

Tulsa Law Review

Volume 22 | Number 2

Winter 1986

Medical Treatment of Handicapped Infants: Who Should Make the Decision

Barbara J. Mangrum

Follow this and additional works at: <https://digitalcommons.law.utulsa.edu/tlr>



Part of the [Law Commons](#)

Recommended Citation

Barbara J. Mangrum, *Medical Treatment of Handicapped Infants: Who Should Make the Decision*, 22 Tulsa L. J. 259 (1986).

Available at: <https://digitalcommons.law.utulsa.edu/tlr/vol22/iss2/6>

This Casenote/Comment is brought to you for free and open access by TU Law Digital Commons. It has been accepted for inclusion in Tulsa Law Review by an authorized editor of TU Law Digital Commons. For more information, please contact megan-donald@utulsa.edu.

MEDICAL TREATMENT OF HANDICAPPED INFANTS: WHO SHOULD MAKE THE DECISION?

I. INTRODUCTION

To what extent does the government have the right to intervene between parent and physician in the decision about the care and treatment of a handicapped newborn? Recent court cases have held that the right to decline medical treatment is a part of our constitutional right to privacy.¹ But who decides in the case of an infant? As Professor Robyn S. Shapiro² has stated, “[T]he defective newborn . . . [has a] substantive right to refuse potentially life-prolonging treatment. However, it is difficult to ensure that the newborn’s right is protected and implemented. The newborn himself cannot assert this right and his right may conflict with the rights of his parents.”³

Society is concerned with the moral fiber of its people as well as their physical well-being.⁴ Therefore, society wants the interests of the handicapped infant protected. Pursuant to the right of privacy, individuals have a right to determine their own medical treatment, but in the case of a handicapped infant, many people must participate in the treatment decision in order to protect the infant’s interest. The Supreme Court decision, *Bowen v. American Hospital Association*⁵ concerning Section 504 of the Rehabilitation Act of 1973,⁶ limited the direct federal involvement in the decision making process. Mandated, blanket regulations are not the answer. Because the factors in each infant’s case vary greatly, an

1. *In re Quinlan*, 70 N.J. 10, ___, 355 A.2d 647, 663, cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976). See also *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, ___, 370 N.E.2d 417, 424 (1977) (right to privacy is a constitutional guarantee “against unwanted infringements of bodily integrity in appropriate circumstances”) (citing *In re Quinlan*).

2. Assistant Adjunct Professor, Marquette University Law School; Assistant Director, Regional Center for the Study of Bioethics, Medical College of Wisconsin; member, Medical College of Wisconsin/Marquette University Law School Liaison Committee; partner in the Menomonee Falls, Wisconsin, law firm of Barr & Shapiro; J.D., Harvard Law School, 1977.

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

4. *Poe v. Ullman*, 367 U.S. 497, 545-46 (1961) (Harlan, J., dissenting).

5. 106 S. Ct. 2101 (1986).

6. 29 U.S.C. § 794 (1982).

ad hoc analysis of each situation would strike a balance among the rights of all parties involved.

II. THE RIGHT OF PRIVACY

Although the right to privacy is crucial to the "baby doe" cases, the Constitution makes no express guarantee of a right to privacy.⁷ The Supreme Court, nevertheless, has found the guarantee in a line of cases beginning in 1886. In *Boyd v. United States*⁸ the Court found that the fourth and fifth amendments protected "the sanctity of a man's home and the privacies of life" from governmental invasions.⁹ Similarly, in *Mapp v. Ohio*¹⁰ the Court found the fourth amendment created a "right to privacy, no less important than any other rights carefully and particularly reserved to the people".¹¹ In the landmark case, *Griswold v. Connecticut*,¹² the Court found that the right to privacy exists in the "penumbras, formed by the emanations from [the] guarantees" in the Bill of Rights.¹³ The Court found these penumbras in the first amendment right of association;¹⁴ the third amendment prohibition against the quartering of soldiers "in any house" in time of peace;¹⁵ the fourth amendment "right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures;"¹⁶ and the fifth amendment privilege against self-incrimination.¹⁷ The Court stated that these guarantees created "zones of privacy."¹⁸

The ninth amendment¹⁹ affords additional rights not specifically enumerated in the Bill of Rights.²⁰ Justice Goldberg in his concurrence

7. *In re Quinlan*, 70 N.J. 10, —, 355 A.2d 647, 663, cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976).

8. 116 U.S. 616 (1886).

9. *Id.* at 630.

10. 367 U.S. 643 (1961).

11. *Id.* at 655-56.

12. 381 U.S. 479 (1965).

13. *Id.* at 484.

14. U.S. CONST. amend. I (specifically, "the right of the people peaceably to assemble"); *Griswold*, 381 U.S. at 484.

15. U.S. CONST. amend. III (specifically, "[n]o Soldier shall, in time of peace be quartered in any house"); *Griswold*, 381 U.S. at 484.

16. U.S. CONST. amend. IV (specifically, "[t]he right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures"); *Griswold*, 381 U.S. at 484.

17. U.S. CONST. amend. V (specifically, "nor shall [a person] be compelled in any criminal case to be a witness against himself"); *Griswold*, 381 U.S. at 484.

18. *Griswold*, 381 U.S. at 484.

19. U.S. CONST. amend. IX (specifically, "[t]he enumeration . . . of certain rights, shall not be construed to deny or disparage others retained by the people").

20. *Griswold*, 381 U.S. at 488-89 (Goldberg, J., concurring).

in *Griswold* stated, "[T]he Ninth Amendment shows a belief . . . that fundamental rights exist that are not expressly enumerated in the first eight amendments."²¹ In the view of Goldberg, Harlan, and White, the right of privacy can be found in the Constitution in the reference to "liberty";²² therefore, it is protected by the fourteenth amendment.²³ The preamble to the Constitution refers to "Blessings of Liberty."²⁴ The fifth amendment states: "nor shall any person . . . be deprived of life, liberty, or property, without due process of law."²⁵ Finally, the fourteenth amendment²⁶ extends this protection to the state level.²⁷ Therefore, the "liberty" interest is protected by due process.²⁸

A person's liberty interests include family privacy. Justice Harlan stated in *Poe v. Ullman*²⁹ that a "most fundamental aspect of 'liberty' [is] the privacy of the home";³⁰ invasion of this privacy can take place "without any physical intrusion whatever into the home."³¹ Therefore, the right to rear a family is implicit in the right of privacy.³² However, this does not mean that the right of privacy is an absolute.³³ The Court has construed this idea of rearing a family to consist of the upbringing and educating of the children.³⁴ For example, the New Jersey Supreme Court in *In re Quinlan*³⁵ did not allow a father to exercise a child's constitutional right to privacy on his *own* behalf.³⁶ The court restricted the parental right of privacy by stating "[the] parental right of privacy has been recognized . . . in the context of determining the rearing of infants

21. *Griswold*, 381 U.S. at 492 (Goldberg, J., concurring).

22. *Id.* at 486 (Goldberg, J., concurring); *Id.* at 500 (Harlan, J., concurring); *Id.* at 502 (White, J., concurring).

23. *Id.* at 499 (Goldberg, J., concurring); *Id.* at 500 (Harlan, J., concurring); *Id.* at 502 (White, J., concurring).

24. U.S. CONST. preamble (specifically "In order to . . . secure the Blessings of Liberty to ourselves and our posterity").

25. U.S. CONST. amend. V.

26. U.S. CONST. amend. XIV, § 1 (specifically, "nor shall any State deprive any person of life, liberty, or property, without due process of law").

27. *Griswold*, 381 U.S. at 493 (Goldberg, J., concurring).

28. *See id.*; *see also* *Roe v. Wade*, 410 U.S. 113, 168 (1973) (Stewart, J., concurring).

29. 367 U.S. 497 (1961).

30. *Id.* at 548 (Harlan, J., dissenting). Harlan's dissent in *Poe* was cited with much approval in *Griswold*.

31. *Id.* at 549 (Harlan, J., dissenting).

32. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 212 n.63 (1983) [hereinafter cited as PRESIDENT'S BIOETHICS COMMISSION].

33. *Poe*, 367 U.S. at 552 (Harlan, J., dissenting).

34. *Griswold*, 381 U.S. at 502 (White, J., concurring).

35. 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).

36. *Id.* at —, 355 A.2d at 664.

and, . . . involved 'continuing life styles.'"³⁷ The court allowed Mr. Quinlan to assert the right of privacy on his *daughter's* behalf.³⁸ Therefore, when a right of privacy is being asserted, it extends only to the point where it infringes upon another's rights. The parents' right to exercise the privacy of the home, therefore, is limited by the child's right to life.³⁹

In *Roe v. Wade*,⁴⁰ the Supreme Court found a right of privacy in the Constitution and applied it to a woman's abortion decision.⁴¹ Subsequently, courts have expanded this right to include personal decisions to decline medical treatment in certain circumstances.⁴² The Court found that the right of personal privacy was limited to some degree by the state's interests in "safeguarding health, in maintaining medical standards, and in protecting potential life."⁴³ Moreover, as pointed out by Justice Rehnquist's dissenting opinion in *Wade*: "[L]iberty is not guaranteed absolutely against deprivation, only against deprivation without due process of law."⁴⁴ Therefore, although the Due Process Clause protects the right of privacy, the protection is limited by another's right to life.

III. LIFE AND DEATH DECISIONS

No one person is equipped to make the life and death decisions for a handicapped infant. The doctors, who possess the necessary medical expertise, lack the personal involvement needed to assess the individual child's interests. Parents, on the other hand, may lack the technical knowledge to evaluate the future medical situation objectively. This Comment compares the positions of the various people involved in the decision.

37. *Id.*

38. *Id. But cf. Smith, In re Quinlan: Defining the Basis for Terminating Life Support Under the Right of Privacy*, 12 TULSA L.J. 150, 161 (1976) (arguing that the right of privacy precludes a guardian from making personal medical decisions for an incompetent patient). The question of whether a minor has a right to privacy has not been squarely addressed by the courts.

39. Comment, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEX. TECH L. REV. 569, 572, 587-88 (1983).

40. 410 U.S. 113 (1973).

41. *Id.* at 152-53.

42. See, e.g., *In re Conroy*, 98 N.J. 321, —, 486 A.2d 1209, 1225 (1985); *In re Quinlan*, 70 N.J. at —, 355 A.2d at 663. These cases allowed a guardian to make the personal decision to decline treatment.

43. *Wade*, 410 U.S. at 154.

44. *Id.* at 173 (Rehnquist, J., dissenting).

A. *The Parents' Input in the Decision*

Parents should be the primary decision-makers.⁴⁵ The other parties involved in the decision should give great deference to the parents' wishes in the matter. As Professor Shapiro observed:

In most cases, parents have a right to make fundamental decisions with regard to their children in areas such as education and lifestyle. The United States Supreme Court has said: "[I]t is cardinal with us that the custody, care and nurture of the child reside first with the parents, whose primary function and freedom include preparation for obligations that the state can neither supply nor hinder."⁴⁶

The parents are in the best position to evaluate the impact of a handicapped child on the family.⁴⁷ Likewise, the family setting affects the interests of the handicapped infant.⁴⁸ A court, or possibly a doctor, may draw this factor to the parents' attention, but only the parents can evaluate the impact this will have on all individuals concerned. The right decision will necessarily vary from family to family.

The family's financial ability is another factor that must be considered. Our society frowns upon measuring the worth of a human life in dollars, but the fact remains that someone must pay for the often extremely expensive medical procedures required for severely handicapped children. In *American Academy of Pediatrics v. Heckler*,⁴⁹ the court pointed out that the family's financial resources had to be taken into consideration. The court stated: "[T]he long-term interests of physically disabled newborns may be affected by thrusting the child into situations where economic . . . effects on the family as a whole are so adverse that the effort to preserve an unwanted child may require concurrent attention to procedures for adoption or other placement."⁵⁰ It would not be fair to parents of a disabled child to mandate that heroic procedures be implemented which would prove to be of little value and yet provide the parents with no funding to pay for the procedures.⁵¹ This was one of the major criticisms of the Department of Health and Human Service regula-

45. See Comment, *supra* note 39 at 571. See also PRESIDENT'S BIOETHICS COMMISSION, *supra* note 32, at 207 & n.62 (discussion of the traditional although rebuttable presumption that parents are the appropriate decisionmakers).

46. See Shapiro, *supra* note 3, at 145-46 (quoting *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944)).

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

48. *Id.*

49. *Id.*

50. *Id.* at 400.

51. Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699, 713 (1982).

tions⁵² discussed in this Comment.

Another factor that parents must consider is the family's religious convictions. The Constitution protects religious beliefs,⁵³ but conduct in pursuit of religious beliefs is not necessarily protected.⁵⁴ For example, courts have ordered blood transfusions for Jehovah's Witnesses whose religious beliefs prohibit such procedures.⁵⁵ Society will not tolerate the practice of religious beliefs that will senselessly endanger a life.⁵⁶ But as long as the decision of the parents is within the realm of reason, the parents should be allowed to give their religious beliefs full weight.⁵⁷

A final consideration is that the parents might face charges of child abuse and neglect.⁵⁸ One commentator argues that parents who withhold medical treatment from their children might be prosecuted for child neglect, or even homicide, if the omission of treatment results in the child's death.⁵⁹

The parents are the ones who must live with the decisions concerning which medical procedures are used.⁶⁰ They, of course, need the guidance of a physician because very few parents have any medical expertise.⁶¹ Parents can best evaluate opinions and facts from all sources in the light of the family's economic, emotional, and religious position,⁶² therefore, much deference should be given to their final decision. The *Heckler* court pointed out that the parent's wishes should be recognized.⁶³

One caveat must be added. Some parents may not be capable or

52. 45 C.F.R. § 84.55 (1985).

53. U.S. CONST. amend. I.

54. *Quinlan*, 70 N.J. at ___, 355 A.2d at 661.

55. *Jehovah's Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd* 390 U.S. 598 (1968); *United States v. George*, 239 F. Supp. 752 (D. Conn. 1965); *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971); *Mulenberg Hosp. v. Patterson*, 128 N.J. Super 498, 320 A.2d 518 (Law Div. 1974); *Powell v. Columbian Presbyterian Medical Center*, 49 Misc.2d 215, 267 N.Y.S.2d 450 (Sup.Ct. 1965).

56. *See Quinlan*, 70 N.J. at ___, 355 A.2d at 661 (cases are cited where the courts have intervened in religious practices such as the handling of poisonous snakes and cases where the courts have required when refused due to religious beliefs).

57. *See* PRESIDENT'S BIOETHICS COMMISSION, *supra* note 32, at 215.

58. *See* Comment, *supra* note 51, at 710.

59. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 217 (1975). *See also* Annas, *Refusal of Lifesaving Treatment for Minors*, 23 J. FAM. L. 217, 221 (1984-85).

60. *See* PRESIDENT'S BIOETHICS COMMISSION, *supra* note 32, at 210-11 (discussing the parents' responsibility in the decision-making and the possible feelings of guilt that may follow the decisions).

61. *See* PRESIDENTS BIOETHICS COMMISSION, *supra* note 32, at 216 (explaining that in order to make good decisions, parents must have relevant, up-to-date medical information).

62. *Heckler*, 561 F. Supp. at 400.

63. *Id.* The court criticized the Secretary of HHS for not considering the wishes of the parents.

willing to make the appropriate decisions.⁶⁴ When the parents' decision leaves the realm of reason, there must be a safety net in place to protect the infant.⁶⁵ The Association for Retarded Citizens argued in its brief in the *Bowen* case that "state laws are based on the premise that the parent generally will act in the best interests of their child, but that that assumption may be faulty in the unusual circumstances of the birth of a handicapped child."⁶⁶

B. *The Doctors' Input in the Decision*

Several of the amicus briefs presented in support of the Department of Health and Human Services in *Bowen* stated that it is the doctor who actually makes the treatment decisions because "parents do not have the informational and emotional resources available to them to make a competent decision immediately after the birth of their disabled child."⁶⁷ In a recent interview with Stuart Gerson, a lawyer representing the American Hospital Association, he stated that if doctors erroneously advise withholding treatment, it is due to a lack of information about available medical procedures, not a discriminative motive.⁶⁸ However, the Department of Health and Human Services, "HHS," maintained that doctors do withhold medical treatment prompted by discrimination.⁶⁹ Judge Muir in *In re Quinlan*⁷⁰ stated:

Doctors . . . to treat a patient, must deal with medical tradition and past case histories. They must be guided by what they do know. The extent of their training, their experience, consultations with other physicians, must guide their decision-making processes in providing care to their patient. The nature, extent and duration of care by societal standards is the responsibility of a physician. The morality and conscience of our society places this responsibility in the hands of the physician. What justification is there to remove it from the control of the medical profession and place it in the hands of the courts?⁷¹

64. See PRESIDENTS BIOETHICS COMMISSION, *supra* note 32, at 211.

65. *Id.* at 216 (suggesting that if parental decision making is faulty, court intervention may be necessary).

66. Amicus Brief of the Association for Retarded Citizens of the United States at 26-28, *Bowen*, 106 S. Ct. 2101 (1986) (quoted in Hoving, *The 'Baby Doe' Cases*, 72 A.B.A. J. 50, 53 (April 1, 1986)).

67. Hoving, *supra* note 66, at 52. For the specific arguments see Amicus Brief of the American Coalition of Citizens with Disabilities at 29, *Bowen*, 106 S. Ct. 2101 (1986); Amicus Brief of American Association on Mental Deficiency at 15 n.29, *Bowen*, 106 S. Ct. 2101 (1986); Amicus Brief of the Association for Retarded Citizens of the United States at 18-26, *Bowen*, 106 S. Ct. 2101 (1986).

68. *Id.*

69. *Bowen*, 106 S. Ct. at 2129 (White, J., dissenting).

70. 137 N.J. Super. 227, 348 A.2d 801 (Super. Ct. Ch. Div. 1975).

71. *Id.* at 259, 348 A.2d at 818.

Professor Robertson argues that withholding treatment that results in death is homicide,⁷² that physicians who withhold treatment are committing homicide, and that physicians can be prosecuted for this.⁷³ He claims that nurses can also be prosecuted as accomplices.⁷⁴

There have been few, if any, of these prosecutions⁷⁵ because this type of crime is not a priority. Prosecutors have an over abundance of murders, rapes, and other crimes of violence with which to deal; the crime of "withholding treatment" is near the bottom of their list.⁷⁶ Although criminal charges are seldom brought against physicians, they have felt the lash of civil suits for malpractice. So, like the parents, criminal and civil liability is a factor that the doctor must consider.

Most doctors are dedicated to the preservation of life and could seek court intervention if the parents' decisions were outside what the doctor would consider reasonable. This provides a safety net for the handicapped infant. Next to the parents, the physician's opinion should be given every consideration. After all, he is the expert in the matter.

C. *The Hospitals' Input in the Decision*

The HHS regulations,⁷⁷ which are no longer in effect due to the recent Supreme Court ruling,⁷⁸ set out a model for an Infant Care Review Committee, "ICRC".⁷⁹ The Court did not rule against this section of the regulations.⁸⁰ It suggested that each hospital have an ICRC. Many commentators have presented this idea, including those working on the President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "President's Bioethics Commission", which "had suggested some form of internal ethical review committee to help sensitize the hospital staff to ethical problems and act as an advisory board when called upon."⁸¹ The model outlined by the

72. Robertson, *supra* note 59, at 224-25. *Contra In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976). This case involved a comatose young woman, Karen Quinlan, for whom there was no hope of recovery to a cognitive state. The court appointed her father as guardian and allowed him to authorize the termination of the extraordinary medical means used in sustaining her life pursuant to Karen's right of privacy. The court did not find such a termination to be homicide, even if death resulted.

73. *See also* Comment, *supra* note 51, at 710.

74. Robertson, *supra* note 59, at 224.

75. Comment, *supra* note 51, at 711.

76. *See* Annas, *supra* note 59, at 221.

77. 45 C.F.R. § 84.55 (1985).

78. *Bowen*, 106 S. Ct. 2101 (1986).

79. 45 C.F.R. § 84.55(a)(1985).

80. *Bowen*, 106 S. Ct. at 2106.

81. *See* Annas, *supra* note 59, at 227.

HHS was to be composed of at least seven members: a lay member, a nurse, a physician, a hospital administrator, a disabled group representative, an attorney, and a member of the institution's medical staff who would serve as chairperson.⁸² The ICRC would review cases that involved treatment termination and one committee member would act as an advocate for the infant "to ensure that all considerations in favor of the provision of life sustaining treatment are fully evaluated and considered."⁸³

Courts have advocated the creation of ethics committees. In 1976, Judge Muir in *In re Quinlan*⁸⁴ stated: "I suggest that it would be more appropriate to provide a regular forum for more input and dialogue in individual situations and to allow the responsibility of these judgments to be shared."⁸⁵ Judge Muir felt that an ethics committee would explore a broader range of options for the patient and would diffuse the responsibility for making judgments.⁸⁶

It must be noted that a few commentators do not feel that these committees would be beneficial. Professor Annas has stated: "It is hard, however, to understand how diffusing the responsibility—which would be the case if you have an ethics committee say it's okay to treat or not to treat—somehow yields a better or more ethical decision Committee decision-making, at least in areas of life and death, is probably the worst kind of decision-making we can have."⁸⁷

Overall, the creation of ethics committees must be encouraged. These committees consider the infant family's wishes in the matter and will also provide a second safety net for the infant if the parents' wishes are not in the child's best interests.

Aside from the parents' wishes, the committee must also consider the hospital's financial resources. The hospital's funding is not limitless. The officials must allocate funds to the various departments.⁸⁸ The expense of care units for extremely premature infants or the equipment necessary for extensive surgical procedures may be beyond a hospital's means.⁸⁹ For the federal government to mandate that such extensive medical facilities be provided is absurd. As the court in *American Acad-*

82. 45 C.F.R. § 84.55(f)(2) (1985).

83. 45 C.F.R. § 84.55 (f)(3)(ii)(E) (1985).

84. 70 N.J. 10, 355 A.2d 647 cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976).

85. *Id.* at ___, 355 A.2d at 668.

86. *Id.* at ___, 355 A.2d at 668-69.

87. See Annas, *supra* note 59, at 228-29.

88. See Heckler, 561 F. Supp. at 400.

89. Bowen, 106 S. Ct. at 2114 n.15.

*emy of Pediatrics v. Heckler*⁹⁰ stated: "Means of funding extensive care . . . and for allocating scarce medical resources between defective newborns and other newborns or other patients were also apparently not considered [in the HHS regulations]."⁹¹

A committee could look at all these factors: the parents' wishes, the doctor's prognosis, and the hospital's capabilities—and render an impartial decision as to whether the child's interests are being protected.

D. *The State's Input in the Decision*

Although the primary care and control of a child is left to the parents,⁹² the state will step in when evidence exists that the parents are not fulfilling their obligations.⁹³ The state can intervene when circumstances show that the child's interests are being jeopardized.⁹⁴ State intervention can be achieved through state courts, state agencies, or a combination of both.⁹⁵ As one court said:

While . . . [the child] "belongs" to his parents, he belongs also to his State . . . [T]he fact [that] the child belongs to the State imposes upon the State many duties. Chief among them is the duty to protect his right to live and to grow up with a sound mind in a sound body, and to brook no interference with that right by any person or organization.⁹⁶

The courts represent the conscience of society.⁹⁷ The common moral judgment of the community at large is upheld by the state⁹⁸ through the courts.⁹⁹ In addition, child care has traditionally been under the authority of the states.¹⁰⁰ So with state agencies monitoring the cases of disabled infants and the courts in position to make final determinations, we have yet another safety net protecting the infant's interests.

E. *The Federal Government's Input in the Decision*

The federal government has stated its interests in preservation of life in the Declaration of Independence as self-evident truths "that all men

90. 561 F. Supp. 395 (D.D.C. 1983).

91. *Id.* at 400.

92. See *Griswold*, 381 U.S. at 502 (White, J., concurring).

93. PRESIDENT'S COMMISSION REPORT, *supra* note 32, at 212.

94. See Comment, *supra* note 39, at 571.

95. PRESIDENT'S COMMISSION REPORT, *supra* note 32, at 214.

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

97. *Griswold*, 381 U.S. at 494 (Goldberg, J., concurring).

98. *Poe*, 367 U.S. at 545-46 (Harlan, J., dissenting).

99. See Comment, *supra* note 39, at 571-72. For a discussion of the court's responsibility to create "guideposts" for decisions involving termination of life see *In re Conroy*, 98 N.J. 321, ___, 486 A.2d 1209, 1221 (1985).

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

. . . are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness"¹⁰¹ and again in the Constitution of the United States which provides that no person will "be deprived of life, liberty, or property, without due process of law."¹⁰²

However, the federal government's interests have to be weighed against the individual's right to privacy.¹⁰³ As the President's Bioethics Commission stated: "a decision to forego life-sustaining treatment has been firmly established as a Constitutionally protected right that can be overcome only by marshalling countervailing considerations of substantial weight."¹⁰⁴

The federal government has made two attempts to regulate the decisions made in the area of medical treatment for disabled infants: The Child Abuse Amendments of 1984¹⁰⁵ and the HHS regulations.¹⁰⁶ The HHS regulations have recently been invalidated by the Supreme Court,¹⁰⁷ but the Child Abuse Amendments are still in place.

The proponents of federal government intervention emphasize uniformity in protecting infants' rights equally in all states.¹⁰⁸ This noble aim, however, must be balanced against an individual's right to privacy.¹⁰⁹ The ultimate result is an ad hoc balancing of each case because each case is different. A mandatory set of rules to be followed in every situation would cause heartache and havoc.

IV. THE COURT'S DETERMINATION OF THE SCOPE OF SECTION 504 OF THE REHABILITATION ACT OF 1973

The event that shocked many people, in particular President Reagan, and eventually led to the controversial HHS regulations was the birth of a Baby Doe in April of 1982.¹¹⁰ The infant was born with Down's Syndrome, which would result in retardation, and with a blockage of his digestive tract that precluded normal feeding.¹¹¹ The parents

101. The Declaration of Independence para. 2 (U.S. 1776).

102. U.S. CONST. amend. V.

103. See *supra* notes 40-44 and accompanying text.

104. See PRESIDENT'S BIOETHICS COMMISSION, *supra* note 32, at 32.

105. Pub. L. No. 98-457, 98 Stat. 1749 (1984) (amendments to Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-5107 (1982)).

106. 45 C.F.R. § 84.55 (1985).

107. *Bowen*, 106 S. Ct. 2101, 2123 (1986).

108. See *Hoving*, *supra* note 66, at 53.

109. See *supra* note 103 and accompanying text.

110. *Bowen*, 106 S. Ct. at 2107.

111. See *Hoving*, *supra* note 66, at 50.

refused to consent to the surgery necessary to correct the blockage and further requested that food and water be withheld.¹¹² Although the hospital sought judicial proceedings to override the parents' decision, the state court refused stating that the parents had made a reasonable treatment decision.¹¹³ The Indiana Supreme Court rejected a petition for a writ of mandamus by a vote of three to one.¹¹⁴ The infant was not given food or water¹¹⁵ and soon died while a stay was being sought in the Supreme Court. The Court subsequently denied certiorari.¹¹⁶

In response to the Bloomington case, President Reagan sent a directive to then HHS Secretary Schweiker¹¹⁷ who said: "The President has instructed me to make absolutely clear to health care providers in this nation that federal law does not allow medical discrimination against handicapped infants."¹¹⁸ This resulted in a letter to approximately 7,000 hospitals on May 18, 1982,¹¹⁹ from the HHS putting them on notice that it was "unlawful [under section 504 of the Rehabilitation Act of 1973¹²⁰] for a recipient of federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render treatment or nutritional sustenance contraindicated."¹²¹ Noncompliance could have resulted in a loss of federal funds.¹²²

Ten months later, in May of 1982, the HHS required that this notice be conspicuously placed in every pediatric ward, maternity ward, delivery ward, and nursery.¹²³ The notice was to have had a toll free, twenty-four-hour "hotline" number that could be called by any person who suspected that a handicapped infant was being denied medical care.¹²⁴ The caller's identity was to be held in strict confidence.¹²⁵ The HHS officials were given authority to take "immediate remedial action" which involved twenty-four-hour access to the hospitals and their medical

112. *Id.*

113. *Id.*

114. *Bowen*, 106 S. Ct. at 2107-08 n.5.

115. *See Hoving, supra* note 66, at 50.

116. *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

117. *Bowen*, 106 S. Ct. at 2108.

118. *See Annas, supra* note 59, at 224.

119. *Id.*

120. 29 U.S.C. § 794 (1982).

121. *See Annas, supra* note 59, at 224.

122. *Id.*

123. *Id.* at 225.

124. *Bowen*, 106 S. Ct. at 2106.

125. *See infra* Appendix.

records.¹²⁶

The American Academy of Pediatrics and others brought suit against HHS and Margaret Heckler, the new HHS Secretary.¹²⁷ In April of 1983, U.S. District Court Judge Gerhard Gesell found the regulations invalid due to the failure of HHS to follow the Administrative Procedure Act of 1946 in promulgating the regulation.¹²⁸ Although Judge Gesell found that procedural problems invalidated the HHS regulation, he also suggested that the HHS was overstepping its bounds substantively.¹²⁹

The HHS did not appeal the district court's ruling, but instead reissued the regulations as proposed rules in July of 1983.¹³⁰ Interested parties were given sixty days to comment on the proposed rules. The HHS was dealing with the procedural process but was ignoring the substantive issue of the proper governmental role in this area.¹³¹

There were few changes between the proposed regulations and the final draft.¹³² However, a new section was added which mandated that each state's child protective services agency establish procedures

126. The first "Baby Doe" regulations appeared at 48 Fed. Reg. 9630-9632 (1983).

127. *Heckler*, 561 F. Supp. at 395.

128. *Id.* at 399. The court found the HHS regulations failed to follow the Administrative Procedure Act of 1946, 5 U.S.C. § 706, concerning the scope of review which reads:

To the extent necessary to decision and when presented, the reviewing court shall decide all relevant questions of law, interpret constitutional and statutory provisions, and determine the meaning or applicability of the terms of an agency action. The reviewing court shall . . . (2) hold unlawful and set aside agency action, findings, and conclusions found to be-(A) arbitrary, capricious, an abuse of discretion, or otherwise not in accordance with law . . .

Also the court found the regulations failed to meet the rule making procedures required by the Administrative Procedure Act of 1946 before rules are to be promulgated. The sections violated were 5 U.S.C. § 553 (b) & § 553(d) (1982) which read:

(b) General notice of proposed rule making shall be published in the Federal Register, unless persons subject thereto are named and either personally served or otherwise have actual notice thereof in accordance with law. The notice shall include-(1) a statement of the time, place, and nature of public rule making proceedings; (2) reference to the legal authority under which the rule is proposed; and (3) either the terms or substance of the proposed rule or a description of the subjects and issues involved. [and]

(d) The required publication or service of a substantive rule shall be made not less than 30 days before its effective date, except—(1) a substantive rule which grants or recognizes an exemption or relieves a restriction; (2) interpretative rules and statements of policy; or (3) as otherwise provided by the agency for good cause found and published with the rule.

129. The court in *Heckler*, 561 F. Supp. at 402, stated:

But defendants and *amici* in support of defendants read the regulation and thus the statute [§ 504] far more broadly. It has been suggested by *amici* that the rule requires doctors and parents to undertake heroic measures to preserve for as long as possible, despite expense and a prognosis of certain death within months, the life of an anencephalic infant lacking all or part of the brain and with no hope of ever achieving even the most rudimentary form of consciousness.

Judge Gesell was suggesting that the regulation was substantively overbroad.

130. 48 Fed. Reg. 30,846-30,852 (1983).

131. See Annas, *supra* note 59, at 226.

132. *Id.*

designed "to prevent medical neglect of handicapped infants."¹³³

The HHS deemed that 97.5 percent of the comments received were supportive of the regulations; however, many of the 16,739 letters were generated through writing campaigns of "right to life" organizations.¹³⁴ Finally, the regulations were put into effect in January of 1984. The regulations read, in part: "[N]ourishment 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."¹³⁵ The size of the notice was to be no smaller than five by seven inches and was to be located where nurses could see it.¹³⁶

Before the final rules were promulgated, Baby Jane Doe was born with multiple congenital defects in Long Island, New York.¹³⁷ After consulting with professionals, the parents decided to forego corrective surgery which was potentially risky but likely to prolong the child's life;¹³⁸ however, it would not improve many of her handicaps.¹³⁹ The parents decided to adopt conservative medical procedures which consisted of antibiotics, good nutrition, and dressing of her exposed spinal sac.¹⁴⁰

On October 16, 1983, an unrelated attorney filed suit in the New York Supreme Court to have a guardian *ad litem* appointed for Baby Jane Doe.¹⁴¹ Subsequent to his appointment, the guardian requested that the hospital initiate the necessary surgery.¹⁴² On October 20, the trial court granted this relief;¹⁴³ but this decision was reversed the following day by the Appellate Division which stated that the "concededly concerned and loving parents" had "chosen one course of appropriate medical treatment over another" and made an informed decision that was "in

133. The mandated procedures for state agencies read in part: "[A] requirement that health care providers report on a timely basis . . . known or suspected instances of unlawful medical neglect of handicapped infants [to the HHS]." 45 C.F.R. § 84.55(c)(1)(i) (1985).

134. See Annas, *supra* note 59, at 226.

135. 45 C.F.R. § 84.55 (1985).

136. *Id.*

137. "[The] multiple birth defects includ[ed] spina bifida, microcephaly (an abnormally small head) and hydrocephalus (an accumulation of fluid in the cranium). There was an extremely high risk that the child would be severely retarded." Hoving, *supra* note 66, at 50.

138. *Bowen*, 106 S. Ct. at 2109.

139. *Id.*

140. See Hoving, *supra* note 66, at 50.

141. *Bowen*, 106 S. Ct. at 2109.

142. *Id.*

143. *Id.*

the best interests of the infant."¹⁴⁴ This decision was affirmed by the New York Court of Appeals but on different grounds.¹⁴⁵

While these actions were in progress, the HHS received a complaint that the infant was being "discriminatorily denied medically indicated treatment."¹⁴⁶ Thereafter, HHS attempted to acquire Baby Jane Doe's medical records in order to ascertain if the hospital was in compliance with section 504.¹⁴⁷ The hospital denied the request because the parents had not consented to the release of these records. Subsequently, HHS filed suit in district court to compel release of the records and lost.¹⁴⁸ The Second Circuit affirmed the decision in *United States v. University Hospital*¹⁴⁹ and held that in the absence of a clear congressional directive "it is congress, rather than an executive agency, that must weigh the competing interests at stake Until congress has spoken, it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit."¹⁵⁰ Baby Jane Doe is severely handicapped but is still alive today.¹⁵¹

The government did not seek certiorari in *University Hospital*.¹⁵² However, it did seek review of the adverse ruling in *Bowen v. American Hospital Association*¹⁵³ which was argued before the Supreme Court on January 15, 1986. In *Bowen*, the Supreme Court invalidated most of the newly promulgated HHS regulations.¹⁵⁴ The Court held that section 504

144. *Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 589, 467 N.Y.S.2d 685, 687 (1983), *aff'd*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983), *cert. denied*, 464 U.S. 1026 (1983). The court further elaborated:

The record confirms that the failure to perform the surgery will not place the infant in imminent danger of death, although surgery might significantly reduce the risk of infection. On the other hand, successful results could also be achieved with antibiotic therapy. Further, while the mortality rate is higher where conservative medical treatment is used, in this particular case the surgical procedures also involved a great risk of depriving the infant of what little function remains in her legs, and would also result in recurring urinary tract and possibly kidney infections, skin infections and edemas of the limbs.

Id. 95 A.D.2d at 589, 467 N.Y.S.2d at 686-87.

145. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 211-13, 456 N.E.2d 1186, 1187-88, 469 N.Y.S.2d 63, 64-65 (1983). On October 28, the New York Court of Appeals affirmed on the grounds that the trial court should not have allowed a petition by a stranger who had no direct interest in, or had any relationship to the involved parties, and had failed to request the aid of the responsible state agency. The court found "no precedent or authority for the proceeding." *Id.*

146. *Bowen*, 106 S. Ct. at 2110.

147. *Id.*

148. *Id.*

149. 729 F.2d 144 (2d Cir. 1984).

150. *Id.* at 161.

151. *See Hoving*, *supra* note 66, at 50.

152. *Bowen*, 106 S. Ct. at 2111.

153. *Id.*

154. *Id.* at 2106, 2123.

did not authorize the HHS to interfere in the decision-making process of parents, hospitals, and state officials concerning handicapped children.¹⁵⁵

V. THE ALTERNATIVE TO THE HHS REGULATIONS

The Supreme Court's decision in *Bowen v. American Hospital Association*¹⁵⁶ does not mean that there are no controls over the well-being of handicapped infants. The decision only struck down the HHS's authority to regulate the decision-making process. Moreover the Court's ruling did not affect the statutes already in place, and it left open the possibility for Congress to continue legislating statutes that directly addressed the problem. The Child Abuse Amendments of 1984 cover this area quite adequately.¹⁵⁷ The Court's decision did not prevent Congress from enacting further legislation to remedy the situation. Congress does have the power to enact legislation regulating the decision-making process.¹⁵⁸ The Court merely ruled that Congress did not delegate that particular power to the HHS, in this instance.¹⁵⁹ Many advocates of the HHS regulations argued that the Child Abuse Amendments of 1984 were not sufficient to adequately protect handicapped infants because they did not create a direct obligation on the hospital.¹⁶⁰ If this should prove to be

155. *See id.* at 2123.

156. *Id.*

157. Child Abuse Amendments of 1984. Pub. L. No. 98-457, 98 Stat. 1749 (1984). Among other changes, Congress amended the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5102 (1982), to include the care and treatment of handicapped infants. Section 121 (3) of the Child Abuse Amendments amended Section 3 of the Act to include this clause:

(3) [T]he term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

158. U.S. Const. art. I, § 8.

159. *Bowen*, 106 S. Ct. at 2120-23.

160. The Association on Mental Deficiency's amicus brief before the Supreme Court in *Bowen* stated:

Section 504 declares that federal funds will not be used in discriminatory ways. The Child Abuse Amendments require the withdrawal of federal funds from state child welfare agencies that do not protect handicapped children from discriminatory denial of treatment.

But if the latter law were interpreted to eliminate enforcement of the former statute [Section 504] the Secretary would be required to deny funds to the welfare agency but would be required to continue funding the recipient who actually engaged in the discriminatory conduct.

the situation, Congress can easily enact necessary statutes.

Another argument that has been made in favor of the federal regulations is that the regulations would create uniformity among the various states: that an infant in one state can be assured of the same protection as an infant in another state. The American Association on Mental Deficiency stated in its amicus brief in *Bowen*:

“[A]s in other areas of civil rights enforcement, experience suggests that states will not be uniformly diligent in carrying out their responsibilities. Federal enforcement capability is therefore appropriate and necessary to guarantee that handicapped children are not denied protection of their right to nutrition or medical care merely because of their state of residence.”¹⁶¹

If this argument proves true, Congress can enact the necessary legislation to ensure uniformity among the various states.

As a result of the provisions in the Child Abuse Amendments of 1984,¹⁶² the Supreme Court's decision did not leave handicapped infants vulnerable to practices of starvation and dehydration in order to accelerate death. The Amendments require that a child be given “medically indicated treatment” which includes nutrition, hydration, and medicine.¹⁶³ These Child Abuse Amendments seem to protect the handicapped infants adequately. In an interview, before the Supreme Court's ruling in *Bowen*, Surgeon General Koop, a supporter of the HHS regulations, admitted the Child Abuse Amendments work to protect the current “Baby Does.” Hence, further federal intervention may not be required.¹⁶⁴ Another plus for the Child Abuse Amendments is that they allow the states, rather than the federal government, to monitor the cases. This was one of the objections to the HHS regulations. Many believed that this area was traditionally a state function and should be left to the states.¹⁶⁵ This is the exact result of the Supreme Court's decision in *Bowen*. Thus, the Child Abuse Amendments are the only federal law governing such cases; and in turn, these amendments pass the authority to the state level.¹⁶⁶ The state is authorized by the Child Abuse

161. Amicus Brief of American Association on Mental Deficiency at 23, *Bowen*, 106 S. Ct. 2101 (1986).

162. Pub. L. No. 98-457, 98 Stat. 1749 (1984).

163. Child Abuse Amendments of 1984, *supra* note 157.

164. Hoving, *supra* note 66, at 53.

165. *Id.* at 52.

166. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984). Congress amended the Child Abuse and Treatment Act, 42 U.S.C. § 5101 (1982) to provide for state intervention in instances of medical neglect of disabled infants. Section 122 of the Child Abuse Amendment amended § 4 (b)(2) of the Act by inserting the following clause:

(K) [W]ithin one year after the date of the enactment of the Child Abuse Amendments of

Amendments to implement procedures or programs to respond to reportings of medical neglect.¹⁶⁷ States now have the authority to pursue any legal remedies, including the initiation of legal proceedings, to prevent the withholding of medically indicated treatment.¹⁶⁸

Another concern of many, when the Supreme Court struck down the HHS regulations, was that various states would lack uniformity in protecting the disabled infant.¹⁶⁹ Possibly, the Child Abuse Amendments have relieved this problem by setting out model guidelines. The Amendments provide for the Secretary of HHS to publish model guidelines which will "serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medically indicated treatment . . . from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions."¹⁷⁰ Therefore, the Child Abuse Amendments may have been the best solution to protect the handicapped infants. They provide protection for these infants across the nation, but allow each state to adopt this protection within its own framework, a major shortcoming of the HHS regulations.

Most people would agree that conservative or ordinary medical treatment should be given in all instances. On the other hand, heroic or extraordinary medical treatment should never be mandated.¹⁷¹ If the parents of the child, the doctor, and possibly the hospital ethics committee agree that heroic measures should be utilized, then heroic medical

1984, have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions (codified at 45 C.F.R. § 1340.15 (1985).

167. *Id.*

168. *Id.*

169. Hoving, *supra* note 66, at 53.

170. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 124 (b)(1), 98 Stat. 1749, 1754 (1984).

171. *In re Quinlan*, 70 N.J. at ___, 355 A.2d at 664. The court stated: "We think that the State's interest *contra* 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."

treatment should be undertaken. But a decision to the contrary must not be construed as euthanasia.¹⁷² This point of view was expressed by Pope Pius XII in an address to anesthesiologists on November 24, 1957.¹⁷³ He made the point that the "interruption of attempts at resuscitation, even when it causes the arrest of circulation, is not more than an indirect cause of the cessation of life."¹⁷⁴ The Pope then expressed the opinion that this was not considered euthanasia.¹⁷⁵ Professor George Annas of Boston University¹⁷⁶ has concluded that most people, including those in the Reagan Administration and the Surgeon General, agree that there can be cases in which an infant can be "so severely ill or so severely handicapped that it actually would be better off, from the infant's perspective, for that infant to die."¹⁷⁷ In addition, "that given the child's suffering, the treatment itself would be worse for the child than death."¹⁷⁸ All things considered, the best alternative is to decide each case on an ad hoc basis.¹⁷⁹

VI. CONCLUSION

Life and death decisions must often be made when a severely handicapped infant is born. The persons closest to the situation should have priority in the decision-making. However, society has an interest in providing a safety net for those infants who might suffer from an unreasonable decision. The parents should be the primary decision makers in conjunction with the physician in charge of the case. It is strongly suggested that every hospital establish an ethics committee to review these decisions. State agencies and courts are present to provide added protection for the infant's interest.

172. *See id.* at 658.

173. *Id.*

174. *Id.*

175. *Id.*

176. George J. Annas has a B.A., 1967, J.D., 1970, M.P.H., 1972, Harvard University. He is the Edward R. Uteley Professor of Health Law at Boston University Schools of Medicine and Public Health. He has published many works including a book titled *RIGHTS OF DOCTORS, NURSES, AND ALLIED HEALTH PROFESSIONALS* (1981). Publications on this subject include *The Baby Doe Regulations: Governmental Intervention in Neonatal Rescue Medicine*, 74 AM. J. PUB. HEALTH 618 (1984) and *Ethics Committees in Neonatal Care: Substantive Protection or Procedural Diversion?*, 74 AM. J. PUB. HEALTH 843 (1984). Professor Annas also writes a column on health law called *Law and the Life Sciences* for *The Hastings Center Report* and a column called *Public Health and the Law* for the *American Journal of Public Health*. These works and others have given Professor Annas a reputation as an expert in medical-legal areas. *See Annas, supra* note 59, at 217.

177. Annas, *supra* note 59, at 223. *But see*, Capron, *Borrowed Lessons: The Role of Ethical Distinctions in Framing Law on Life-Sustaining Treatment*, 1984 ARIZ. ST. L.J. 647, 657.

178. *See Annas, supra* note 59, at 223.

179. *But see* Capron, *supra* note 177, at 657.

The Supreme Court in *Bowen* left the authority to police the decision-making process to the states. The only other federal involvement is the Child Abuse Amendments of 1984. At last, these Amendments inherently pass the authority to the states. This is as it should be because blanket mandatory requirements cannot be applied. Each case must be decided on its own merits because each case is different; therefore, an ad hoc decision-making process must be utilized.

Barbara J. Mangrum

APPENDIX

NOTICE

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office for Civil Rights

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW. SECTION 504 OF THE REHABILITATION ACT OF 1973 STATES THAT

“NO OTHERWISE QUALIFIED HANDICAPPED INDIVIDUAL SHALL, SOLELY BY REASON OF HANDICAP, BE EXCLUDED FROM PARTICIPATION IN, BE DENIED THE BENEFITS OF, OR BE SUBJECTED TO DISCRIMINATION UNDER ANY PROGRAM OF ACTIVITY RECEIVING FEDERAL FINANCIAL ASSISTANCE.”

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

Handicapped Infant Hotline

U.S. Department of Health and Human Services

Washington, D.C. 20201

Phone 800-~~368~~-1019 (Available 24 hours a day) - TTY Capability

In Washington, D.C. call 863-0100

OR

Your State Child Protective Agency

Federal Law prohibits retaliation or intimidation against any person who provides information about possible violation of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your state.

