatment that the hospital is willing to provide. If the parents refuse to comply with the decision reached by the committee, they must either transfer their infant to another hospital willing to follow the parents' choice of treatment or face their case being referred by the hospital to a local child protection agency or prosecutor if they leave their infant at the hospital.<sup>239</sup> As a practical matter, it may be impossible to transfer a critically ill newborn to another facility since the move itself may pose a threat to the infant's life. Such power on the part of the hospital could be perceived as coercive. Nevertheless, it should be noted that the actual occurrence of this scenario is not unlikely since the promulgation of the final HHS rule. Under the HHS rule, hospitals face the possibility of having their federal monies cut off if they have a policy of allowing nontreatment decisions within their facility that could be labeled "discriminatory."

Of course, such decisionmaking power would be curtailed if the function of the ethics committee were merely to review decisions previously rendered by physicians and parents of a handicapped newborn. A review could take the form of an immediate check on nontreatment decisionmaking; or it could constitute a post hoc, inhouse records review that takes place days, even weeks, after an actual decision is rendered. However, if the review is to provide any sort of protection against self-serving or inappropriate decisions, the committee must meet as quickly as possible after the nontreatment decision is reached in order to initiate a review or court action by the local child protection agency or prosecutor.

Finally, it must be determined when the ethics committee will be called into play. Will the committee meet each time a handicapped child with a life-threatening condition is born? When the parents and physician disagree regarding appropriate treatment? Only when a nontreatment decision has been reached? The *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* gives little guidance other than promoting the idea of case review by an ethics-type of hospital committee. The Commission states:

---

238. In fact, to deny patients input in the decisionmaking of their critically ill infant could constitute a violation of their right to privacy under certain circumstances. See generally *supra* text accompanying notes 187-201.

239. Given the frequency that costs of neonatal intensive care and therefore costs to society are mentioned with regard to the advisability of treatment, it is conceivable that an ethics committee could conclude that treatment is inappropriate, refusing to indulge the parents' wishes to treat the infant.



Such policies should provide for internal review whenever parents and the attending physician decide that life sustaining therapy should be foregone. Other cases such as when the physician and parents disagree, might well also be reviewed. The policy should allow for different types of review and be flexible enough to deal appropriately with the range of cases that could arise. . . . This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases.<sup>240</sup>

A hospital ethics committee would provide certainty in the law since physicians and parents would be protected from prosecution if they follow the ethics committee procedures outlined in the statute. Moreover, a hospital ethics committee allows flexibility and the opportunity for educated and well-reasoned input into a complicated situation. It could also be perceived, however, as a bureaucratic and cumbersome procedure. Even if the least intrusive function for the ethics committee were adopted, that of review after a nontreatment decision has been rendered, for reasons outlined earlier,<sup>241</sup> it may still be difficult to find qualified persons to serve on the committee or to convene the committee on short notice. The process necessarily takes time, time that may be critical for the handicapped infant denied life-preserving treatment that must be performed as soon as possible after birth, time that prolongs the anxiety of the parents and keeps health professionals from their normal routine.

More importantly, instituting a hospital ethics committee does not eliminate the problem of disparate decisionmaking. The physicians who originally acquiesce in the parents' nontreatment decision are likely to be the same physicians who serve on the ethics committee, presenting the medical aspects of the case from their own perspective. An infant with Down's syndrome and a tracheoesophageal fistula may be denied treatment in Bloomington, Indiana or in New Haven, Connecticut, while he may be aggressively treated in Indianapolis, Indiana or in Knoxville, Tennessee. As the President of the American Academy of Pediatrics noted, there is no consensus for the treatment of severely defective infants.<sup>242</sup> Therefore, even with community input on the committee, the decision to actively treat or deny life-preserving care will vary from locality to locality<sup>243</sup> depending on how "liberal" or "conservative" the community is with regard to nontreatment decisions.<sup>244</sup>

---

240. PRESIDENT'S COMMISSION, *supra* note 51, at 227.

241. See *supra* text accompanying note 237. This procedural difficulty is increased if the committee's duties extend to decisions regarding *all* nontreatment decisions, not just neonatal decisions.

242. Committee on Bioethics, *supra* note 141, at 565.

243. In fact, it is doubtful that consistent decisionmaking will even exist within a particular hospital since the physicians, such as the attending physician for the infant and parents, composing the committee may vary from case to case so that each will present the medical analysis from his own personal perspective.

244. Interestingly, proponents of the rights of handicapped infants have been labeled "the new right" by the press. Wall St. J., Aug. 30, 1983, at 24, col. 1. It is ironic that the conservatives are perceived as advocates of the rights of handicapped infants and liberals as the opponents, in that they favor a "pro-choice" perspective and therefore oppose restrictions on nontreatment

One proposed model statute alleviates this problem of disparate decision-making somewhat by adding another layer of bureaucracy into the ethics committee procedure. In his article entitled *Medical Treatment of Defective Newborns: An Answer to the 'Baby Doe' Dilemma*,<sup>245</sup> Robyn Shapiro suggests that certain nontreatment decisions reached by an ethics committee be reviewed by a "Medical Treatment Panel," which will render a final decision reviewable only by a state court.<sup>246</sup> Depending upon how many panels an "appropriate number of Medical Treatment Panels"<sup>247</sup> is determined to be, such a procedure could conceivably achieve consistent decisionmaking within the jurisdiction of each particular medical treatment panel.

A number of authors also suggest that providing better information will help to ensure fairness in nontreatment decisionmaking regarding handicapped newborns. For example, Carol Lynn Berseth, a neonatologist who advocates the use of hospital ethics committees, stresses the importance of education:

Parents and policy makers need to be aware of the spectrum of birth defects that occur, the longitudinal outcome of these infants, the technical support that can feasibly be offered to defective infants, as well as the emotional, physical, and financial costs of acute and chronic care for those infants. Parents can receive intensive specific education at the time they are faced with a single ethical decision.<sup>248</sup>

The Arizona statute mandates that parents receive information regarding support services available for handicapped persons.<sup>249</sup> Clinical information, suggested by Dr. Berseth, could be supplied as well. Dr. Berseth also proposes that physicians receive a formal education in this area. "The establishment of courses in medical school curricula to educate students in the bioethical and humanistic aspects of medical care should be commended and further encouraged."<sup>250</sup> Like the ethics committee alternative, mandatory education allows much flexibility. But information alone does not promote either consistency in decisionmaking or certainty in the law; in fact it provides no safeguard against inappropriate decisionmaking.

Unlike these first alternatives, which are directed toward the decisionmaking process itself, the next four alternatives are directed toward identifying a class of infants for whom treatment may be lawfully withheld. T.S. Ellis, in his article *Letting Defective Babies Die: Who Decides?*<sup>251</sup> proposes that

---

decisionmaking. Ordinarily, it is the liberals who favor rights for handicapped and other "disadvantaged" individuals. Nevertheless, no liberal editorialists have written in defense of the handicapped infants who are being discriminated against in some nontreatment decisionmaking.

245. Shapiro, *Medical Treatment of Defective Newborns: An Answer to the "Baby Doe" Dilemma*, 20 HARV. J. ON LEGIS. 137 (1983).

246. *Id.* at 150-51.

247. *Id.* at 151.

248. Berseth, *supra* note 51, at 429.

249. ARIZ. REV. STAT. ANN. § 36-2283 (West Supp. 1983).

250. Berseth, *supra* note 51, at 429.

251. Ellis, *supra* note 50.

legislators list, on the basis of expert testimony, the various defective newborn conditions that present treatment dilemmas, in addition to categories of treatment in order of ascending complexity and expense, on a graph called a decision matrix.<sup>252</sup>

This matrix would presumably identify the serious newborn conditions that give rise to difficult treatment decisions as well as other areas indicating the need for legislation.<sup>253</sup> Such a proposal would allow little flexibility, since permissible nontreatment areas would be specifically designated and could only be altered to reflect advances in technology by amendments to the statute. It would, however, provide consistent decisionmaking and certainty. Nevertheless, it is doubtful that such a project could be completed. As was outlined earlier, given that there are several thousand possible congenital anomalies in addition to inherited metabolic diseases and congenital infections, some of which may occur in conjunction with a congenital anomaly, the likelihood of accurately legislating all the possible malformations and acceptable treatment decisions is slim.

John Robertson in his article *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*<sup>254</sup> also attempts to establish criteria to identify the class of infants for whom treatment may be withheld. Robertson suggests that:

[T]he risks of delegating treatment discretion to parents, physicians, or committees can be . . . lessened if specific criteria are developed to describe defective characteristics and the familial or institutional situations in which treatment may be withheld from defective infants. If recognized by the courts or legislature, such criteria would represent a collective social judgment, rather than idiosyncratic choices of parents and committees, as to when social costs outweigh individual benefits.<sup>255</sup>

In a footnote Robertson also suggests:

A better situation might be to constitute formally a decisionmaking body with medical community and lay representation . . . and delegate to it the development of the appropriate criteria and relevant clinical indicators. To prevent obsolescence in the criteria, and to monitor for the extent of nontreatment and the effectiveness of developed standards, the body could be permanently constituted and perform similar functions with regard to other biomedical problems.<sup>256</sup>

If the second of Robertson's proposals were adopted, the criteria would be flexible, unlike Ellis' decision matrix, since the established decisionmaking body would alter the criteria to reflect advances in medical technology and surgical techniques. Moreover, it would establish consistency in decisionmaking and certainty in the law. Physicians and parents who followed the criteria adopted by the decisionmaking body in their nontreatment decisionmaking

---

252. *Id.* at 419.

253. *Id.*

254. Robertson, *supra* note 50.

255. *Id.* at 266.

256. *Id.* at 266 n.276.

would be free from fear of prosecution. Like Ellis' proposal though, it is doubtful that specific criteria could be outlined in a complete and yet workable manner, even by a decisionmaking body composed of experts in neonatology.<sup>257</sup> Even if these experts could agree on a solution to each case with all of its possible variables, such criteria would be too cumbersome to be used by physicians or parents. It would be unreasonable to expect a physician to thumb through pages of text in an attempt to find his particular patient—a blind Down's syndrome infant with a gastrointestinal infection.

A simpler mechanism for isolating individuals who are eligible for this sort of nontreatment decision is proposed by E.H.W. Kluge in his article *The Euthanasia of Radically Defective Neonates: Some Statutory Considerations*.<sup>258</sup> Kluge proposes that a brain-death type of analysis be applied to cases involving defective newborns in order to determine if the defective newborn is a "person."<sup>259</sup> Kluge argues "human beings" may be distinguishable from "persons;" while the term "human being" has essentially biological import, the term "person" is associated with "the concept of being with conscious awareness: of a morally responsible agent."<sup>260</sup> Kluge, therefore, attempts to clarify this distinction by legislatively defining the term "person" to be

any biological entity of the species homo sapiens that possesses the present functional capability for conscious awareness, or any human being whose cerebrum is structurally sufficiently like that of a normal adult human being that, if it were fully operational without structural change, it would evince neurological activity of the same nature as that of a normal adult human being<sup>261</sup>

whereas, the term "human being" is defined as "any living biological entity that is a member of the species homo sapiens."<sup>262</sup>

While Kluge's proposal might eliminate disparate decisionmaking and provide clear guidance for physicians and parents involved in nontreatment decisionmaking, it is extremely limited.<sup>263</sup> First, it is difficult to argue seriously that a handicapped newborn human being is not a "person." True, some handicapped newborns will have no concept of self and no ability to desire rights,<sup>264</sup> but to claim that some handicapped newborns are not persons, deserving of human rights, is dangerous because it is difficult, even impossible, to

---

257. Robertson uses the word "standards," *id.*, so that it is not clear if he means that specific cases or merely broad guidelines should be identified. Nevertheless, in text he uses an extremely specific example to identify a basis for developing criteria, *id.* at 267, so he seems to mean that specific cases or conditions would constitute appropriate criteria.

258. Kluge, *The Euthanasia of Radically Defective Neonates: Some Statutory Considerations*, 6 DALHOUSIE L.J. 229 (1980).

259. *Id.* at 246-49.

260. *Id.* at 245.

261. *Id.* at 252. Presumably Kluge's use of the words "fully operational" means "fully mature," in the context of infant brain development structure.

262. *Id.*

263. Because Kluge's standard is essentially death of the infant, it is unlikely that it will become obsolete with the advances of medical technology. Nothing can be done medically for a braindead infant.

264. See generally W. REICH, *supra* note 70, at 723-35.

predict the mental and physical potential of handicapped infants at birth. In addition, under Kluge's proposal, the only infants for whom life-saving medical treatment may be withheld are those who have serious neurological disorders. For example, treatment could be withheld from infants with anencephaly, hydrocephaly, holoprosencephaly, and from infants with severe intracranial bleeding or serious congenital brain infections but not from extremely premature infants suffering multiple complications or from infants with hopeless conditions such as DiGeorge's Syndrome or Potter's Syndrome. In short, Kluge's proposal is too inflexible to cover cases of infants with hopeless, but non-neurological, conditions for whom prolonged treatment means prolonged suffering.

A proposal in a note by Elizabeth MacMillan also identifies a class of defective infants for whom treatment may be withheld,<sup>265</sup> but the standard she advocates differs markedly from the previously discussed proposals. This is because all of the other proposals are based on a quality-of-life analysis. For example, even Robertson, who is critical of attempts to define a quality of life<sup>266</sup> or to determine which human offspring are "persons,"<sup>267</sup> suggests the development of criteria that might find that certain multiple-handicapped infants have a life not worth living such that they are "not owed ordinary treatment."<sup>268</sup> Ellis and Kluge specifically mention a quality-of-life judgment entering into their respective criteria, Ellis with his inclusion of the category "Quality of Life and Care Provided" in the decision matrix<sup>269</sup> and Kluge with his distinction between "human beings" and "persons."<sup>270</sup>

MacMillan, on the other hand, attempts to develop a standard that satisfies three criteria:

First, the standard should protect the best interests of the child and accommodate the interests of the other participants insofar as they are compatible with those of the child. Second, the system should provide certainty and consistency of application in line with legal doctrine, yet retain enough flexibility to handle unforeseeable situations. Finally, the standard should not undermine widely held moral values of our society: the sanctity of life, the equal right of all citizens to life and medical treatment, and the duty of society to protect the weak and the helpless.<sup>271</sup>

MacMillan rejects the quality-of-life standard as not satisfying these three criteria<sup>272</sup> and instead promotes a medical feasibility standard whereby a treatment may only be withheld from a handicapped infant "if it cannot benefit the infant—that is, if the treatment inevitably will prove futile once ad-

---

265. Note, *supra* note 77.

266. Robertson, *supra* note 50, at 252-55.

267. *Id.* at 246-51.

268. *Id.* at 267.

269. Ellis, *supra* note 50, at 420.

270. Kluge, *supra* note 258, at 252.

271. Note, *supra* note 77, at 619-20.

272. *Id.* at 620-23.

ministered or will cause the infant's condition to deteriorate."<sup>273</sup> Thus the only infants for whom treatment may be withheld are those who cannot benefit from treatment. As was outlined previously, HHS uses this standard in their January 12 final rule.<sup>274</sup>

Like Kluge's proposal, this standard is narrow. However, it provides a mechanism for consistent decisionmaking and certainty in the law without sacrificing flexibility. It is true that physicians differ with regard to what treatment they would term "beneficial" to patients. A person who believes a Down's syndrome infant is better off dead is unlikely to promote repair of esophageal atresia as being "beneficial" from a quality-of-life perspective. From a medical perspective, however, any physician would be hard pressed to claim that surgically repairing the esophageal malformation is not medically beneficial to the infant since the surgery will greatly reduce the chance of aspiration and will certainly lengthen the expected lifespan of the infant. Disparate decisions may still exist in areas where physicians disagree about an infant's terminal prognosis. For example, one physician may immediately withhold treatment for a severely handicapped premature infant with intracranial bleeding, while another physician may first attempt to treat the intracranial bleeding before withdrawing treatment upon recognition that further treatment is futile. Nevertheless, a medical feasibility standard will prevent situations such as the case of Infant Doe where treatment was clearly medically beneficial to the infant. Moreover, the medical feasibility standard is broad enough to avoid becoming obsolete as medical technology progresses; the age and weight at which premature infants are treated may become younger and smaller as medical procedures advance, but a concept defining the point at which treatment is "beneficial" will still be relevant.

Finally, several authors also suggest that specifically outlining decisionmaking procedures, in addition to establishing a standard, will yield more consistent treatment decisions. Robertson, for example, suggests that attending physicians be required to follow specified procedures such as stating in writing their reasons for withholding treatment.<sup>275</sup> He also suggests the establishment of a post hoc review of all nontreatment decisionmaking.<sup>276</sup> Similarly, Mac-Millan, in addition to her medical feasibility standard,<sup>277</sup> suggests a somewhat cumbersome procedure requiring initial verification by physicians of the existence of a condition where treatment will not benefit the infant.<sup>278</sup> These procedures could be improved by requiring that at least two physicians licensed to practice pediatrics verify the diagnosis and prognosis and then state in writing their reasons for making the determination that further treatment will not

---

273. *Id.* at 623.

274. *See supra* text accompanying notes 145-49.

275. Robertson, *supra* note 50, at 267.

276. *Id.*

277. Note, *supra* note 77, at 627-32.

278. *Id.* at 628-29.

medically benefit the patient.<sup>279</sup> An ethics committee could be established to meet periodically to review nontreatment decisions and judicial intervention would only be necessary if the parents refuse treatment without the medical nonfeasibility diagnosis. Another procedure that would add fairness and compassion to the decisionmaking process is the addition of a mechanism to facilitate the parents' ability to give up custody of the child to the state.<sup>280</sup> As Robertson points out, "while parental discretion to terminate the parental relationship may be justified, it does not follow that parents should also have the right to decide whether the child lives or dies."<sup>281</sup> Statutes should include procedures for parents to give up custody of the child in the event that treatment is still medically feasible for the child, but the parents do not feel they can financially or emotionally cope with raising a handicapped child.<sup>282</sup>

The optimal legislative route is dependent upon the legislator's ultimate goal for the legislation. Those who find a quality-of-life analysis appropriate should choose a flexible procedure, such as the ethics committee approach without additional restrictive standards. If the committee meets immediately after a nontreatment decision is rendered it can reverse an obviously inappropriate decision while generally allowing parents and physicians much freedom to decide which infants have a quality of life worth preserving. Without some objective standard to guide the committee's deliberations, this procedure would not necessarily curtail disparate decisionmaking in the least. It would allow, however, for consideration of the family's financial and emotional circumstances, as well as the personal views of the physician and parents. Those who oppose a quality-of-life analysis would favor the imposition of an objective standard, such as the medical feasibility standard, because such a standard is flexible enough to reflect advances in medical technology but not so flexible as to facilitate nontreatment decisions based on subjective views of the infant's or the family's quality of life.

### CONCLUSION

In reaction to the Infant Doe case that occurred in Bloomington, Indiana, a federal regulation has been promulgated and three state statutes were passed. Because of the complexity of neonatology and therefore the extreme difficulty in drafting good legislation in this area, each of the promulgated or enacted attempts are replete with problems. While the federal rule provides flexibility

---

279. Such a procedure would prevent obstetricians from being the "expert" presenting the medical prognosis for the infant, which is what occurred in the Infant Doe case.

280. This mechanism is present in the Louisiana statute. LA. REV. STAT. ANN. § 40:1299.36.2.A (West Supp. 1983). Under the Louisiana statute, however, nonindigent parents must reimburse the state for the cost of care.

281. Robertson, *supra* note 50, at 263.

282. The children could then be put up for adoption or placed in foster homes, if possible. However, the reality of a future for these infants should not be overlooked. See Glick, *Pediatric Nursing Homes*, 309 NEW ENG. J. MED. 640 (1983).

and consistency of decisionmaking, it is an overly intrusive and cumbersome procedure. Similarly, although the Louisiana and Arizona statutes may provide some degree of certainty in the law and consistency of decisionmaking, they are extremely inflexible, and therefore do not adequately resolve the nontreatment dilemmas present in neonatology. The Indiana statute, while attempting to add certainty to the law, consistency of decisionmaking, and flexibility, succeeds only in confusing existing law.

Of the alternative legislative solutions proposed, only two are truly workable. Legislation could require that some sort of hospital ethics committee be established to review nontreatment decisions. Alternatively, a medical feasibility standard could be imposed on the decisionmaking process in order to identify the group of handicapped infants for whom treatment may be lawfully withheld. The first alternative offers little control over disparate decisionmaking but some degree of certainty in the law and much flexibility, allowing the possibility of considerations of the infant's quality of life as well as the family's circumstances to enter into the decisionmaking deliberations. The second alternative provides certainty in the law as well as consistency of decisionmaking but is only flexible in the sense that it will easily respond to advances in medical technology; it specifically disallows a quality of life analysis. The legislative response deemed preferable will depend on the legislator's moral, ethical and philosophical leanings regarding the treatment of handicapped newborns.

Freedom in personal decisionmaking is an extremely important right and one that has been recognized by the Supreme Court.<sup>283</sup> However, the law has traditionally protected the weak; legislation specifically protects the rights of handicapped persons.<sup>284</sup> Certainly, a handicapped newborn is among the weakest, most vulnerable persons in our society. His only natural guardians, his parents, are the very persons most threatened by his existence since he represents for them an undeniable financial and emotional burden. If his parents fail to seek his best interests, no one else exists who might naturally intervene; no one else could possibly know this child other than the physician. Given the increasing costs of medical care, it becomes progressively more tempting for us, as a society, to decide medical matters from purely utilitarian perspectives; to decide not to incur the substantial financial burden of another handicapped child who will never "contribute" to society. We may do this blatantly by enacting legislation facilitating nontreatment decisions without adequate standards or review; or we may be more subtle, restricting federal reimbursement programs such as Medicare or Medicaid so that they do not finance medical treatments for certain handicapped infants.<sup>285</sup>

---

283. For a discussion regarding the parents' right to privacy, see *supra* text accompanying notes 187-201.

284. See, e.g., Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1976).

285. Subtle, indirect discrimination can be equally dangerous. Our nation is preoccupied with health care costs and is attempting to reduce health care expenses in various areas. One of the most recent attempts by the federal government to reduce health care costs is the promulgation of Diagnosis-Related Groups (DRGs). This is a new system of reimbursement to health care



We treat handicapped infants differently than we treat others; terminally ill cancer patients are not ordinarily starved and dehydrated, even if their condition is determined to be hopeless. Nor do we allow the husband of a woman neurologically crippled with multiple sclerosis to starve or dehydrate his wife.<sup>286</sup> It has been argued that it is appropriate to treat handicapped infants differently because they are not really "persons."<sup>287</sup> Such a distinction is extremely dangerous for at least two reasons. First, it is difficult, if not impossible, to determine accurately the future potential or limitations of a handicapped person at birth. Second, history has taught us that inhuman deeds can be committed against those labeled "nonpersons."<sup>288</sup> Even John Stuart Mill, perhaps the most famous defender of utilitarianism and personal freedom, particularly freedom to frame one's own life plan, stated:

The sole end for which mankind [is] warranted, individually or collectively, in interfering with the liberty of action of any of their number is [that of] self protection . . . [T]he only purpose for which power can be rightfully exercised over any member of a civilized community against his will is to prevent harm to others.<sup>289</sup>

Obviously, a handicapped newborn should be considered a person—a "member of a civilized community" who poses no threat to others, but who himself is in need of protection. Surely it is wrong to allow him to be harmed simply because he does not contribute to the gross national product.

---

providers which will be phased-in over the next three years. The concept involves changing the method of federal medicare payment for inpatient hospital services from a cost-based, retrospective reimbursement system to a prospective payment system based on diagnosis. 49 Fed. Reg. 234, 234 (1984) (to be codified at 42 C.F.R. pts. 405, 409 & 489) (final Jan. 3, 1984). Hospitals subject to this prospective payment system will be paid a specific amount for each discharge based on the individual case's classification into one of 468 DRGs, regardless of the actual cost incurred per case. *See generally id.* at 243-49. According to HHS Secretary Margaret Heckler, this system gives hospitals an incentive to increase admissions and discharge patients early. American Medical News, Dec. 16, 1983, at 1, col. 2. Although the DRG prepayment system is not intentionally discriminatory toward handicapped newborns, it indirectly encourages discrimination. Of the 468 DRGs, only seven apply to infants. 48 Fed. Reg. 39,876, 39,884 (1983). Of these seven, one is "dead or transferred" neonate. *Id.* Moreover, the longest period for which even the most seriously ill newborn may be placed in the hospital under a DRG category is 38 days. *Id.* Infants who exceed this "outlier cutoff" period become a financial albatross for the hospital because a hospital has little hope for recovering the additional costs incurred by an extended, expensive hospitalization. This is because hospitalization for these infants is likely to exceed 38 days and hospitals are limited in the number of "outliers" they can claim. Undoubtedly, physicians will be under pressure from hospitals to minimize costs so that infants who require extensive and most probably unreimbursable care are placed in a compromised position.

286. In fact, two physicians who terminated life support, including nutrition and fluids, for a nearly braindead comatose patient were charged with murder. American Medical News, Sept. 16, 1983, at 1, col. 1. The charge was later vacated. American Medical News, Oct. 28, 1983, at 1, col. 1.

287. *See, e.g.,* Robertson, *supra* note 50, at 246-51; W. REICH, *supra* note 70, at 727.

288. The first to be killed in the "killing centers" in Nazi Germany were the aged, the infirm, the senile, and mentally retarded and defective children. *See* Alexander, *Medical Science Under Dictatorship*, 241 NEW ENG. J. MED. 39 (1949).

289. J.S. MILL, ON LIBERTY 10 (D. Spitz ed. 1975).