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## **“New” Rights for Handicapped Newborns: Baby Doe and Beyond**

### INTRODUCTION

“[P]arents wouldn’t be killing their own baby if it weren’t for the baby’s own good.”<sup>1</sup> The article over which that caption appears is part of the recent national debate concerning withholding food and medical treatment from handicapped infants. The emotional issues involved have pitted the Reagan administration, championing the rights of the handicapped, against almost the entire medical community.

Public and governmental concern culminated in the passage of the “Child Abuse Amendments of 1984” [hereinafter referred to as Amendments].<sup>2</sup> The Amendments to the Child Abuse Prevention and Treatment Act<sup>3</sup> were signed into law on October 9, 1984 by President Reagan. Under the Amendments, states are required to adopt procedures that allow child protective service agencies to “pursue any legal remedies, including the authority to initiate legal proceedings . . . as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.”<sup>4</sup> Further, the definition of child abuse is expanded to include medical neglect.<sup>5</sup> The only situations not included in that definition are those when, in the treating physicians “reasonable medical judgment,” the infant is irreversibly comatose or the treatment would merely prolong dying, be ineffective, futile or inhumane.<sup>6</sup>

The purpose of this Comment is to focus on the rights of the parents and infant when non-treatment decisions are made, as well as to explore the perceptions of the medical community concerning those rights.

### I. GETTING THE PUBLIC’S ATTENTION

The difficult decision whether to save handicapped infants has

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1. The Village Voice, Nov. 13, 1984, at 8, col. 2.

2. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 101, 98 Stat. 1749 (1984) (to be codified as amended at 42 U.S.C. §§ 5101-06).

3. 42 U.S.C. §§ 5101-06 (1982).

4. U.S. Code Cong. Ad. News (98 Stat.) 1749, 1752-53 (to be codified as amended at 42 U.S.C. § 5103).

5. *Id.* at 1752.

6. *Id.*

been an issue in the medical community for many years.<sup>7</sup> Recently, modern medicine has enabled doctors to save infants who in previous times were considered hopeless.<sup>8</sup> However, the practice of euthanasia in the nursery rooms has continued on a "relatively large scale without much public notice or concern because it [is] typically a 'low visibility' physician's decision."<sup>9</sup> Such practices are obscured from the public's view because "[o]nly the health professionals involved [know] of the decision not to treat, and they [are] all in agreement with the practice. . . . 'Doctors have long withheld life-saving medical support from grossly malformed infants, allowing them to die at birth and often only telling the parents that their babies were stillborn.'"<sup>10</sup>

In the early 1970's, media attention was focused on two incidences of non-treatment at Johns Hopkins University Hospital. One of these was reported in the *Washington Post* as follows:

For fifteen days—until he starved to death—the newborn infant lay in a bassinet in a back corner of the nursery at the Johns Hopkins University Hospital. A sign said "Nothing by mouth."

The baby's life could have been saved by a simple operation to correct the intestinal blockage that kept him from digesting any food.

But because he was born a mongoloid, the parents refused to give the hospital permission to operate. And without that permission, the doctors said they had no legal right to perform the operation.<sup>11</sup>

In 1972, the second incident at Johns Hopkins came to light, this time involving a child born with Down's syndrome.<sup>12</sup> The child suffered from an intestinal blockage and the parents refused to consent to corrective surgery.<sup>13</sup> Doctors at the hospital unsuccessfully sought a court order permitting them to perform the surgery.<sup>14</sup> "Thereafter, all supportive therapy, including intravenous feeding,

7. Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. MED. 393, 398 (1982).

8. *Id.*

9. *Id.*

10. *Id.*; see also Time, Mar. 25, 1974, at 84.

11. Ellis, *supra* note 7, at 399. See also *Washington Post*, Oct. 15, 1971, at A1, col. 1.

12. Down's syndrome is reported by Ellis to be a: [C]ondition [of] chromosomal abnormality producing mental retardation of various degrees. The mental retardation can be severe. . . . Often . . . it is accompanied by serious heart and bowel defects that mandate surgical intervention to avoid the death of the neonate. If surgical measures are taken, newborns with Down's Syndrome accompanied by heart defects or bowel obstructions have life expectancies slightly shorter than normal (40-60 years).

Ellis, *supra* note 7, at 396.

13. Ellis, *supra* note 7, at 400.

14. *Id.*

was discontinued and the infant eventually succumbed to dehydration."<sup>15</sup> This second incident provided an impetus to form a "God Committee" at Johns Hopkins to review the treatment decisions in similar cases.<sup>16</sup> Such cases, while capturing the public spotlight, were not rare at the time. The physician in charge of the first incident mentioned above was reported to have stated that "[s]imilar life and death decisions are made at least twice a week at the hospital."<sup>17</sup>

Open acknowledgment that selective non-treatment decisions were being made by the medical community occurred in 1973. Duff and Campbell reported in the *New England Journal of Medicine* that:

After careful consideration of each of these 43 infants, parents and physicians in a group decision concluded that prognosis for meaningful life was extremely poor or hopeless, and therefore rejected further treatment. The awesome finality of these decisions, combined with a potential for error in prognosis, made the choice agonizing for families and health professionals.<sup>18</sup>

Public attention next focused on the issue in 1975-76. This time the issue was not framed in terms of non-treatment of a newborn, rather it was framed in terms of the right to die. At the center of the case was Karen Ann Quinlan.<sup>19</sup> On April 15, 1975, Karen Quinlan stopped breathing for at least two fifteen-minute periods.<sup>20</sup> She was taken to the hospital in a comatose condition.<sup>21</sup> A physician who examined her stated that she was in a "chronic persistent vegetative state."<sup>22</sup>

Karen's father, Joseph Quinlan, sought to be appointed as his daughter's guardian with the express power to authorize the discontinuance of "all extraordinary medical procedures . . . sustaining Karen's vital processes and hence her life."<sup>23</sup> The New Jersey Supreme Court pointed out that although Karen was "irreversibly doomed to [be] no more than a biologically vegetative remnant of life,"<sup>24</sup> she still had a constitutional right of privacy to personally decide upon continuance of the life-support apparatus.<sup>25</sup>

Indeed, the medical community was opposed to the removal of

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15. *Id.*

16. *Id.*

17. *Id.* at 399.

18. Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 N. ENGL. J. MED. 890 (1973).

19. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

20. *Id.* at 23, 355 A.2d at 653-54.

21. *Id.* at 23, 355 A.2d at 654.

22. *Id.* at 24, 355 A.2d at 654.

23. *Id.* at 18, 355 A.2d at 651.

24. *Id.* at 38, 355 A.2d at 662.

25. *Id.* at 39, 355 A.2d at 663.

the respirator sustaining Karen's life. Specifically, although the doctors and medical experts testified that Karen retained only a vegetative function of her brain,<sup>26</sup> they noted that the presence of a vegetative function meant that the brain was not biologically dead, according to the report of the Ad Hoc Committee of the Harvard Medical School.<sup>27</sup>

In addressing the issue of Karen's right to privacy, the court stated:

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not alter-

26. *Id.* at 24, 355 A.2d at 654.

We have an internal vegetative regulation which controls body temperature which controls breathing, which controls to a considerable degree blood pressure, which controls to some degree heart rate, which controls chewing, swallowing and which controls sleeping and waking. We have a more highly developed brain which is uniquely human which controls our relation to the outside world, our capacity to talk, to see, to feel, to sing, to think. Brain death necessarily must mean the death of both of these functions of the brain, vegetative and the sapient. Therefore, the presence of any function which is regulated or governed or controlled by the deeper parts of the brain which in laymen's terms might be considered purely vegetative would mean that the brain is not biologically dead.

*Id.*

27. *Id.* at 27, 355 A.2d at 656. The court, partially quoting the 1968 report of the Ad Hoc Committee of the Harvard Medical School, noted that:

From ancient times down to the recent past it was clear that, when the respiration and heart stopped, the brain would die in a few minutes; so the obvious criterion of no heart beat as synonymous with death was sufficiently accurate. In those times the heart was considered to be the central organ of the body; it is not surprising that its failure marked the onset of death. This is no longer valid when modern resuscitative and supportive measures are used. These improved activities can now restore "life" as judged by the ancient standards of persistent respiration and continuing heart beat. This can be the case even when there is not the remotest possibility of an individual recovering consciousness following massive brain damage. ["A Definition of Irreversible Coma," 205 *J. A. M. A.* 337, 339 (1968)].

The Ad Hoc standards, carefully delineated, included absence of response to pain or other stimuli, pupillary reflexes, corneal, pharyngeal and other reflexes, blood pressure, spontaneous respiration, as well as "flat" or isoelectric electroencephalograms and the like, with all tests repeated "at least 24 hours later with no change." In such circumstances, where all of such criteria have been met as showing "brain death," the Committee recommends with regard to the respirator:

The patient's condition can be determined only by a physician. When the patient is hopelessly damaged as defined above, the family and all colleagues who have participated in major decisions concerning the patient, and all nurses involved, should be so informed. Death is to be declared and *then* the respirator turned off. The decision to do this and the responsibility for it are to be taken by the physician-in-charge, in consultation with one or more physicians who have been directly involved in the case. It is unsound and undesirable to force the family to make the decision. [205 *J. A. M. A.*, *supra* at 338 (emphasis in original)].

*Id.* at 27-28, 355 A.2d at 656-57.

ing the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon the discontinuance of the life-support apparatus, even if it meant the prospect of natural death.<sup>28</sup>

The court countered the state's claim that it had an overriding interest in the preservation of life by noting that Karen's situation differed from others for whom medical treatment had been ordered. The court explained that those cases involved a minimal bodily invasion and the chances of recovery were very good. Karen's condition, on the other hand, required a great bodily invasion and her prognosis was poor. In the latter case, the court reasoned, the state's interest "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately, there comes a point at which the individual's rights overcome the State interest."<sup>29</sup>

As such, the court stated that it had no hesitancy in deciding "that no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life."<sup>30</sup>

The court then discussed the major constitutional cases dealing with the right to privacy.<sup>31</sup> Relying on *Roe v. Wade*,<sup>32</sup> the court stated that "[p]resumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions."<sup>33</sup>

Thus affirming Karen's independent right of choice, the court next considered whether Joseph Quinlan could assert his daughter's right of privacy. It stated:

Our affirmation of Karen's independent right of choice, however, would ordinarily be based upon her competency to assert it. The sad truth, however, is that she is grossly incompetent and we cannot discern her supposed choice based on the testimony of her previous conversations with friends, where such testimony is without sufficient probative weight. 137 *N.J. Super.* at 260. Nevertheless we have concluded that Karen's right of privacy

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28. *Id.* at 39, 355 A.2d at 663.

29. *Id.* at 40-41, 355 A.2d at 664-65.

30. *Id.* at 39, 355 A.2d at 663.

31. *See, e.g.*, *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Stanley v. Georgia*, 394 U.S. 557 (1969); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

32. *Roe v. Wade*, 410 U.S. 113 (1973).

33. *Quinlan*, 70 N.J. at 40, 355 A.2d at 663 (citing *Roe v. Wade*, 410 U.S. 113, 153 (1973)).

may be asserted on her behalf by her guardian under the peculiar circumstances here present.

. . . The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances.<sup>34</sup>

In regard to Joseph Quinlan's right of privacy in the matter, the court determined that there was no parental constitutional right on which to base the power to discontinue the respirator.<sup>35</sup> The only cases recognizing parental rights of privacy have, the court noted, dealt with the rearing of children and "continuing life styles."<sup>36</sup>

Following the *Quinlan* case, a number of states enacted "Natural Death Acts."<sup>37</sup> These acts allowed a person to sign a declaration stating that life sustaining measures should not be taken in case of terminal illness. They did not, however, deal with the termination of food or life support of a newborn infant. In April of 1982, that issue was once again brought to the attention of the American public.

A baby boy born in Bloomington, Indiana, became known to the outside world as Baby Doe.<sup>38</sup> The infant was born with Down's syndrome and a tracheoesophageal fistula.<sup>39</sup> This blockage of his digestive tract precluded normal feeding.<sup>40</sup> It was, however, surgically correctable.<sup>41</sup> Physicians at the hospital presented the parents of the infant with two treatment options, either: (1) begin intravenous feedings and prepare for possible surgical repair of the esopha-

34. *Id.* at 41, 355 A.2d at 664.

35. *Id.* at 42, 355 A.2d at 664.

36. *Quinlan*, 70 N.J. at 42, 355 A.2d at 664 (citing *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923)).

37. See ALA. CODE §§ 22-8A-1-10 (1984); ARK. STAT. ANN. §§ 82-3801-04 (Supp. 1983); CAL. HEALTH AND SAFETY CODE §§ 7185-95 (Deering 1985); DEL. CODE ANN. tit. 16 §§ 2501-08 (1983); D.C. CODE ANN. § 6-2401 (Supp. 1984); IDAHO CODE §§ 39-4501-08 (Supp. 1984); KAN. STAT. ANN. §§ 65-28,101-09 (1980); NEV. REV. STAT. §§ 449,540-90 (1979); N.M. STAT. ANN. §§ 24-7-1-11 (1981); N.C. GEN. STAT. §§ 90-320-22 (Supp. 1983); OR. REV. STAT. §§ 97.050-90 (1983); TEX. CIV. CODE ANN. 4590h (Vernon Supp. 1985); VT. STAT. ANN. tit. 18, §§ 5251-62 (Supp. 1984); VA. CODE §§ 54-325.8:1-12 (Supp. 1984); WASH. REV. CODE ANN. §§ 70.122.010-905 (Supp. 1985).

38. *In re Infant Doe*, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *writ of mandamus dismissed sub. nom.*, *Indiana ex rel. Infant Doe v. Baker*, No. 482-S-140 (Ind. May 27, 1982) (case mooted by child's death). The court records have been sealed in this case. Much of the information available comes from medical sources.

39. Pless, *The Story of Baby Doe*, 309 NEW. ENG. J. MED. 664 (1983). The term tracheoesophageal fistula is defined as a "congenital abnormality involving a communication between the trachea and esophagus; often associated with esophageal atresia. . . ." STEDMAN'S MEDICAL DICTIONARY 536 (5th ed. 1982).

40. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 397 (1983).

41. *Id.*

gus, or (2) do nothing but provide palliative care.<sup>42</sup> The parents refused to authorize surgery and the child was not fed intravenously.<sup>43</sup> Rather, the child was placed on phenobarbital and morphine, as needed, for pain and restlessness.<sup>44</sup>

Hospital administrators, once they learned of the decision, became concerned about civil and criminal liability. On April 10, 1982, the hospital administrators requested that a state court judge review the legality of the parents' and physicians' decision.<sup>45</sup> The judge decided that there were no legal ramifications regarding the decision not to treat or feed the infant.<sup>46</sup> Nevertheless, on April 13, the judge appointed a private guardian for Baby Doe.<sup>47</sup>

The first action taken by Baby Doe's guardian and the local prosecutor was the filing of two motions in the Monroe County Circuit Court, which asked the court to order treatment of Baby Doe and to remove him from the custody of his parents based on their decision not to feed or treat him.<sup>48</sup> The court ruled that the parents had not abandoned the child and denied both motions.<sup>49</sup> Rather, the court held that the parents had simply chosen one alternate form of treatment over another.<sup>50</sup> A writ of mandamus was filed in the Indiana Supreme Court the following day.<sup>51</sup> The writ was denied for "purely procedural reasons."<sup>52</sup>

In the interim, a Canadian teacher and an Indiana couple had offered to adopt the child.<sup>53</sup> On April 15, the couple sought to intervene in the proceedings as potential adoptive parents and asked the court to order hydration and nutrition for the infant.<sup>54</sup> Once again, the court ruled that the parents had not abandoned the child and that they had shown "parental interest" by choosing the form of treatment he was receiving.<sup>55</sup>

The next step came the same day, when the county prosecutor announced that an attorney from his office was being sent to Washington with an emergency request to the United States Supreme

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42. Rothenberg, *Down's Syndrome Babies: Decisions Not to Feed and the Letter From Washington*, 1 PULMINARY MED. & TECH. 47, 49 (1984).

43. Pless, *supra* note 39, at 664.

44. *Id.*

45. Rothenberg, *supra* note 42, at 49; *see also supra* note 38.

46. *Id.*

47. *Id.*

48. *Id.*

49. *Id.*

50. *Id.*

51. *Id.*

52. *Id.*

53. *Id.*

54. *Id.*

55. *Id.*



Court to overturn the Indiana courts' decisions.<sup>56</sup> The question became moot when, at 10:03 p.m. that day, the hospital announced the death of Baby Doe.<sup>57</sup> The death of Baby Doe set in motion a series of federal government responses that culminated in the Child Abuse Amendments of 1984.<sup>58</sup>

## II. THE FEDERAL GOVERNMENT RESPONDS

A great deal of public attention was focused on the case of Baby Doe. On April 30, 1982, President Reagan issued a directive to the Department of Health and Human Services [hereinafter referred to as HHS].<sup>59</sup> The directive began, "[t]he recent death of a handicapped newborn child in Indiana . . . raised the question whether federal laws protecting the rights of handicapped citizens are being adequately enforced."<sup>60</sup> The directive also instructed the Secretary of HHS to:

[N]otify health care providers of the applicability of section 504 of the Rehabilitation Act of 1973 to the treatment of handicapped patients. That law forbids recipients of federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps. Regulations under this law specifically prohibit hospitals and other providers of health services receiving federal assistance from discriminating against the handicapped.

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Our nation's commitment to equal protection of the law will have little meaning if we deny such protections to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced.<sup>61</sup>

Consequently, on May 18, 1982, the HHS's Civil Rights office issued a notice to health care providers.<sup>62</sup> The notice repeated the heightened public concern about the medical care for infants born with birth defects.<sup>63</sup> It pointed out that "[r]eports suggest that operable defects have sometimes not been treated, and instead infants

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56. *Id.*

57. *Id.*

58. *See supra* note 2.

59. Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, 49 Fed. Reg. 1622 (1984) [the Department of Health and Human Services is hereinafter referred to as HHS].

60. Rothenberg, *supra* note 42, at 50.

61. 49 Fed. Reg. 1622-23 (1984).

62. Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers, 47 Fed. Reg. 26027 (1982).

63. *Id.*

have been allowed to die."<sup>64</sup> The notice continued by *reminding* parties of the applicability of section 504 of the Rehabilitation Act of 1973.<sup>65</sup> The notice stated that:

[I]t 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>66</sup>

HHS recognized that health care providers may not have full control over the infant when parental consent has been refused.<sup>67</sup> "Nevertheless," the agency stated, "a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization."<sup>68</sup>

The notice directed hospitals to review their conduct in the following areas to ensure that they were not engaging in discriminatory practices:

Counseling of parents should not discriminate by encouraging them to make decisions which, if made by the health care provider, would be discriminatory under section 504.

Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.<sup>69</sup>

The notice warned health care providers that failure to comply with section 504 would subject a hospital to possible termination of fed-

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64. *Id.*

65. *Id.* Section 504 of the Rehabilitation Act of 1973 provides in pertinent part as follows:

No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of the Congress, and such regulation may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

29 U.S.C. § 794 (1982). For text of § 706(7)(B), *see infra* note 95.

66. 47 Fed. Reg. 26027 (1982).

67. *Id.*

68. *Id.* (citing 45 C.F.R. § 84.4(b)(1)(v)).

69. *Id.*

eral assistance.<sup>70</sup>

### III. BABY DOE REGULATIONS I

On March 7, 1983, HHS followed up the aforementioned notice with an interim final rule entitled "Nondiscrimination on the Basis of Handicap."<sup>71</sup> This rule was not issued pursuant to the Federal Administrative Procedure Act's [hereinafter referred to as APA]<sup>72</sup> notice and comment period requirement.<sup>73</sup> The Secretary of HHS felt that dispensing with the notice and comment period was necessary, since "[a]ny delay would leave lives at risk."<sup>74</sup> Thus, the rule took effect less than thirty days after publication.<sup>75</sup>

The rule provided a toll free number for persons to report suspected violations of section 504.<sup>76</sup> It also provided that a notice be posted "[i]n a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery."<sup>77</sup> The notice was to state, in part:

DISCRIMINATORY FAILURE TO FEED AND CARE  
FOR HANDICAPPED INFANTS IN THIS FACILITY IS  
PROHIBITED BY FEDERAL LAW

. . . .

*Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:*

Handicapped Infant Hotline. . . .<sup>78</sup>

The interim final rule also stated that information received through the Handicapped Infant Hotline that amounted to child abuse or neglect would be referred to state agencies "in order to give States an opportunity to make their own investigation and to

70. *Id.*

71. Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9630 (1983).

72. 5 U.S.C. §§ 551-76 (1982). The Federal Administrative Procedure Act [hereinafter cited as APA], enacted in 1946, provides procedural requirements administrative agencies must follow with regard to rule making.

73. 5 U.S.C. 553 (1982). The Secretary of HHS found that:

[T]his interim final rule is exempt from the requirements [of the thirty-day notice period] of 5 U.S.C. § 553. Under 45 CFR §§ 80.6(d) and 84.61, the Secretary is already authorized to specify the manner in which recipients make available information concerning federal legal protections against discrimination toward the handicapped. The exception to the 10-day waiting period of 45 CFR § 80.8(d)(3) and the exception to 45 CFR § 80.6(c) to allow access outside normal business hours are minor technical changes and are necessary to meet emergency situations.

48 Fed. Reg. 9630, 9631 (1983).

74. 48 Fed. Reg. at 9631.

75. *Id.*

76. *Id.*

77. *Id.*

78. *Id.*

take appropriate action."<sup>79</sup> When effective state action was taken, HHS anticipated that no further federal efforts would be necessary. However, the rule did provide that "for those cases where direct federal action appears helpful, the Secretary will have at his disposal the usual means of federal civil rights enforcement."<sup>80</sup> As such, the rule made it "possible for the Secretary to conduct immediate investigations and to make immediate referrals to the Department of Justice for such legal action as may be necessary to save the life of a handicapped child who is subjected to discrimination by a recipient."<sup>81</sup>

Further, and to the ire of the medical community, the interim final rule provided for immediate departmental access to records and facilities of hospitals, which was not "limited to normal business hours."<sup>82</sup> This clause was to become operative "[w]hen, in the judgment of the responsible Department official, immediate access [was] necessary to protect the life or health of a handicapped individual."<sup>83</sup>

The medical community immediately went on the attack. The American Academy of Pediatrics filed suit against the Secretary of HHS, Margaret M. Heckler.<sup>84</sup> The Academy attacked the procedure under which the rule was promulgated.<sup>85</sup> Judge Gesell, stating that the Administrative Procedure Act<sup>86</sup> was "designed to curb bureaucratic actions taken without consultation and notice to persons affected,"<sup>87</sup> invalidated the rule.<sup>88</sup> Still, even though the court invalidated the rule on procedural grounds, Judge Gesell stated that "[g]iven the language of the statute and its similarity to other civil

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79. *Id.*

80. *Id.*

81. *Id.*

82. *Id.* at 9630.

83. *Id.*

84. *American Academy of Pediatrics*, 561 F. Supp. at 395.

85. *Id.* at 398. See *supra* note 73 for the exemption upon which the Secretary of HHS relied.

86. 5 U.S.C. §§ 551-76 (1982).

87. *American Academy of Pediatrics*, 561 F. Supp. at 398.

88. *Id.* at 403. See also 48 Fed. Reg. 17588 (1983). The rule was invalidated under § 706(2)(A) and § 553(b) and (d) of the APA. Section 553(b) is the general notice provision of the APA. It states that "when the agency for good cause finds . . . that notice and public procedure thereon are impracticable, unnecessary, or contrary to the public interest," the section concerning notice does not apply. 5 U.S.C. § 553(b)(B) (1982). (Recall that the Secretary of HHS issued the rules without notice because to delay would leave lives at risk. See *supra* note 74 and accompanying text.) Additionally, § 553(d) has an exception dispensing with the thirty-day advance publication requirement for "good cause." 5 U.S.C. § 553 (1982). Nevertheless, the court rejected arguments based on these exceptions, reasoning that "[s]uch an argument could as easily be used to justify immediate implementation of any sort of health or safety regulation, no matter how small the risk for the population at large or how long-standing the problem." 561 F. Supp. at 401.

rights statutes which have been broadly read, it cannot be said that section 504 does not authorize some regulation of the provision of some types of medical care to handicapped newborns.”<sup>89</sup>

The rule thus invalidated, the Department of HHS tried once again to remedy the problem through regulations aimed at hospitals receiving federal financial assistance.<sup>90</sup> On July 5, 1983, HHS issued a notice of proposed rulemaking concerning nondiscrimination on the basis of handicap for infants.<sup>91</sup> The new proposal provided for a thirty-day comment period, as required by the APA.<sup>92</sup>

#### IV. BABY DOE REGULATIONS II

In issuing the notice of proposed rulemaking, HHS again relied on section 504 of the Rehabilitation Act of 1973.<sup>93</sup> The proposed rules stated that:

Section 504 is in essence an equal treatment, non-discrimination standard. Congress patterned Section 504 on Title VI of the Civil Rights Act, which prohibits discrimination based on race. Programs or activities receiving federal financial assistance may not deny a benefit or service solely on grounds of a person's handicap, just as they may not deny a benefit or service on grounds of a person's race.<sup>94</sup>

These rules were more definitive. They provided a definition of “handicapped individual” based on the Rehabilitation Act.<sup>95</sup> They also delineated when section 504 would apply. Specifically, the proposed rules explained that:

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; thus, its denial would not violate Section 504.

Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. Thus, Section 504 does not require the imposition of futile therapies which merely temporarily prolong the process of dying of an infant born terminally will [sic], such as a child born with anencephaly or intracranial bleeding.<sup>96</sup>

89. *American Academy of Pediatrics*, 561 F. Supp. at 402.

90. Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30846 (1983).

91. *Id.*

92. *Id.*

93. See *supra* note 65 and accompanying text.

94. 48 Fed. Reg. at 30846.

95. *Id.* Specifically, the Rehabilitation Act of 1973 defines a handicapped individual as “any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such an impairment.”

29 U.S.C. § 706(7)(B) (1982).

96. 48 Fed. Reg. at 30846-47.

The proposed rules were an attempt to limit a physician's decision concerning the treatment of handicapped infants to a bona fide medical judgment. The doctor was to consider the benefits to the patient that treatment would provide, as opposed to any risks from the treatment. Any decision based on a doctor's subjective beliefs about handicapped individuals was not considered a *bona fide* medical judgment. Rather, it was considered to be based on the doctor's personal belief about what life would be worth living. The proposed rules analogized the situation of a handicapped infant to that of a black infant denied medical care simply because of his race.<sup>97</sup> Such a decision would not be a medical judgment. The proposed rules similarly stated that "[a] judgment not to correct an intestinal obstruction or repair the heart of a Down's syndrome infant because the infant suffers the handicap of Down's syndrome is likewise not a medical judgment."<sup>98</sup>

Under the proposed rules, the failure to provide medical treatment for a life-threatening defect because an infant suffered from another defect which was not life-threatening, would be a violation of section 504. For instance, a retarded child born with a detached esophagus, that prevented feeding, could not be denied surgery to correct the esophagus simply because he or she was retarded. The decision to do so would be discriminatory because children of normal intelligence would not be denied the life saving surgery.

The rules did not provide that corrective surgery must be performed when, based upon a physician's legitimate medical opinion, a child would die imminently. Such would be the case with anencephaly.<sup>99</sup> Nor did the rules prohibit withholding extraordinary care to extremely low-birthweight infants.<sup>100</sup> However, the proposed rules stated that, "[a]t the same time, the basic provision of nourishment, fluids, and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment."<sup>101</sup> Further, it was provided that "[e]ven if a handicapped infant faces imminent and unavoidable death, no health care provider should take upon itself to cause death by starvation or dehydration. Routine nursing care to provide comfort and cleanliness is required to

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97. *Id.* at 30847.

98. *Id.*

99. *Id.* at 30852. Anencephaly is defined as a condition occurring in one out of every 1,000 births that is marked by the partial or total absence of the brain. Ellis, *supra* note 7, at 397.

100. 48 Fed. Reg. at 30852. For a horrifying and heartrending account of the results of doctors overzealously treating an extremely premature infant for the sake of medical research, see Stinson, *On the Death of a Baby*, 244 ATL. MONTHLY 64 (July, 1979).

101. 48 Fed. Reg. at 30852.

respect the dignity of such an infant.”<sup>102</sup>

Once again, the medical community attacked the proposed rules with vigor. Among the concerns of physicians, was that crank calls would be received over the Handicapped Infant Hotline, causing federal investigators to descend on hospitals and thereby monopolize the doctors' and staff's time.<sup>103</sup> Additionally, the rules were attacked as a “flawed and ill-defined set of rules under which physicians are to perform their medical duties.”<sup>104</sup> A pair of commentators even suggested that children born with anencephaly should not be fed since it was an “empty futile gesture, one which ‘merely temporarily [prolongs] the process of dying of an infant born terminally ill.’ ”<sup>105</sup>

On January 12, 1984, HHS issued its “final rules” on the subject.<sup>106</sup> The rules were comprehensive and exhaustive. HHS had received almost 17,000 comments in response to its notice of proposed rulemaking of July 5, 1983.<sup>107</sup> The Department's statistics indicated that 97.5% of the persons responding supported the rules, while only 2.5% opposed them.<sup>108</sup> Of interest is the fact that of 141 newborn care specialists or pediatricians who commented, 27.7% favored the rules and 72.3% opposed them.<sup>109</sup> Of 253 responding physicians who were not pediatricians, 55.3% favored the rules and 44.7% opposed them.<sup>110</sup> And, as to the 322 nurses who commented, 97.5% supported the rules, while only 2.5% opposed them.<sup>111</sup> Among the nurses that responded favorably, one stated:

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

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102. *Id.*

103. Holden, *HHS Preparing to Issue New Baby Doe Rules*, 221 SCI. 1269, 1270 (1983).

104. American Society of Law & Medicine Committee on the Legal and Ethical Aspects of Health Care for Children, *Comments and Recommendations on the “Infant Doe” Proposed Regulations*, 11 L. MED. & HEALTH CARE 203 (1983).

105. Paris & Fletcher, *Infant Doe Regulations and the Absolute Requirement to Use Nourishment and Fluids for the Dying Infant*, 11 L. MED. & HEALTH CARE 210 (1983).

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

107. *Id.*

108. *Id.* at 1623.

109. *Id.*

110. *Id.*

111. *Id.*

die."<sup>112</sup>

A doctor who opposed the rules commented that:

Recently I have treated a 13-month old black child who has congenital heart disease, spastic encephalopathy, vomiting, repeated bouts of bilateral pneumonia, internal squint of the left eye, and mental deficiency. He is one of the thousands of children who are the victims of the neonatal intensive care units located in every medical center. He was born premature, weighing two pounds and ten ounces. With modern treatment and instruments he survived. These children have no future and are a terrible burden on their parents and this nation.

\* \* \* What good is it treating these premature babies? Will it not be better if they are left to die? \* \* \* We are compounding our problems by bringing into life thousands of congenitally sick babies which nature has rejected.<sup>113</sup>

The Association for Retarded Citizens stated an opposing view, in support of the standard of providing medically beneficial treatment:

No quality of life or other such considerations are acceptable to the ARC. Although we are primarily a parent organization and many ARC members have had significant difficulty (financial, emotional, etc.) raising their mentally retarded child, we come down strongly on the side of the child.

Available medical and other technology is not able to fully predict the future capacity of most mentally retarded children, especially in the first days and weeks of life. Our members can cite numerous examples of improper and wrong advice given to them by physicians about the future capacities of their children.<sup>114</sup>

A contrary opinion, suggesting different articulations of standards, was stated by the American Medical Association:

**QUALITY OF LIFE.** In the making of decisions for the treatment of seriously deformed newborns . . . the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the

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112. *Id.* at 1645.

113. *Id.* at 1629 (submitted by an Ala. physician; deletions in original).

114. *Id.*



potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.<sup>115</sup>

With some changes in the proposed rules, based on the comments received, the final rules were adopted.<sup>116</sup>

## V. A NEW CASE ARISES

In the meantime, another case concerning a handicapped infant was working its way through the legal system. At the center of this controversy was a baby who became known to the public as Baby Jane Doe.<sup>117</sup> She was born on October 11, 1983, and suffered from multiple handicaps.<sup>118</sup> Among the disorders she suffered at birth were: spina bifida, "a failure of the closure of the bones and the coverings of the spinal cord;"<sup>119</sup> microcephaly, "a small head circumference, bespeaking increased pressure in the cranial cavity;"<sup>120</sup> and, hydrocephalus, "a condition in which fluid fails to drain from the cranial areas."<sup>121</sup> The infant was transferred to Stony Brook Hospital with the expectation that surgery would be performed to correct the spina bifida and hydrocephalic conditions.

The parents refused to consent to the surgery.<sup>122</sup> Rather, they elected to follow what was deemed a "conservative course of treatment."<sup>123</sup> If surgery had been performed, the risk of infection associated with spina bifida might have been significantly reduced<sup>124</sup> and may have increased the child's life span.<sup>125</sup> However, it carried with it neurological complications of surgical repair.<sup>126</sup> On the other hand, the conservative course of treatment consisted of treatment through antibiotic therapy.<sup>127</sup> Indeed, while the mortality

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115. *Id.*

116. 45 C.F.R. § 84 (1984).

117. *Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 467 N.Y.S.2d 685, *aff'd*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (N.Y. App. Div. 1983); *United States v. University Hosp., State Univ. of N.Y. at Stony Brook*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

118. *Weber v. Stony Brook Hospital*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.

119. *Id.*

120. *Id.*

121. *Id.*

122. *Id.*

123. *Id.*

124. *Id.* at 589, 467 N.Y.S.2d at 686.

125. DeKornfeld, *Baby Jane Doe*, 1 PULMONARY MED. & TECH. 43 (1984).

126. *Id.*

127. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 589, 467 N.Y.S.2d at 686.

rate is higher when the conservative course of treatment is followed, it does not place the infant in imminent danger of death.<sup>128</sup>

On October 16, 1983, Lawrence Washburn petitioned the Supreme Court of the State of New York, Suffolk County, seeking the appointment of a guardian *ad litem* for Baby Jane Doe.<sup>129</sup> He also sought an order directing the hospital to perform the surgical procedures.<sup>130</sup> Washburn was an attorney from Vermont who had no connection with the infant or her family.<sup>131</sup>

The New York Supreme Court, Suffolk County, appointed William Weber as guardian *ad litem* for the infant.<sup>132</sup> It subsequently found that Baby Jane Doe was "in need of immediate surgical procedures to preserve her life," and ordered that the surgical procedures be performed."<sup>133</sup> The parents and hospital filed an appeal in the supreme court, appellate division.<sup>134</sup>

The issue the appellate division addressed was whether the parents had "been neglectful of their newborn infant in failing to provide her with 'adequate \* \* \* medical \* \* \* care'"<sup>135</sup> according to New York statutes.<sup>136</sup> First, the court noted that the proceeding was proper under the *parens patriae* doctrine, pursuant to which a state may act "as the general guardian of all infants."<sup>137</sup> Second, the court found that in accordance with the *parens patriae* doctrine, a state "may direct medical treatment of a minor, in appropriate circumstances, over parental objection."<sup>138</sup> As such, the court determined that the parents had simply "chosen one course of appropriate medical treatment over another"<sup>139</sup> and, therefore, reversed the lower court and vacated the order appointing the guardian *ad litem*.<sup>140</sup>

On appeal, the New York Court of Appeals found that the supreme court had "abused its discretion as a matter of law by permitting [the] proceeding to go forward."<sup>141</sup> It thus affirmed the ap-

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128. *Id.*

129. *United States v. University Hosp.*, 575 F. Supp. at 610.

130. *Id.*

131. *United States v. University Hosp.*, 729 F.2d at 146.

132. *United States v. University Hosp.*, 575 F. Supp. at 610.

133. *Id.*

134. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 587, 467 N.Y.S. 2d at 685.

135. *Id.* at 587, 467 N.Y.S.2d at 686.

136. N.Y. JUDICIARY § 1012(f)(i)(A) (McKinney 1983).

137. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686 (citing *Hawaii v. Standard Oil Co.*, 405 U.S. 251, 257 (1972)).

138. *Id.* (citing *Prince v. Massachusetts*, 321 U.S. 158, 166-67 (1944); *In re Storax*, 52 N.Y.2d 363, 377 (1981); *Bennett v. Jeffreys*, 40 N.Y.2d 543, 546 (1976)).

139. *Id.* at 589, 467 N.Y.S.2d at 687.

140. *Id.* at 590, 467 N.Y.S.2d at 687.

141. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 210, 210-11, 456 N.E.2d 1186, 1187, 469 N.Y.S.2d 63, 64 (1983).

pellate division's dismissal<sup>142</sup> on a different ground; particularly, that Washburn, according to the court, had circumvented the procedures of the New York Family Court Act<sup>143</sup> by applying directly to a justice of the supreme court.<sup>144</sup>

The New York Family Court Act provides that child neglect proceedings may be initiated by a child protective agency or a "person on the court's direction."<sup>145</sup> Primary responsibility for initiating proceedings has, therefore, been assigned by the legislature to child protective agencies; all others may only file petitions if directed by the court to do so.<sup>146</sup> Thus, Washburn's actions failed because he sought court action directly, rather than going through a child protective agency. Such statutory violations were condemned by the court for the additional reason that they would give the right to any person "to institute judicial proceedings which would catapult him into the very heart of a family circle, there to challenge the most private and most precious responsibility invested in the parents for the care and nurture of their children."<sup>147</sup>

Nevertheless, the litigation and controversy concerning Baby Jane Doe continued. For, while the state court proceedings were still in progress, a complaint was filed with the Department of HHS alleging that the infant was being "discriminatorily denied medically indicated treatment on the basis of her physical and mental handicaps."<sup>148</sup>

HHS obtained a copy of the record of the state court proceedings, which included medical records pertaining to the infant through October 19, 1983.<sup>149</sup> The record was reviewed by the Surgeon General of the United States who, among other things, determined that:

An appropriate determination concerning whether the current care of Infant Jane Doe is within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment, cannot be made without immediate access to, and careful review of, current medical records and other sources of information within the possession or control of the hospital.<sup>150</sup>

Thus, beginning on October 22, 1983, HHS repeatedly requested that the University Hospital provide it with access to all of Baby

142. *Id.* at 211, 456 N.E.2d at 1187-88, 469 N.Y.S.2d at 64-65.

143. N.Y. JUDICIARY §§ 1111-12 (McKinney 1982). *See infra* notes 145-46 and accompanying text.

144. 60 N.Y.2d at 211, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.

145. *Id.* at 212, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.

146. *Id.*

147. *Id.* at 213, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.

148. *United States v. University Hosp.*, 575 F. Supp. 607, 611 (E.D.N.Y. 1983).

149. *United States v. University Hosp.*, 729 F.2d 144, 147 (2d Cir. 1984).

150. *Id.*

Jane Doe's medical records.<sup>151</sup> The University Hospital refused to release the records.<sup>152</sup> It based its decision on the refusal of the parents to consent to a release of the records and on "serious concerns both as to the Department's jurisdiction and the procedures the Department has employed in initiating an inquiry."<sup>153</sup> Consequently, the United States filed an action seeking an order directing University Hospital to allow HHS access to the medical records.<sup>154</sup>

This action was based upon section 504 of the Rehabilitation Act of 1973<sup>155</sup> and a regulation promulgated under said statute.<sup>156</sup> Specifically, section 84.61 of Title 45 of the Code of Federal Regulations incorporates by reference the provisions of section 80.6(c), which provides that recipients of federal financial assistance shall permit the Department of HHS access to records to determine whether the recipient is complying with the Act.<sup>157</sup> As such, the government sought the medical records to determine whether the failure to perform the surgery on Baby Jane Doe was in violation of section 504.<sup>158</sup>

In addressing the standards for determining the government's right of access to records, the district court explained that the regulations were designed so that the government could determine whether the recipient of federal financial assistance was discriminating against someone in violation of the Act.<sup>159</sup> The court, therefore, reasoned that if a recipient was clearly not violating the Act by discriminating against handicapped persons, HHS could not obtain the records.<sup>160</sup>

Accordingly, the next issue the court considered was whether the hospital had violated the prohibition against discrimination. The court found it to be undisputed that the hospital had not discriminated on the basis of Baby Jane Doe's handicap because it was at all times willing to perform the operation, but had simply not done so

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151. *Id.*

152. *Id.*

153. 729 F.2d at 148.

154. 575 F. Supp. at 609.

155. *Id.* See also *supra* note 65. The government was arguing the case under § 504 rather than the final rules discussed *supra*, because the rules were not issued until January 12, 1984 and the case was argued on November 17, 1983.

156. 575 F. Supp. at 609.

157. *Id.* 45 C.F.R. § 80.6(c) (1984) provides in part that:

"Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part. Information of a confidential nature obtained in connection with compliance evaluation or enforcement shall not be disclosed except where necessary in formal enforcement proceedings or where otherwise required by law."

158. 575 F. Supp. at 609.

159. *Id.* at 613-14.

160. *Id.* at 614.

because of the parents' refusal to consent to the procedures.<sup>161</sup> Without the parents' or other guardians' consent, the hospital could not legally perform the operation. As such, the court found the hospital had not violated the Rehabilitation Act by discriminating against Baby Jane Doe "solely by reason of her handicap."<sup>162</sup>

The court went on to explain that the papers submitted demonstrated conclusively that the parents' decision to refuse to consent to surgery was a reasonable one based on the medical options available and on a "genuine concern for the best interests of the child."<sup>163</sup> It added that even if the parents' decision had been based on discriminatory considerations, and had not been based on a reasonable medical consideration, the hospital would not have violated the Act.<sup>164</sup>

The court thus found it unnecessary to address the hospital's contention that a release of the infant's medical records to the HHS without the parents' consent would violate the constitutional right to privacy and New York legislation concerning the doctor-patient relationship.<sup>165</sup> "It would be highly paradoxical," the court observed, "if an individual's right to privacy could be asserted by that individual's parent . . . purportedly acting in that individual's own best interests, for the purpose of precluding an inquiry into the question of whether the parent . . . was in fact acting in the individual's best interests."<sup>166</sup>

On appeal to the United States Court of Appeals for the Second Circuit,<sup>167</sup> the government alleged that the district court's finding that no discrimination had occurred could only apply to the period up to October 19 (the eight days for which medical records were available at the time the proceedings were at the state level).<sup>168</sup> It stressed that "[m]edical decisionmaking is a dynamic process,"<sup>169</sup> and that whatever Baby Jane Doe's condition was before October 19, it may have changed so that the hospital's action was in fact discriminatory under section 504. The government also contended that the records were necessary to determine whether the hospital's failure to seek a court order overriding the parent's decision was in itself discrimination in violation of section 504<sup>170</sup> and, therefore, that the district court erred in finding that the parents' refusal to

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161. *Id.*

162. *Id.* (emphasis added).

163. *Id.* at 614-15.

164. *Id.* at 615.

165. *Id.*

166. *Id.* at 616-17.

167. *United States v. University Hosp.*, 729 F.2d 144 (1984).

168. *Id.* at 149.

169. *Id.*

170. *Id.*

consent to surgery "conclusively established the hospital's nondiscrimination."<sup>171</sup>

On the other hand, the hospital argued that section 504 was never intended to serve as a basis for federal intervention in medical decisionmaking.<sup>172</sup> Additionally, the hospital contended that the physician-patient privilege and the constitutional right of privacy barred access to the records.<sup>173</sup>

The precise issue identified by the court was one of statutory construction: "[W]hether section 504 authorizes HHS to investigate medical treatment decisions involving defective newborn infants."<sup>174</sup> With the issue thus framed, the court first reviewed the unsettled regulatory history of section 504. It observed that in May of 1976, the Department of Health, Education and Welfare [hereinafter referred to as HEW], the predecessor to HHS, had requested comments on fifteen critical issues pertaining to section 504.<sup>175</sup> Among these issues was "'[w]hether a regulation should contain provisions concerning [institutionalized] patients' rights to receive or refuse treatment.'"<sup>176</sup> In response to the comments received, HEW indicated that "to promulgate rules on . . . [this] subject is beyond the authority of section 504."<sup>177</sup>

The court continued by noting that HEW's limited view of the guidelines was reflected in HEW's first set of proposed regulations, which were criticized for lacking specificity.<sup>178</sup> It observed that the final section 504 regulations, issued in May of 1977, offered more specific guidance as to the type of discrimination prohibited by the Act, while emphasizing the "basic requirement of equal opportunity to receive benefits. . . ."<sup>179</sup> The court quoted the agency as follows:

"[A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness."<sup>180</sup>

The court then observed that it was not until five years after the issuance of the final regulations that HHS took the position that

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171. 729 F.2d at 149.

172. *Id.*

173. *Id.*

174. 729 F.2d at 151.

175. *Id.* at 152 (citing 41 Fed. Reg. 29548) (1976). [The Department of Health, Education and Welfare is hereinafter referred to as HEW].

176. *Id.* at 152 (citing 41 Fed. Reg. at 20296-97) (1976).

177. *Id.* at 152 (citing 41 Fed. Reg. 29548, 29559) (1976).

178. *Id.* at 152; *see also* 45 C.F.R. § 84.52 (1984).

179. *Id.* at 152 (*quoting* 45 C.F.R. § 84, Appendix A, ¶ 36 (1984)).

180. *Id.*

section 504 "made it unlawful for hospitals receiving 'Federal financial assistance' to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition."<sup>181</sup> It noted that the interim final rules that had been proposed, had been struck down in *American Academy of Pediatrics v. Heckler* as (1) "a product of 'haste and inexperience,'"<sup>182</sup> and (2) due to the Secretary of HHS's failure to follow the procedural requirements of the APA.<sup>183</sup> The court also mentioned the second set of HHS's final rules, Baby Doe Regulations II, which were promulgated after oral argument on this appeal and modified the proposed rules in several major respects.<sup>184</sup>

In sum, the court found that the regulatory history of section 504 was inconsistent inasmuch as "HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW."<sup>185</sup> Thus lacking the "benefit of an administering agency's longstanding, consistent interpretation to which we otherwise might have looked for guidance," the court turned to the statutory language to settle the issue.<sup>186</sup>

In its process of statutory construction, the court began by looking at the language of the statute. First, the court inquired as to whether Baby Jane Doe was a handicapped individual under the statute.<sup>187</sup> While it was clear to the court that she suffered from impairments, it was not as convinced that the impairments limited her "major life activities."<sup>188</sup> The hospital argued that the term major life activities should be limited to programs of education, vocational rehabilitation and training. As such, it contended that newborns were excluded under the Act.<sup>189</sup> The court did not agree. It held that Baby Jane Doe was handicapped as defined under the Act, explaining that "it would defy common sense to rule that she is not presently *regarded* as handicapped under section 706(7)(B)(iii)."<sup>190</sup>

Next, the court had to determine whether Baby Jane Doe could be considered as an "otherwise qualified individual" who was "sub-

181. 729 F.2d at 152.

182. *Id.* at 153 (quoting *American Academy of Pediatrics*, 561 F. Supp. at 400).

183. *Id.* at 153 (citing *American Academy of Pediatrics*, 561 F. Supp. at 401).

184. *Id.* at 154.

185. *Id.* The court further observed that "[n]otwithstanding HHS's claims to the contrary, . . . the current view also represents something of a retreat from the interpretation HHS adopted just last year." *Id.*

186. *Id.* See *supra* note 65 for language of § 504.

187. *Id.* at 155. Section 504 refers to 29 U.S.C. § 706(7) for the definition of "handicapped individual." See *supra* note 95 for the text of 29 U.S.C. § 706(7)(B).

188. *Id.*

189. *Id.*

190. *Id.*

jected to discrimination" within the meaning of section 504.<sup>191</sup> It noted that cases construing the clause were generally those involving educational institutions.<sup>192</sup> Quoting from one such Second Circuit case,<sup>193</sup> the court recognized that "it is now clear that [the phrase "otherwise qualified handicapped individual"] refers to a person who is qualified *in spite of* her handicap and that an institution is not required to disregard the disabilities of a handicapped applicant, provided the handicap is relevant to reasonable qualifications for acceptance."<sup>194</sup> Thus, the court stated, it was established that section 504 prohibits discrimination against a handicapped individual only where the handicap is unrelated to the services in question.<sup>195</sup> However, in instances where medical treatment is at issue, the court pointed out that the "otherwise qualified" criterion of section 504 could not meaningfully be applied.<sup>196</sup> Specifically, the court explained that the handicap itself gives rise to the need for medical services in such situations.<sup>197</sup>

Third, in addressing the contention that Baby Jane Doe may have been "subjected to discrimination," the court attacked the government's argument by stating that a determination of whether a particular decision was discriminatory would invariably require lengthy litigation to determine whether a decision not to treat was based on a "bona fide medical judgment."<sup>198</sup> Before finding that "Congress intended to spawn this type of litigation under section 504," the court stated that it "would want more proof than is apparent from the face of the statute."<sup>199</sup> As such, the court next reviewed the legislative intent behind section 504.

The court determined that the void in the legislative history, in addition to a number of measures limiting federal involvement in medical treatment decisions which were passed prior to the enactment of the Rehabilitation Act, provided the best clues to congressional intent regarding section 504's coverage of health services.<sup>200</sup> Specifically, the court quoted the very first section of the medicare law, which provides in pertinent part:

"Nothing in this subchapter shall be construed to authorize any Federal officer or employee to exercise any supervision or control

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191. *Id.* at 156.

192. *Id.*

193. *Doe v. New York Univ.*, 666 F.2d 761 (2d Cir. 1981).

194. *United States v. University Hosp.*, 729 F.2d at 156 (quoting *Doe v. New York Univ.*, 666 F.2d 761, 775 (2d Cir. 1981)).

195. 729 F.2d at 156.

196. *Id.*

197. *Id.*

198. *Id.* at 157.

199. *Id.*

200. *Id.* at 158-60.



over the practice of medicine or the manner in which medical services are provided. . . ."<sup>201</sup>

Similarly, the court cited the Professional Standards Review Organization provisions of the Social Security Act,<sup>202</sup> which also evidences a policy against the involvement of federal personnel in medical treatment decisions.

As such, the court stated that it could not "presume that by enacting section 504, congress intended the federal government to enter the field of child care, which as HHS has recently acknowledged, has traditionally been occupied by the states."<sup>203</sup> The court went on to hold that:

Our review of the legislative history has shown that Congress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants when the statute was enacted in 1973, when it was amended in 1974, or at any subsequent time.

\* \* \* Until Congress has spoken, it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.<sup>204</sup>

The court thus concluded by confirming the district court's finding that the hospital had not discriminated against Baby Jane Doe because it had always been willing to perform the corrective surgery on her if only her parents would consent.<sup>205</sup> The court felt that by "[r]equiring the hospital either to undertake surgery notwithstanding the parents' decision or alternatively, to petition the state court to override the parents' decision, would impose a particularly onerous affirmative action burden upon the hospital."<sup>206</sup> As such, the court affirmed the district court.<sup>207</sup>

An additional blow to the federal regulatory attempts to prohibit nontreatment decisions under section 504 came on May 23, 1984, when the United States District Court for the Southern District of New York invalidated the final rules issued on January 12, 1984.<sup>208</sup> The district court cited as its authority *United States v. University Hospital*.<sup>209</sup>

Associations supporting the right of handicapped individuals then turned their attention to the United States Congress. Bills

201. *Id.* at 160 (quoting 42 U.S.C. § 1395 (1982) (first enacted in 1965)).

202. 42 U.S.C. § 1320c (1982 and Supp. 1983).

203. 729 F.2d at 160.

204. *Id.* at 161.

205. *Id.* at 160.

206. *Id.*

207. *Id.* at 161.

208. *American Hosp. Assoc. v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984), *cert. granted*, 105 S. Ct. 3475 (1985). See *supra* text pp. 138-42, *Baby Doe Regulations II*.

209. *Id.*

were introduced to amend the Child Abuse Prevention and Treatment Act.<sup>210</sup> The legislation that emerged, the Child Abuse Amendments of 1984,<sup>211</sup> was the result of compromise on the part of handicapped rights groups, right to life supporters and a large number of medical organizations.<sup>212</sup> The noted exception to the medical groups supporting the bill was the American Medical Association.<sup>213</sup> The American Medical Association walked out of negotiations because the language of the bill failed to include as a consideration when making non-treatment decisions, the infant's future quality of life.<sup>214</sup> Nevertheless, on October 9, 1984, the bill was signed into law.<sup>215</sup>

## VI. BABY DOE REGULATIONS III

On December 10, 1984, HHS once again issued a notice of proposed rulemaking.<sup>216</sup> This notice deals largely with changes in grant requirements under the Child Abuse Amendments.<sup>217</sup> Other changes required by the Amendments were to be the subject of future rulemaking procedures.<sup>218</sup> In the proposed rules, HHS has declared that "disabled infants must under all circumstances receive appropriate nutrition, hydration and medication."<sup>219</sup> In addition, the infants "must be given medically indicated treatment."<sup>220</sup> The rules indicate HHS's continuing concern that the death of handicapped infants is being caused or hastened by a failure of doctors to order feeding of disabled newborns.

Of importance is the fact that the "reasonable medical judgment" that a physician is to exercise when making a nontreatment decision is given meaning by the proposed rules. The judgment "must be one that would be made by a reasonably prudent physician. . . . It is not to be based on subjective 'quality of life' or other abstract concepts."<sup>221</sup>

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210. See *supra* note 3.

211. See *supra* note 2.

212. The Village Voice, Nov. 27, 1984, at 8, col. 1. Among the Medical Organizations supporting the bill were the American Hospital Association, the American Academy of Pediatrics, the Catholic Health Association, the National Association of Children's Hospitals and Related Institutions, the American College of Obstetricians and Gynecologists, the American Nurses Association, and the American College of Physicians.

213. The San Diego Union, Oct. 10, 1984, at A6, col. 1.

214. The Village Voice, *supra* note 212.

215. 42 U.S.C.S. § 5101(b)(6) (Supp. 1985).

216. Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48160 (1984) (to be codified at 45 C.F.R. § 1340).

217. *Id.*

218. *Id.*

219. *Id.* at 48163.

220. *Id.*

221. *Id.*

Additionally, the proposed rules urge the establishment of Infant Care Review Committees.<sup>222</sup> These review committees are expected to develop guidelines for the treatment of disabled infants and act as a guide to hospital staffs and families concerning the availability of community resources to help deal with a child's handicap.<sup>223</sup> Most importantly, the committees are to review treatment and nontreatment decisions within the hospital. When a committee feels that appropriate decisions are not being made, it must contact the State Child Protective Service Agency for immediate legal intervention.<sup>224</sup> In a separate procedure, HHS has established interim guidelines for review committees.<sup>225</sup> In addition to medical personnel, the committees must consist of a social worker, a representative from the legal community, a representative of a disability group, and a lay community member.<sup>226</sup> Further, the committees are required to maintain records of their deliberations, which include a summary of cases considered and the disposition of these cases.<sup>227</sup>

The authority and procedure by which the review committee acts when there is a disagreement between the family and physician concerning treatment has also been established. When a family wishes to continue life-sustaining treatment, its wishes are to be followed.<sup>228</sup> When there is disagreement and the family refuses to consent, the review committee is to consider the case. If the committee agrees with the family, the committee should "recommend" that treatment be withheld.<sup>229</sup> However, if the committee disagrees with the family, it *must* recommend to the hospital that the case be referred to a child protective services agency.<sup>230</sup> In that situation, every effort is to be made to prevent the infant's condition from worsening until "such time as the court or agency renders a decision or takes other appropriate action."<sup>231</sup>

## VII. THE STATE APPROACH

The Child Abuse Amendments of 1984 require states to include medical neglect in their child abuse prevention legislation.<sup>232</sup> A number of states had already considered the issue prior to the pas-

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222. *Id.* at 48165.

223. *Id.* at 48162.

224. *Id.*

225. 49 Fed. Reg. at 48170-73 (1984).

226. *Id.* at 48171.

227. *Id.*

228. *Id.* at 48172.

229. *Id.*

230. *Id.*

231. *Id.*

232. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 101, 98 Stat. 1749 (1984).

sage of the Amendments.<sup>233</sup> Five states had passed legislation concerning newborns<sup>234</sup> and two had passed resolutions.<sup>235</sup>

Specifically, the 1982 California resolution condemns the treatment of Baby Doe and expresses distress that an infant would be "allowed to die by calculated neglect because the infant was born mentally retarded."<sup>236</sup> Further, it declares that neither hospitals nor courts should "selectively deprive infants of life sustaining nourishment" based upon an evaluation of the handicapped child's existence.<sup>237</sup> It concludes by declaring that "no handicapped infants in the state shall be denied food, water, or medical attention solely on the basis of handicap."<sup>238</sup>

In comparison, the Pennsylvania law is entitled "Infanticide."<sup>239</sup> It provides that any infant born alive is entitled to full constitutional protection and that physicians must provide to all infants "that type and degree of care and treatment which, in the good faith judgment of the physician, is commonly and customarily provided to any other person under similar conditions and circumstances."<sup>240</sup> If the parents fail to consent to treatment, the physician is under an affirmative duty to notify the juvenile court.<sup>241</sup> Moreover, the law provides that a knowing violation is a third degree felony subjecting the violator to a seven year prison sentence.<sup>242</sup>

### VIII. IS THERE A NEED FOR LEGISLATION?

"Withholding necessary medical care from defective newborns in order to cause their death is a common practice in many medical centers across the United States."<sup>243</sup> A number of studies indicate

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233. Feldman & Murray, *State Legislation and the Handicapped Newborn: A Moral and Political Dilemma*, 12 L. MED. & HEALTH CARE 156, 163 (1984). The states which have considered legislation are Arizona, Arkansas, California, Connecticut, Delaware, Illinois, Indiana, Louisiana, Maryland, Michigan, Missouri, Nevada, North Carolina, Oklahoma, Pennsylvania, Rhode Island, Tennessee, West Virginia, and Wisconsin.

234. ARIZ. REV. STAT. ANN. § 36-2281 (Supp. 1984); IND. CODE ANN. § 31-6-4-3(f) (West Supp. 1984) (passed following the Baby Doe case); L.A. REV. STAT. ANN. § 40:1299.36.1 (West Supp. 1984); R.I. GEN. LAWS § 40-11-3 (Supp. 1983); 18 PA. CONS. STAT. ANN. § 3212(b) (1983).

235. S. Con. Res. 75, 5 Cal. Stats. and Amends. to Code Res. Ch. 178 at 6872 (1982); S. J. Res. 17, Tenn. Pub. Acts 996-97 (1983).

236. S. Con. Res. 75, *supra*.

237. *Id.*

238. *Id.*

239. 18 PA. CONS. STAT. ANN. § 3212.

240. *Id.*

241. *Id.*

242. *Id.*

243. J. ROBERTSON, LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS 213 (A. Doudera and J. Peters ed. 1982).

that doctors favor euthanasia of defective newborns.<sup>244</sup> One report states that 50% of the doctors surveyed, given complete anonymity, favor euthanasia for Down's syndrome children with an intestinal obstruction.<sup>245</sup> Another indicates that 76.8% of pediatric surgeons would acquiesce in such a decision by parents.<sup>246</sup> Further, 23.6% of the pediatric surgeons surveyed indicate they would encourage parents to refuse consent for treatment of a newborn with intestinal atresia and Down's syndrome.<sup>247</sup> Dr. Helen McKilligin, who reported the first study, stated that, "[t]his shows that some physicians chose to view a relatively simple operation as an insurmountable barrier and so excuse their . . . attitude."<sup>248</sup> The study in *Pediatrics* also reports that 62% of the respondents who believe that children with Down's syndrome "are capable of being useful and bringing love and happiness into the home," would still acquiesce in a parents' non-treatment decision.<sup>249</sup>

Doctors need not acquiesce to parents' decisions not to treat an infant. All states have a proceeding to allow a guardian to be appointed to consent on behalf of a child to medical treatment. A number of cases have, in fact, been brought.<sup>250</sup> In these cases, the courts have appointed guardians to consent to treatment.<sup>251</sup> Furthermore, in addition to statutory authority, courts may authorize treatment under the *parens patriae* doctrine. Under the doctrine, a court of equity "has both the power and the responsibility to care for and protect all those persons who, by virtue of some legal disability are unable to protect themselves."<sup>252</sup> The Massachusetts Supreme Judicial Court identified three state interests protected by the doctrine: 1) A longstanding interest in protecting the welfare of children living within its borders;<sup>253</sup> 2) An interest in preserving

244. *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, HASTINGS CTR. REP., Apr. 1976, at 2.

245. *Id.*

246. 48 Fed. Reg. at 30848 (1983); see also *Ethical Issues in Pediatric Surgery*, 60 PEDIATRICS 588 (1977).

247. *Id.*

248. *Treating the Defective Newborn*, *supra* note 244, at 2.

249. *Ethical Issues*, *supra* note 246, at 595.

250. A few by way of example are: *In re Hamilton*, 657 S.W.2d 425 (Tenn. App. 1983); *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009 (1979), *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979); *In re Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978); *In re Jensen*, 54 Or. App. 1, 633 P.2d 1302 (1981); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (1962); *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d (1955).

251. *Id.*

252. *In re Minor*, 375 Mass. at 745, 379 N.E.2d at 1060.

253. *Id.* at 754-55, 379 N.E.2d at 1066. Quoting from *Prince v. Massachusetts*, 321 U.S. 158, 165 (1944), the court stated:

Indeed, this interest "is no mere corporate concern of official authority. It is the interest of youth itself, and of the whole community, that children be both safeguarded from abuses and given opportunities for growth into free and independent . . . [individuals]."

life; and, 3) An interest in protecting the ethical integrity of the medical profession, and in allowing hospitals the full opportunity to care for people under their control.<sup>254</sup> Accordingly, courts have held that a state's interest in youth cannot even be outweighed by a parental claim of religious freedom.<sup>255</sup> Further, "[p]arents may be free to become martyrs themselves. But it does not follow that they are free . . . to make martyrs of their children."<sup>256</sup>

Nevertheless, a California appellate court recently recognized an almost insurmountable deference to parental wishes.<sup>257</sup> The case, entitled *In re Phillip B.*,<sup>258</sup> involved a mildly retarded<sup>259</sup> twelve-year old boy suffering from Down's syndrome and a congenital heart defect that had already caused damage to his lungs. As long as the heart defect remained uncorrected, it was determined that damage to his lungs would increase to the point where his lungs would be unable to carry and oxygenate blood. During the deterioration of the lungs, it was said that Phillip would suffer from a progressive loss of energy and vitality until he was forced to lead a bed-to-chair existence.<sup>260</sup> Death would follow.

Phillip's parents refused to consent to the corrective surgery. A petition was filed seeking to have him declared a dependent child for the special purpose of insuring that he receive the surgery. The district court dismissed the petition. In affirming the dismissal, the appellate court said that "[i]t is fundamental that parental autonomy is constitutionally protected."<sup>261</sup> Further, it declared that, "[i]nherent in the preference for parental autonomy is a commitment to diverse lifestyles, including the right of parents to raise their children as they think best."<sup>262</sup>

Without the surgery Phillip is "certain to die a slow, painful death in the next five to ten years, with the last years full of agony and suffering. With it, he has the potential for a long life of ordinary health."<sup>263</sup> However, the new rules and regulations promulgated by the Department of HHS provide absolutely no help to a child in Phillip's position, for they apply only to children under one

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*Id.*

254. 375 Mass. at 755, 379 N.E.2d at 1066.

255. *In re Hamilton*, *supra* note 250, 657 S.W.2d at 429.

256. *In re Jensen*, 54 Or. App. at 7, 633 P.2d at 1302 (1981) (citing *Prince*, *supra* note 253).

257. *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied sub nom.*, *Bothman v. Warren B.*, 445 U.S. 949 (1980).

258. *Id.*

259. ROBERTSON, *supra* note 243, at 221.

260. *In re Phillip B.*, 92 Cal. App. 3d at 800, 156 Cal. Rptr. at 50.

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

262. *Id.*, 156 Cal. Rptr. at 51.

263. ROBERTSON, *supra* note 243, at 222.

year old.<sup>264</sup> The California court should have heeded the well-reasoned advice of Justice Asch in *In re Weberlist*,<sup>265</sup> wherein he concluded that “ [t]here is a strident cry in America to terminate the lives of *other* people — deemed physically or mentally defective.’ This court was not constituted to heed that cry. Rather, . . . it is our function to secure to each his opportunity for ‘life, liberty and the pursuit of happiness.’ ”<sup>266</sup>

### CONCLUSION

“Physicians may hold excessive power over decision making by limiting or controlling the information made available to patients or families. It seems appropriate that the profession be held accountable for presenting fully all management options and their expected consequences.”<sup>267</sup> By controlling the information regarding newborns, physicians can control life and death decisions concerning infants. The infant once born is imbued with all the protections our society provides others. These rights apply whether or not a child is handicapped. Further, the child is entitled to protection by the state under the *parens patriae* doctrine.

The medical community—particularly the American Medical Association—fights regulatory and statutory attempts to insure the rights of these newborns. It wants to keep the decisions regarding the life and death of these children a “low visibility” physician’s decision. The presumed decision would be made on the child’s probable “quality of life.” Such is the standard that has been in place on an *ad hoc* basis for years, yet it does not work. Sixty-two percent of doctors in a survey who recognized that Down’s syndrome children have a relatively high potential under the “Quality of Life” standard, nevertheless, would allow those children to be euthanized. Furthermore, there is absolutely no consistency to decisions made on an *ad hoc* basis. A child who might be treated in one institution could be denied care in another. Additionally, doctors are unable to resolve a standard for themselves. On the one hand, they view as unethical the discontinuance of a respirator for a person who is classified as a vegetative remnant of life, yet acquiesce to the euthanasia of a child capable of bringing love into a home.

Equally so, doctors cannot be expected to perform in a legal abyss. They must know it is proper to withhold treatment from a child to whom it would serve no benefit. Doctors must know when

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264. 49 Fed. Reg. at 48163 (1984).

265. *In re Weberlist*, 79 Misc. 2d 753, 360 N.Y.S.2d 783 (1974).

266. *In re Cicero*, 101 Misc. 2d at 755-56, 421 N.Y.S.2d at 968 (1979) (quoting Justice Asch, *In re Weberlist*, 79 Misc. 2d at 755-56).

267. 289 N. ENGL. J. MED. at 894.

a child is born what their obligations are to it. They have no duty to prolong the dying process when it is inevitable, but they are under an equal duty not to hasten the death of a child by withholding food from it. Physicians should not act with dismay when government attempts to prevent this. The American psyche cannot tolerate images of children being starved to death.

The medical community has a right not to be hauled into court when a reasonable medical judgment has been made. The case of Baby Jane Doe is an excellent case in point. All the medical evidence indicated that the treatment the child was receiving was within the bounds of a *bona fide* medical judgment. While others may have pursued another course, it is not a court's duty to second guess a reasoned opinion. The reasoned medical decision must be made on medical considerations alone and, if a decision is made on any other basis, doctors should not expect to be shielded from the courts. The medical profession has a right to certainty. This certainty is provided by definite parameters within which a *bona fide* medical judgment can be made. These parameters are not set by state and federal regulations alone, but also by the values of our society. It is incumbent upon physicians, as well as state and federal legislators, to put the interest of the child first, as it serves no useful purpose to require a child and family to undergo needless months of suffering while legal wrangling over the child's life takes place. As a society, we must also realize that the handicapped and their families have special needs that we must all share. The parents of these children are in no way responsible for their condition, and their misfortune must not be their burden to bear alone.

The medical community urges the implementation of ethics review committees as an answer to government regulation and legislation. Such committees would not be of help to individual children in urgent need of medical care. Their function would be to review treatment decisions and create policy on how future cases would be handled. Needless to say, a number of infants could die before a discernable policy was established. Review committees will only provide another shield between doctors and courts. Physicians must realize that they are not an institution that has been empowered by our society to determine who lives and who dies. Legislation in the area is an attempt to create a reasonableness standard for doctors regarding life and death decisions of newborns. Their right to make a reasonable medical judgment will not be impinged. Once they step beyond that judgment, they are invading the protected right of individuals. By creating a reasonableness standard for doctors, society will ensure that doctors will be held to the same standard which applies to the rest of society.



To hold doctors to any less standard would be to allow them to discriminate based on their notions of which particular human life is superior. Discrimination by doctors in this area is most unsettling because it is discrimination against life itself.

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