

NOTES

THE HHS' FINAL RULE ON HEALTH CARE FOR HANDICAPPED INFANTS: EQUAL PROTECTION NOT GUARANTEED

INTRODUCTION

Thousands of severely defective babies are born in the United States each year.¹ Their births require parents, physicians, hospitals, and society as a whole to determine when, if ever, life-sustaining treatment should be withheld from these infants.² This difficult decision has been magnified by modern medicine's increasing ability to save or extend the lives of defective newborns.³

Despite advances in neonatal care, pediatric euthanasia frequently occurs without public knowledge.⁴ Although the legal⁵ and medical⁶

1. The number of defective infants has been estimated at 30,000 per year. See *Medical Ethics: The Right to Survival, 1974: Hearing on the Examination of the Moral and Ethical Problems Faced with Agonizing Decision of Life and Death Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare*, 93d Cong., 2d Sess. 26 (1974). For tables showing the reported incidence of selected congenital malformations by U.S. Census Region (including Puerto Rico), see CENTERS FOR DISEASE CONTROL: CONGENITAL MALFORMATIONS SURVEILLANCE REPORT, 1980, issued Feb. 1982, at 3-6 (data based on 763,419 births in 955 hospitals).
2. These infants usually suffer from one of two types of congenital abnormalities. The first type includes infants with severe physical defects resulting in permanent physical handicap or paralysis, and sometimes mental retardation. Examples of such defects include anencephaly (a condition in which the brain is entirely or substantially absent) and meningocele (abnormal development of the brain or spinal cord).
The second type includes permanent handicaps combined with one or more surgically correctable physical defect. For example, an infant may suffer from Down's syndrome with tracheo-esophageal fistula. (Downs is a chromosomal abnormality producing varying degrees of mental retardation. A tracheo-esophageal fistula is a condition that blocks the passage from the mouth to the stomach and thus prevents oral feeding.)
For a thorough discussion of these various conditions, see W. NELSON, TEXTBOOK OF PEDIATRICS (R. McKay & V. Vaughan 10th ed. 1975); K. SWAIMAN & F. WRIGHT, THE PRACTICE OF PEDIATRIC NEUROLOGY (1975).
3. "Between 1970 and 1980, the death rate in the first 28 days of life [the neonatal period] was almost halved, the greatest proportional decrease in any decade since national birth statistics were first gathered in 1915." PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIOR RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 197 (1983). [hereinafter cited as PRESIDENT'S COMMISSION]. See also Kwang-Sun Lee, *Neonatal Mortality: An Analysis of the Recent Improvement in the United States*, 70 AM. J. PUB. HEALTH 15 (1980).
4. Surveys show that passive euthanasia is not uncommon and that many physicians comply with parental wishes to stop treatments for at least some abnormal infants. A. Shaw, J. Randolph, and B. Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIAT. 588 (Supp. 1977); D. Todres, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIAT. 197 (1977); and *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, 6 HASTINGS CENTER REP. 2 (1976).
"[D]octors have long withheld lifesaving medical support from grossly malformed in-

professions have long debated the ethics of foregoing life-sustaining treatment for newborns,⁷ the issue has recently attracted unprecedented public attention.⁸ Perhaps the best known case was that of "Infant Doe."

Born in April, 1982, "Infant Doe" suffered from Down's syndrome⁹

ants, allowing them to die at birth and often only telling the parents that their babies were stillborn." *The Hardest Choice*, TIME, Mar. 25, 1974, at 84.

Infanticide, however, is nothing new. Throughout history mankind has tolerated and even accepted its practice. Infanticide has served many different functions such as controlling adult sex ratios and populations; economic interests; superstition; and eliminating defective children. For a good discussion of infanticide, see V. Rosenblum & M. Budde, *Historical and Cultural Considerations of Infanticide*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN I* (D. Horan & M. Delahoyde eds. 1982). See also Williamson, *Infanticide: An Anthropological Analysis*, in *INFANTICIDE AND THE VALUE OF LIFE 61* (M. Kohl ed. 1978).

5. See, e.g., Longino, *Withholding Treatment From Defective Newborns: Who Decides, and on What Criteria?*, 31 U. KAN. L. REV. 377 (1983); Portels, *The Elin Daniels Case: An Examination of the Legal, Medical, and Ethical Considerations Posed When Parents and Doctors Disagree Whether to Treat a Defective Newborn*, 18 FORUM 709 (1983); Shapiro, *Medical Treatment of Defective Newborns: An Answer to the "Baby Doe" Dilemma*, 20 HARV. J. ON LEGIS. 137 (1983); Ellis, *Letting Defective Babies Die, Who Decides?*, 7 AM. J.L. & MED. 393 (1982); Brant & McNulty, *Treating Defective Newborns: The Ethical Dilemma*, 10 HUM. RTS. 34 (1982); Clarke, *The Choice to Refuse or Withhold Medical Treatment: The Emerging Technological and Medical Ethical Consensus*, 13 CREIGHTON L. REV. 795 (1980); Shaw, *Genetically Defective Children: Emerging Legal Considerations*, 3 AM. J.L. & MED. 333 (1977); Horan, *Euthanasia: Medical Treatment and the Mongoloid Child, Death or a Treatment of Choice?*, 27 BAYLOR L. REV. 76 (1975); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975); Note, *Withholding Treatment from Defective Infants: "Infant Doe" Postmortem*, 59 NOTRE DAME L. REV. 224 (1983) [hereinafter cited as *Postmortem*]; Comment, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEX. TECH L. REV. 569 (1983); Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699 (1982); Note, *Birth-Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599 (1975); Note, *Euthanasia: Criminal, Tort, Constitutional and Legislative Considerations*, 48 NOTRE DAME LAW. 1202 (1973).
6. See, e.g., Strong, *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, 11 LAW, MED. & HEALTH CARE 168 (1983); Koop, *Ethical and Surgical Considerations in the Care of the Newborn with Congenital Abnormalities*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN 89* (D. Horan & M. Delahoyde eds. 1982); Brown and McLone, *Treatment Choices for the Infant with Meningomyelocele*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN 69* (D. Horan & M. Delahoyde eds. 1982); Silverman, *Mismatched Attitudes about Neonatal Death*, 11 HASTINGS CENTER REP. 12 (1981); Campbell and Duff, *Moral and Ethical Dilemma: Seven Years into the Debate About Human Ambiguity*, 447 ANNALS 19 (1980); Black, *Selective Treatment of Infants with Myelomeningocele*, 5 NEUROSURGERY 334 (1979); Lorber, *Spina Bifida: To Treat or Not to Treat? Selection - The Best Policy Available*, 147 NURSING MIRROR 14 (1978); Diamond, *The Deformed Child's Right to Life*, in *DEATH, DYING AND EUTHANASIA 127* (D. Horan and D. Mall eds. 1977); McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 339 J. A.M.A. 172 (1974); Duff & Campbell, *Moral and Ethical Dilemma in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973).
7. Other professions have also discussed this issue: See, e.g., R. STINSON & P. STINSON, *THE LONG DYING OF BABY ANDREW* (1983) (parents of defective infant); Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 LAW, MED. & HEALTH CARE 120 (1982) (ethicist); Boyle, *Treating Defective Newborns: Who Decides? On What Basis?*, 63 HOSP. PROG. 34 (1982) (philosopher); McCarthy, *Treating Defective Newborns: Who Judges Extraordinary Means?*, 62 HOSP. PROG. 45 (1981) (clergy).
8. See, e.g., Lyon, *Life at any Price: Are Survivors Glad to Pay?*, Chi. Tribune, Feb. 10, 1983, at 14, col. 3; Tift, *Debate on the Boundary of Life*, TIME, Apr. 11, 1983, at 68, col. 1.
9. Down's syndrome is a chromosomal abnormality that produces varying degrees of mental retardation. See NELSON, *supra* note 2. Most infants with Down's syndrome do not require any unusual medical care at birth. For the few that do, the most common problems are gastrointestinal blockage and congenital heart defects. See PRESIDENT'S COMMISSION, *supra* note 3, at 203. Many of those afflicted with Down's syndrome are able to live fairly normal, productive lives. M. BUTSHAW & Y. PERRET, *CHILDREN WITH HANDICAPS, A MEDICAL PRIMER* (1981).

and an incomplete esophagus.¹⁰ After considering the alternatives,¹¹ his parents and physicians withheld treatment and nourishment. The Indiana court upheld their decision,¹² and "Infant Doe" died while a county prosecutor and an Indiana University law professor were preparing to appeal the case to the United States Supreme Court.¹³ The case triggered nationwide debate over whether the parent's decision was justified.¹⁴

The debate was accelerated recently with the birth of "Baby Jane Doe" in New York on October 11, 1983.¹⁵ Baby Jane Doe was afflicted with mental retardation as well as multiple birth defects.¹⁶ Her parents decided to forego surgery and opted for a "conservative" course of

10. This condition is called tracheo-esophageal fistula. It blocks the passage from the mouth to the stomach thereby preventing oral feeding. This condition can be corrected in most patients; 78% of patients without other anomalies survive corrective treatment. NELSON, *supra* note 2, at 803-05.

11. The parents could grant or refuse consent to life-sustaining treatment for their infant. The delivering obstetrician recommended treatment consisting of only sedation to keep the infant free of pain based on his opinion that the infant had no chance of having a minimally adequate quality of life. *In re the Treatment and Care of Infant Doe*, No. GU8204-004A (Ind. Cir. Ct., Apr. 12, 1982), *cert. denied sub nom. Doe v. Bloomington Hospital*, — U.S. —, 104 S. Ct. 394 (1983) [hereinafter cited as *Infant Doe*]. Opposing that alternative, a consulting pediatrician recommended that the infant be transferred to a hospital in Indianapolis for immediate surgery. *Id.*

The infant's father testified that he and his wife felt a minimally adequate quality of life was never possible for a Down's syndrome child. Thus, they directed that medical treatment, food, and water be withheld in accordance with the delivering obstetrician's recommendation. *Id.* at 3.

12. After holding hearings on the matter, the Monroe County Superior Court ordered the hospital to comply with the parents' non-treatment decision. *Id.* The court also appointed the Monroe County Department of Public Welfare as infant Doe's guardian for purposes of appeal, *id.* at 4; however, the Department declined to appeal.

On April 13, 1982, the juvenile referee *pro tem*, of the Monroe county Juvenile Court, denied a petition for an order to have custody of the child taken from the parents after finding no probable cause to suspect parental neglect. *Postmortem*, *supra* note 5, at 234. On April 14, 1982, the Monroe County prosecutor unsuccessfully appealed both rulings to the Indiana Supreme Court. *Id.* at 235.

On April 15, 1982, the Monroe County Juvenile Court denied both an injunction to force hospital officials to keep Infant Doe alive and a temporary restraining order to require the infant's parents to provide nutrition and medical care. *Id.* at 235 n.77.

A subsequent appeal to the Indiana Court of Appeals was dismissed as moot on February 3, 1983, due to the infant's death. The United States Supreme Court denied a petition for writ of certiorari to the Indiana Court of Appeals. *Doe v. Bloomington Hospital*, — U.S. —, 104 S. Ct. 394 (1983). All records other than the original Monroe County Superior Court's original order have been sealed.

13. *Postmortem*, *supra* note 5, at 235.

14. See, e.g., *The Stormy Legacy of Baby Doe: Should the Government Try to Save Severely Afflicted Infants*, TIME, Sept. 26 1983, at 58: *How can Doctors decide new life will be worth living?* Chi. Tribune, Feb. 8, 1983, at 14, col. 1; Trafford, *Doctor's Dilemma: Treat or Let Die?*, U.S. NEWS & WORLD REP., Dec. 6, 1982, at 58, col. 1; *Practice of Neglecting Badly Deformed Babies Stirs Troubled Debate*, Wall St. J., July 21, 1982, at 1, col. 1; *Was Indiana Couple Entitled to Allow Their Baby to Die?*, Chi. Tribune, May 22, 1982, at 6, col. 1.

15. See, e.g., *The Case of Baby Jane Doe*, NEWSWEEK, Nov. 14, 1983, at 45-46; *Whose lives are they anyway?*, TIME, Nov. 14, 1983; Wash. Post, Nov. 18, 1983, at A1, col. 3; N.Y. Times, Nov. 7, 1983, at 23, col. 4; NAT'L L. J., Nov. 7, 1983, at 6, col. 4.

16. Baby Jane Doe's defects included spina bifida with hydrocephalus, microcephaly, and other neurological defects. *Weber v. Stony Brook Hospital*, 467 N.Y.S.2d 685 (App. Div. 1983). For a discussion of these defects, see Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J. L. & MED. 393, 395 (1983).

medical treatment.¹⁷ Although the Suffolk County Supreme Court ordered the surgery,¹⁸ the Appellate Division reversed after finding no evidence that Baby Jane Doe was being deprived of adequate medical care or that her life was in "imminent danger."¹⁹ The New York Court of Appeals affirmed on procedural grounds.²⁰

The federal government entered the case when the Department of Health and Human Services (HHS) brought an action in the United States District Court²¹ alleging that University Hospital violated section 504 of the Rehabilitation Act of 1973²² by discriminating against a handicapped person. The HHS also alleged that the hospital violated 45 C.F.R. § 80.6(c)²³ by refusing to allow the HHS access to Baby Jane Doe's medical records. The District Court summarily dismissed the case.²⁴ The court would not allow the HHS access to the records if the hospital did not violate section 504.²⁵ Since the hospital lacked the legal right to perform the surgical procedures,²⁶ the court held that the hospital did not violate section 504 by discriminating against the infant and, therefore, denied the HHS access to her records.²⁷ The Second Circuit Court of Appeals affirmed the dismissal.²⁸

17. *Weber*, 467 N.Y.S.2d at 686. This conservative course of treatment became the subject of court challenge. *Id.*

18. *Id.*

19. *Id.*

20. *Weber v. Stony Brook Hospital*, 60 N.Y.2d 208, 456 N.E.2d 1186 (N.Y. Ct. App. 1983). Under section 1034 of the New York Family Court Act, the legislature assigned the primary responsibility for initiating child neglect proceedings to child protective agencies or persons acting at the family court's direction. In this case the procedure was initiated at the behest of a person unrelated to the family. The court stated that to allow any person to thus bypass the statutory requirements "would catapult him into the very heart of a family circle" to challenge the parents' responsibility to care for their children. *Id.* at 1188. Although the court stated there might be appropriate occasions for court action without consulting with a child protective agency, it found no such circumstances to justify this proceeding. *Id.*

21. *United States v. University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983).

22. See *infra* notes 47, 95 and accompanying text.

23. 45 C.F.R. § 80.6(c), incorporated by reference in 45 C.F.R. § 84.61, provides that the HHS may obtain access to such records as may be pertinent to ascertain whether or not federal fund recipients are discriminating against handicapped persons.

24. *University Hospital*, 575 F. Supp. at 616. The court did, however, reject defendants' claims that (1) the suit was barred by laches, *id.* at 611; (2) access to the records was barred by New York's physician-patient evidentiary privilege, *id.*; and (3) Medicare and Medicaid do not constitute "Federal Financial assistance" within the meaning of section 504. *Id.* at 612. Further, the court ruled that the entire hospital, not just its neonatal unit, was the "program or activity" covered by the statute. *Id.* at 612-13.

25. *Id.* at 614.

26. The hospital lacked legal authority to perform surgery because Baby Jane Doe's parents refused to consent to the surgery. *Id.*

27. *Id.* at 616.

28. *United States v. University Hospital*, No. 83-6343, slip op. (2d Cir. Feb. 23, 1984). Although similar issues were raised on appeal, the government alleged for the first time that the infant's records were necessary to determine whether the hospital's failure to seek a state court order overturning the parents' decision and compelling surgery was itself violative of section 504. *Id.* at 1911. The defendants, on the other hand, argued that section 504 provides no authority for this action. *Id.* at 1912. Although the court assumed that the entire hospital was covered by section 504, *id.* at 1915, it held that the statute did not authorize the type of investigation initiated by the HHS. *Id.* at 1939. After reviewing the statute's legislative history, the court determined that Congress never contemplated that section 504 would apply to treatment decisions involving defective newborns. *Id.* at 1938. Thus, the court held that until

These two cases are not isolated examples. Several courts have dealt with this issue; many have reached results contrary to the *Infant Doe* and *Baby Jane Doe* decisions. While the courts in the *Infant Doe* and *Baby Jane Doe* cases granted priority to parental rights of privacy,²⁹ other courts have granted priority to the defective infant's right to life.³⁰ This inconsistency is largely attributable to the courts' inability to clearly define the nature and extent of the rights and interests of the parties involved.³¹

For example, while the defective infant clearly has a right to life,³² commentators are split on whether these infants have a right to die.³³

Congress has spoken on this issue, it would be an unwarranted exercise of judicial power to approve the HHS investigation. *Id.* at 1939.

29. For example, in *Infant Doe*, *supra* note 11, the Monroe County court felt that the value of parental autonomy outweighed the infant's right to life where "a minimally adequate quality of life was non-existent." Letter from Judge John Baker of the Monroe County Superior Court to anonymous person 2 (June 8, 1983) (discussing rationale of the *Infant Doe* decision). The court also stated that the fourteenth amendment to the Constitution had been "often misquoted to stand for the right of life" but that its actual purpose is to protect familiar rights from undue governmental interference. *Id.* at 3.

See also *In Re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980). Phillip was a twelve year old Down's Syndrome child with a congenital heart condition. Without treatment the condition would cause a gradual deterioration of the lungs and eventual death. Phillip's parents refused to consent to surgery. The court upheld the parents' decision and stated that the state must overcome a "serious burden of justification" before abridging the parental autonomy presumption. *Id.* at 802, 156 Cal. Rptr. at 51.

30. See, e.g., *Matter of Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Bronx County Sup. Ct. 1979). Here, the parents of a newborn daughter with spina bifida and myelomeningocele refused to consent to corrective surgery for their child. The surgery could lessen the degree of paralysis and possibly prevent mental retardation; whereas untreated, the condition would cause death or extensive paralysis and mental retardation. Noting that parental rights are not absolute and that the state can exercise its *parens patriae* power to protect neglected infants, the New York Court ordered treatment. *Id.* at 702, 421 N.Y.S.2d at 967. The court stated: "But, where, as here, a child has a reasonable chance to live a useful, fulfilled life, the court will not permit parental inaction to deny that chance." *Id.*, 421 N.Y.S.2d at 968. "[I]t is our function to secure to each his opportunity for '[l]ife, liberty and the pursuit of happiness'." *Id.* (quoting *Matter of Weberlist*, 79 Misc. 753, 757; 360 N.Y.S.2d 783, 787 (N.Y. County Sup. Ct. 1972)).

In *In re Elin Daniels*, No. 81-15577FJO1, slip op. (Fla. Cir. Ct., June 23, 1981), the infant suffered from spina bifida with meningomyelocele. Without surgery death was imminent. With surgery, however, the child could live from six years to adulthood. Elin's parents consistently refused to consent to any form of treatment. After the hospital petitioned the court to order surgery, the court ruled in favor of the hospital and declared that parents do not have a right to refuse their child potentially life-saving treatment. *Id.*

Finally, in *In re Jeff and Scott Mueller*, Nos. 81J300 and 81J301, slip op. (Ill. 5th Cir., May 15, 1981) (order granting custody), the parents and attending physicians decided not to surgically separate Siamese twins joined at the waist. Upon petition to the court, the court awarded custody to the Illinois Department of Children and Family Services and authorized surgery and medical treatment for the twins. The court stated that the Illinois state constitution granted the twins an "inalienable right to life" that could not be disregarded by any "individual; professional group, legal, medical, or otherwise. . . ." *Id.* at 1.

31. The different parties include infant, parent, physician, and society in general. For an extensive discussion of these rights and interests, see Longino, *supra* note 5, at 383-98.
32. "No person shall . . . be deprived of life . . . without due process of law. . . ." U.S. CONST. amend. V. The fourteenth amendment requires that states provide the same guarantee. U.S. CONST. amend. XIV, § 1.
33. In determining the extent of an infant's right to medical treatment, some commentators argue that health care providers and courts should only consider the infant's right to life. See, e.g., Diamond, *Treatment Versus Nontreatment for the Handicapped Newborn*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 55 (D. Horan & M. Delahoyde eds. 1982); Koop, *supra* note 6, at 89. The common law "regards life itself as sacred and unalienable and

Moreover, the parents' general right to determine their infant's best interests,³⁴ a right which may conflict with the child's interests,³⁵ is protected by an expanding right to privacy.³⁶ The U.S. Constitution fails to resolve potential conflicts between parental and infant interests because it does not clearly delineate the extent of parents' right to privacy.³⁷ Furthermore, although the state has the power of *parens patriae*³⁸ to protect helpless children,³⁹ it must generally overcome a

prohibits anyone from committing suicide or licensing his own destruction." Clarke, *supra* note 5, at 815.

Underlying the "right to die" view are quality of life considerations. Thus, this position assumes that whenever the infant's potential quality of life is sufficiently low, death is preferable to continued existence. For a discussion of the quality of life standard, see Longino, *supra* note 5, at 395-97; Silverman, *supra* note 6.

34. "[T]here is a presumption, strong, but rebuttable, that parents are the appropriate decisionmakers for their infants. Traditional law, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents." PRESIDENT'S COMMISSION, *supra* note 3, at 212.

35. Parents can generally be expected to advance the child's best interests. Parham v. J.R., 442 U.S. 584, 602 (1979). However, their willingness to promote the defective infant's best interests can be influenced by other interests such as the financial burden of caring for a defective infant as well as the infant's effect on the family unit. For example, in one 1976 case, six months of treatment for a premature baby cost \$104,403.20. Stinson & Stinson, *On the Death of a Baby*, 7 J. MED. ETHICS 5, 10 (1981). As one commentator perceptively observed:

[I]f the child is treated at home, difficult and demanding adjustments must be made.

Parents must learn how to care for a disabled child, confront financial and psychological uncertainty, meet the needs of other siblings, and work through their own conflicting feelings. Mothering demands are greater than with a normal child, particularly if medical care and hospitalization are frequently required. Counseling or professional support may be nonexistent or difficult to obtain. Younger siblings may react with hostility and guilt, older with shame and anger. Often the normal feedback of child growth that renders the turmoil of childrearing worthwhile develops more slowly or not at all. Family resources can be depleted (especially if medical care is needed), consumption patterns altered, or standards of living modified. Housing may have to be found closer to a hospital, and plans for further children changed. Finally, the anxieties, guilt, and grief present at birth may threaten to recur or become chronic.

Robertson, *supra* note 5, at 257-58.

"Some families, however, find the experience of living through such a crisis a deepening and enriching one, accelerating personality maturation, and giving one a new sensitivity to the needs of spouse, siblings and others." *Id.* at 259. Thus, when parents consider family interests in deciding whether to raise a defective infant, they should recognize that some families find the experience beneficial.

36. PRESIDENT'S COMMISSION, *supra* note 3, n.63.

Familial privacy has received increasing protection from law throughout this century. In the earlier stages of legal development, the source of this protection was sometimes found in the constitutional right of religious freedom; it has gradually evolved into a more secular protection generally referred to as the right of privacy. The substantive core includes the authority of parents to establish family values, to set goals for the family and for its individual members, and to make decisions affecting the welfare of family members free from interference by agencies of the state. . . . The society as a whole benefits from promoting diversity, and privacy law has played an increasing role in protecting diverse life-styles and values.

For cases that established a liberty interest which was later expanded to a parental right to privacy, see Meyer v. Nebraska, 262 U.S. 390 (1923) (right to raise a child); Pierce v. Society of Sisters, 268 U.S. 510 (1925) (parents' right to control education of their children); Wisconsin v. Yoder, 406 U.S. 205 (1972) (parents' right to direct religious upbringing of children); Griswold v. Connecticut, 381 U.S. 479 (1965) (right to marital privacy); Roe v. Wade, 410 U.S. 113 (1973) (qualified right to terminate pregnancy).

37. *Postmortem*, *supra* note 5, at 228.

38. Under the *parens patriae* doctrine, the state has the right and duty to act as "the general guardian of all infants, idiots and lunatics." Hawaii v. Standard Oil Co., 405 U.S. 251, 256

strong presumption for parental freedom and authority.⁴⁰

The indefinite nature and extent of the rights of the parties involved in decisions to withhold treatment from defective infants lends confusion to this issue. Extensive ethical considerations, increased public concern, and inconsistent court decisions necessitate legislative guidance to establish a framework which ensures fair and consistent decisions.

The Federal Government has responded to this need through regulation. The Department of Health and Human Services recently released its final rules concerning this complex problem.⁴¹ Moreover, Congress is currently considering a bill that specifically includes the protection of handicapped infants as part of the Child Abuse Prevention and Treatment and Adoption Reform Act.⁴²

This note contends that although the HHS rules make a major advancement in the establishment of a proper framework, they do not represent the ideal solution. Congress must remedy the rules' shortcomings with corrective provisions by passing new legislation. This note briefly discusses the history and substance of the final rules. It then examines the constitutional and statutory framework of these rules. Finally, it analyzes the final rules' various provisions and shortcomings and proposes recommendations to advance the effectiveness of the final rules.

HISTORY OF THE HHS FINAL RULES REGARDING DEFECTIVE INFANTS

Within a month of "Baby Doe's" death,⁴³ the Department of Health and Human Services' Office for Civil Rights, at the prompting of the Reagan Administration,⁴⁴ issued a "notice" reminding hospitals and health care providers that withholding life-saving treatment from defective newborns could result in the withdrawal of federal financial

(1972)(citing 3 W. BLACKSTONE, COMMENTARIES 47). The doctrine gives states the right to intervene and preserve the physical or mental well-being of these individuals and promote their best interests despite the adverse interests of others. *See Prince v. Massachusetts*, 321 U.S. 158 (1943).

39. [A]s persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children, but may also supervise parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.

PRESIDENT'S COMMISSION, *supra* note 3, at 212-13.

40. For example, in *In re Phillip B.*, 42 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980), the court stated that the state must overcome a "serious burden of justification" before abridging the parental autonomy presumption. *Id.* at 802, 156 Cal. Rptr. at 51.

41. *See infra* notes 66-80, 118-52 and accompanying text.

42. S. 1003, 98th Cong., 1st Sess., 129 CONG. REC. S 4284 (daily ed. April 7, 1983). *See also infra* note 153.

43. *See Infant Doe* discussion *supra* notes 9-13.

44. On April 30, 1982, President Reagan issued a directive to the HHS to remind federal fund recipients of the applicability of section 504. Interim Final Rule, *infra* note 48, at 9630.

assistance.⁴⁵ The notice was promulgated under section 504 of the Rehabilitation Act of 1973⁴⁶ which prohibits discrimination against the handicapped by any federal fund recipient.⁴⁷

On March 7, 1983, the HHS issued an "interim final rule" stating its intent to enforce section 504 in cases involving the denial of treatment to handicapped newborns.⁴⁸ Although these initial rules were struck down on procedural grounds by a federal district court in April, 1983,⁴⁹ the HHS issued a new "proposed rule" less than three months later.⁵⁰

The new proposed rule essentially restated the initial rule. First, it reemphasized that section 504 of the Rehabilitation Act of 1973 prohibits the denial of medical treatment to defective infants on the basis of handicap.⁵¹ Second, it required hospitals to post a notice stating in large print: "Discriminatory failure to feed and care for handicapped infants is prohibited by federal law."⁵² Third, the proposed rule authorized HHS investigation teams to promptly respond to situations necessitating immediate remedial action.⁵³ Fourth, hospitals under investigation were required to provide the HHS with twenty-four hour

45. Notice to Health Care Providers, 47 FED. REG. 26,027 (1982) (notice issued May 18, 1982, applying 45 C.F.R. § 84 to health services for handicapped children). In the notice the HHS reminded health care providers at approximately 7,000 hospitals which receive federal assistance that existing HHS regulations apply § 504 of the Rehabilitation Act of 1973 to health services and treat Down Syndrome as a handicap within the meaning of § 504. PRESIDENT'S COMMISSION, *supra* note 3, at 226 n.95.

46. 29 U.S.C. § 794 (Supp. V 1981).

47. Section 504 states:

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

Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (Supp. V 1981).

Interpreting § 504, the notice stated:

[I]t is unlawful . . . to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life threatening condition if:

(1) the withholding is based on the fact that the infant is handicapped; and
(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

Notice to Health Care Providers, *supra* note 45, at 26,027.

48. Nondiscrimination on the Basis of Handicap, Interim Final Rule, 48 FED. REG. 9630 (1983) (modifying 45 C.F.R. § 84.61).

49. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). The HHS failed to issue the rule in accordance with Administrative Procedure Act (A.P.A.) notice requirements found in 5 U.S.C. § 553(b) and (d). *American Academy of Pediatrics*, 561 F. Supp. at 400. Moreover, the court declared the interim final rule invalid "as an arbitrary and capricious agency action which fails to meet the standard required under the A.P.A., 5 U.S.C. § 706(2)(A)." *Id.* at 399. Thus, the court ordered the HHS Secretary to invalidate the rule. *Id.* at 404.

50. Nondiscrimination on the Basis of Handicap Relation to Health Care for Handicapped Infants, Proposed Rule, 48 FED. REG. 30,846 (July 5, 1983) (proposed rules modifying 45 C.F.R. § 84.61) [hereinafter cited as Proposed Rule].

51. In clarifying its position, the HHS stated:

It is only when non-medical considerations, such as subjective judgments that an unrelated handicap makes a person's life not worth living, are interjected in the decision-making process that the section 504 concerns arise.

Id. at 30,847. Thus, section 504 does not apply to "medical decisions" made by parents and doctors to withhold treatment. *Id.*

52. *Id.* at 30,851.

53. *Id.* (proposed rule, to be codified at 45 C.F.R. § 84.61(c)).

access to hospital records and facilities.⁵⁴

Unlike the interim final rule, the proposed rule established an additional requirement that state child protective agencies enact procedures for identifying, investigating, and reporting cases involving the withholding of medically indicated treatment.⁵⁵ Moreover, the proposed rule allowed a two month comment period to comply with Administrative Procedure Act notice and comment requirements.⁵⁶ The rule would not become effective until HHS personnel evaluated comments received during this period.⁵⁷

Hospital and physician groups heavily criticized the proposed rule.⁵⁸ The American Academy of Pediatrics presented a detailed alternative to the proposed rule that rejected the applicability of section 504 and suggested instead that all hospitals, as a condition of participation in the Medicare program, establish a review committee.⁵⁹ These committees would develop hospital policies, monitor compliance, and review, on an emergency basis, specific cases involving the withholding of life-sustaining treatment.⁶⁰ The American Medical Association (AMA), however, opposed any government intervention, including government mandated hospital review boards.⁶¹ The AMA insists that section 504 was never intended to give the HHS authority to intervene in medical decisions.⁶²

After receiving and analyzing approximately 17,000 comments concerning the proposed rule,⁶³ and after holding a number of meetings to discuss the proposed rule with representatives of interested groups,⁶⁴ the HHS released its "final rule" on January 12, 1984.⁶⁵

The final rules are a hybrid. Like their predecessors,⁶⁶ the final rules are promulgated under section 504 of the Rehabilitation Act of 1973⁶⁷ and require hospitals to post warning notices that list a toll-free

54. *Id.* (proposed rule, to be codified at 45 C.F.R. § 84.61(d)).

55. *Id.* (proposed rule, to be codified at 45 C.F.R. § 84.61(e)).

56. The A.P.A. requires (inter alia) that notice, a comment period, and publication of the rule be given 30 days prior to its effective date, 5 U.S.C. § 533(b)-533(d).

57. Proposed Rule, *supra* note 50, at 30,846.

58. See, e.g., Annas, *Baby Doe Redux: Doctors as Child Abusers*, 13 HASTINGS CENTER REP. 26 (1983); Strong, *supra* note 6. For other critics, see *The New Right's Baby*, Wall St. J., Aug. 30, 1983, at 28, col. 1; *Baby Doe Needs No Big Brother*, N.Y. Times, July 26, 1983, at 20, col. 1.

59. Final Rule, *infra* note 63, at 1623.

60. *Id.*

61. *Baby Doe's: Children of life or death?*, Chi. Tribune, Jan. 15, 1984, at E1, col. 4.

62. *Id.*

63. *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, Final Rule*, 49 FED. REG. 1622, 1623 (1984)(amending 45 C.F.R. § 84) [hereinafter cited as Final Rule].

64. *Id.*

65. *Id.* at 1622. Although the title to 49 FED. REG. states "Final Rule," the text uses the plural form—"final rules." The author will use the plural form.

66. See discussion on section 504, *supra* notes 47, 51.

67. Final Rule, *supra* note 63, at 1622.

In interpreting section 504, the HHS set forth the applicable standard of care in the guidelines: "[H]ealth care providers may not, solely on the basis of present or anticipated physical or mental impairment of an infant, withhold treatment or nourishment from the infant who, in spite of such impairment, will medically benefit from the treatment or nour-

number for reporting abuses.⁶⁸ The notice, though, has a new heading⁶⁹ and need not be posted where "parents of infant patients will see it."⁷⁰ The final rules also adopt, without substantial change, the proposed rules' provision that state child protection agencies establish procedures to fully utilize their authority to prevent neglect of handicapped infants.⁷¹

The final rules have essentially eliminated the federal investigative squads⁷² by shifting the major responsibility for policing child neglect to hospitals and state governments. Unlike the proposed rules,⁷³ the final rules provide that a hospital need not report to a state agency until the hospital has internally reviewed a case and concluded that it should be reported.⁷⁴ Similarly, the state agencies need not report a case to the HHS immediately,⁷⁵ but merely on a "timely" basis.⁷⁶

The final rules grant hospitals significant responsibility in policing

ishment." *Id.* at 1653. The guidelines state that treatment which merely prolongs a defective infants' death is not considered medically beneficial treatment. *Id.* In determining medically beneficial treatment, the Department will respect "reasonable medical judgments." *Id.* Thus, section 504's effectiveness depends on the construction of "medically beneficial treatment" and the allowable latitude of "reasonable medical judgment." See *infra* notes 109 and 139.

68. Final Rule, *supra* note 63, at 1651. Notice A reads in part:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free; available 24 hours a day; TDD capability). The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

Cf. Proposed Rule, *supra* note 50, at 30,851.

69. See Notice A, *supra* note 68.

70. Final Rule, *supra* note 63, at 1651.

71. *Id.* *Cf.* Proposed Rule *supra* note 50, at 30,851.

72. The proposed rule encouraged a "vigorous federal role in enforcing the protections of section 504." Proposed Rule, *supra* note 50, at 30,846. The proposed rule also required state child protection agencies to immediately notify the HHS Office for Civil Rights "of each report of suspected medical neglect of a handicapped infant." *Id.* at 30,851. In cases where the HHS determined that immediate remedial action was necessary to protect a handicapped infant's life or health, the HHS could order an immediate investigation and make referrals to the Department of Justice for the necessary legal action to save the infant's life. *Id.* at 30,849. These federal investigation squads were the major sore spot with physicians and hospitals. *Chi. Tribune*, Jan. 15, 1984, at E-1, col. 4.

73. The proposed rules mandated that state agencies require health care providers to report "immediately" to the agency any "suspected cases of medical neglect of handicapped infants." Proposed Rule, *supra* note 50, at 30,851.

74. The final rules require that health care providers report to state agencies "on a timely basis . . . circumstances which they determine to constitute known or suspected instances of unlawful medical neglect of handicapped infants." Final Rule, *supra* note 63, at 1651.

75. The proposed rules required the agencies to immediately notify the HHS Office of Civil Rights. Proposed Rule, *supra* note 50, at 30,851.

76. Final Rule, *supra* note 63, at 1651.

infant neglect by encouraging hospitals to establish Infant Care Review Committees (ICRC's) to oversee questions of withholding care for critically ill infants.⁷⁷ The purpose of these committees is to assist the health care provider in developing "standards, policies, and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases."⁷⁸ The rules also encourage state agencies to consult with ICRC's and to give careful consideration to the committees' analysis and recommendations.⁷⁹ The final rules, however, do not require the establishment of ICRC's.⁸⁰ Thus, each hospital has complete discretion to determine the committee's composition and procedure or to determine whether to establish a committee at all.

ANALYSIS OF HHS FINAL RULES

Constitutional and Statutory Framework

Effectiveness of the final rules initially depends upon the constitutional and statutory authority under which the rule was promulgated. If the rules' authority is susceptible to challenge, the rules' effectiveness could be vitiated in one swift blow.

Pursuant to congressional authority,⁸¹ the HHS instituted rules requiring federal fund recipients, namely health care providers and state child protection agencies, to implement certain procedures for the protection of defective infants. By conditioning the receipt of federal funds on the implementation of required procedures, the HHS is clearly operating under the "spending power."⁸²

The United States Constitution authorizes Congress "to lay and collect taxes . . . and provide . . . for the general welfare of the United States."⁸³ The Supreme Court has frequently held that this clause authorizes Congress to provide financial assistance to state and local governments "to promote the general welfare."⁸⁴

77. *Id.* This position is consistent with the recommendation by the President's Commission. *See* PRESIDENT'S COMMISSION, *supra* note 3, at 227.

A model ICRC is set forth in the final rules. The rules call for a committee with at least seven members including a nurse, practicing physician, hospital administrator, representative of the legal profession, representative of a disability group, a lay person, and a member of the hospital's medical staff. Moreover, one ICRC member shall be designated to act as the infant's "special advocate" to ensure that all considerations favoring treatment are fully considered and evaluated by the ICRC. Final Rule, *supra* note 63, at 1652.

78. Final Rule, *supra* note 63, at 1652.

79. *Id.* at 1651-52.

80. *Id.* at 1651.

81. Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794; Rehabilitation Act Amendments of 1974, 29 U.S.C. § 706; Education of the Handicapped Act, § 606, 20 U.S.C. § 1405 as amended by Pub. L. No. 94-142, 89 Stat. 795; Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, § 321, 42 U.S.C. § 4581, as amended; Drug Abuse Office and Treatment Act of 1972 § 497, 21 U.S.C. § 1174, as amended.

82. *See infra* notes 83-89 and accompanying text.

83. U.S. CONST. art. VIII, § 8. This clause is known as the "spending power".

84. *See, e.g.,* Massachusetts v. Mellon, 262 U.S. 447 (1923); United States v. Butler, 297 U.S. 1

Congress' power to provide for the general welfare is independent from its other enumerated powers.⁸⁵ Congress can take any action to further the general welfare provided it does not violate some other constitutional provision such as the first, fifth, or fourteenth amendments.⁸⁶ Determining what furthers the nation's "general welfare" is uniquely a congressional function.⁸⁷ Moreover, the Supreme Court has held that Congress has the power to condition spending of appropriated funds.⁸⁸ Therefore, given such judicial deference, the constitutional limits on the HHS's spending power, as delegated by Congress,⁸⁹ seem all but illusory.

Arguably, however, the tenth amendment can limit congressional spending power.⁹⁰ In *Pennhurst State School v. Halderman*,⁹¹ the Supreme Court set forth a procedural requirement that the Federal Government must satisfy before it can enforce grant conditions. The Court ruled that Congress must explicitly state its intent before imposing conditions on the states through its spending power.⁹² The holding appears applicable when a federal agency has taken broad statutory language to write restrictive rules or mandates. Since *Pennhurst* places a premium on specificity, the statutory language that supposedly warrants these rules or mandates will be read narrowly and will be strictly construed against the claimant.⁹³

While it does not vitiate constitutional spending power, *Pennhurst*

(1936); *Steward Machine Co. v. Davis*, 301 U.S. 548 (1937); *Oklahoma v. U.S. Civil Service Commission*, 330 U.S. 127 (1947). For a criticism of the Court's acquiescence to Congress' spending power, see ADVISORY COMMISSION ON INTERGOVERNMENTAL RELATIONS, IN BRIEF: THE FEDERAL ROLE IN THE FEDERAL SYSTEM: THE DYNAMICS OF GROWTH 15 (1980).

85. *Butler*, 297 U.S. at 65.

86. *Id.* at 73-74. Federal grant conditions to guarantee the handicap's right to equal protection clearly do not violate these constitutional provisions. To the contrary, the right to equal protection is a fundamental constitutional right. U.S. CONST. amend XIV, § 1.

87. In *Helvering v. Davis*, 301 U.S. 619 (1937), the Supreme Court stated: "When money is spent to promote the general welfare, the concept of welfare or the opposite is shaped by Congress, not the states." *Id.* at 645.

88. *Oklahoma v. U.S. Civil Services Commission*, 330 U.S. 127 (1947). See also *Oklahoma v. Schweiker*, 655 F.2d 401 (D.C. Cir. 1981); *Lau v. Nichols*, 414 U.S. 563 (1974); *Fullilove v. Klutznick*, 448 U.S. 448 (1980).

89. See list of statutes, *supra* note 81.

90. The Supreme Court left this possibility open in *National League of Cities v. Usery*, 426 U.S. 833 (1976). However, considering the Supreme Court's refusal to clarify *Usery*, and the unanimity of the lower federal courts, it is unlikely that *Usery* will limit federal grant conditions. See, e.g., *North Carolina v. Califano*, 445 F. Supp. 532 (E.D.N.C. 1977), *aff'd*, 435 U.S. 962 (1978). For an extensive list of lower federal court decisions uniformly rejecting *Usery* based claims of unconstitutionality, see CAPPALLI, FEDERAL GRANTS AND COOPERATIVE AGREEMENTS: LAW, POLICY, AND PRACTICE § 10:13 (1982).

91. 451 U.S. 1 (1981).

92. Viewing a grant as a contract document, Justice Rehnquist held that grant conditions imposed by federal agencies are enforceable only if Congress clearly expressed its intent to impose those conditions so that states can knowingly decide whether or not to accept those funds. "Accordingly, if Congress intends to impose a condition on the grant of federal moneys, it must do so unambiguously." *Id.* at 17. Some commentators, however, interpret the holding under eleventh amendment doctrine and not contract analogy. See, e.g., Baker, *Making the Most of Pennhurst's "Clear Statement Rule"*, 31 CATH. U.L. REV. 439 (1982).

93. CAPPALLI, *supra* note 90, at § 10:10.

does require an analysis of section 504 of the Rehabilitation Act of 1973 to determine whether the HHS reasonably construed the statute when it created the rules designed to protect defective infants.⁹⁴

Section 504 states:

No otherwise qualified handicapped individual in the United States, as defined in section 7(7) of this Act, 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.⁹⁵

While the statute clearly creates individual rights, the specific scope of these rights is unclear. Some commentators believe that the HHS final rules exceed the authority granted to the Department under section 504.⁹⁶ They argue that the legislative history of section 504 makes no mention of handicapped infants,⁹⁷ that infants do not fit under the definition of "handicapped individuals,"⁹⁸ and that the statute was not intended to cover medical judgments concerning the type of treatment given any handicapped individual.⁹⁹ Yet, reasoned authority to the contrary indicates that the HHS acted properly under section 504.

First, section 504 was enacted to eliminate discrimination against handicapped persons. One may reasonably conclude that decisions to withhold treatment from infants, which are based in part on stereotypes and prejudices concerning the quality of a handicapped individual's life,¹⁰⁰ do not constitute "medical judgments"¹⁰¹ and therefore section 504 does apply.

Second, although Congress originally defined "handicapped individual" in vocational terms,¹⁰² it realized that such a narrowly drawn

94. For an extensive discussion of section 504, *see id.* § 20:01-20:67.

95. 29 U.S.C. § 794. This reading edits out the 1978 addition which is not relevant to this discussion. Before 1978, this provision was numbered section 504. For purposes of this note, 29 U.S.C. § 794 shall be referred to as section 504.

96. *See, e.g., American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Although the court decided the case on other grounds, it stated:

As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. . . . Moreover, until the April, 1982, communication from President Reagan the record does not reflect any official indication that the section was subject to this interpretation during the many years it had by then already been in effect.

Id. at 401. *See also* Final Rule, *supra* note 63, at 1635.

97. Final Rule, *supra* note 63, at 1635.

98. *Id.*

99. *Id.*

100. *Id.* at 1635.

101. As the final rules demonstrate, a contrary view would lead to an unacceptable result: [A]lthough the section 504 analysis may be more subtle (at least in some cases), it is an anomalous and bizarre theory that section 504 can properly be used to require that a ramp be built in a hospital to assure that handicapped persons not be denied access to medical services solely on the basis of their handicaps but that statute may not properly be used to prevent the intentional act of allowing other handicapped persons to die in that hospital, solely because of their handicaps. The Department cannot subscribe to this theory.

Id.

102. *See* 29 U.S.C. § 706(b) (Supp. III 1973).

definition detracted from the purpose of section 504 "to prevent discrimination against all handicapped individuals, regardless of their need for, or ability to benefit from . . . any other Federally-aided programs."¹⁰³ Congress therefore enlarged the definition to include "an person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such impairment, or (C) is regarded as having such an impairment."¹⁰⁴

Given the statute's broad language, and its similarity to other Civil Rights statutes which have been broadly construed,¹⁰⁵ section 504 authorizes some departmental regulation concerning the provision of medical care to handicapped infants.¹⁰⁶ Because defective infants have impairments of at least some "major life activities,"¹⁰⁷ they fall within the statutory definition of "handicapped individuals."¹⁰⁸ Moreover, since many defective newborns can benefit medically from treatment or services,¹⁰⁹ these infants are "otherwise qualified"¹¹⁰ to receive that treatment or service.¹¹¹

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

104. 29 U.S.C. § 706(7)(B) (Supp. V 1981). The accompanying regulations further clarify the definition of handicapped. Under these regulations:

(i) "Physical or mental impairment" means (A) any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the . . . body systems . . . or (B) any mental or psychological disorder. . . .

(ii) "Major life activities" means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.

(iii) "Has a record of such an impairment" means has a history of, or has been misclassified as having, a mental or physical impairment that substantially limits one or more major life activities.

(iv) "Is regarded as having an impairment" means (A) has a physical or mental impairment that does not substantially limit major life activities but that is treated by a recipient as constituting such a limitation; (B) has physical or mental impairment that substantially limits major life activities only as a result of the attitudes of others toward such impairment; or (C) has none of the impairments of this section but is treated by a recipient as having such an impairment.

45 C.F.R. § 84.3(j)(2) (1982). A "qualified handicapped person" is defined as ". . . (4) with respect to other services, a handicapped person who meets the essential eligibility requirements for the receipt of such services." *Id.* § 84.3(k)(4).

105. S. REP. NO. 890, 95th Cong., 2d Sess. 19 (1978).

"The joint explanatory statement accompanying the conference report on H.R. 14225 (the Rehabilitation Act Amendment of 1974) stressed this parallel relationship between section 504 and Title VI of the Civil Rights Act of 1964, and noted that application of the provisions relating to discrimination on the basis of race, creed, color or national origin would assure administrative due process, and provide for administrative consistency within the Federal Government."

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

107. *See supra* note 104 and accompanying text.

108. *Id.*

109. *See, e.g.,* PRESIDENT'S COMMISSION, *supra* note 3, at 197. However, as the final rule states: "Futile treatment or treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant." Final Rule, *supra* note 63, at 1653. For examples of such medically beneficial treatment, *see id.* at 1654.

110. *See supra* note 104 and accompanying text.

111. Final Rule, *supra* note 63, at 1636.

Furthermore, since Medicaid and Medicare constitute federal financial assistance, health care providers receiving these funds are programs receiving "Federal financial assistance" within the meaning of the statute.¹¹² Defective infants are handicapped individuals otherwise qualified to receive the benefits of federally-funded medical programs. Thus, they are within the protection of section 504.

Third, the fact that the legislative history reveals that Congress did not specifically mention handicapped infants in section 504 is insignificant since Congress approved section 504 with very little debate.¹¹³ The Senate Committee report merely repeats or paraphrases the words of section 504.¹¹⁴

By adopting section 504, Congress simply granted equality to the handicapped. It did not exclude any particular class of handicapped people. A later session of Congress removed any doubt about who is included in the coverage of section 504 by stating that the statute "was enacted to prevent discrimination against *all* handicapped individuals . . . in . . . health services."¹¹⁵ Although the Congress that enacted the statute did not fully address the purpose and intent of section 504, this later session of Congress was sufficiently contemporaneous with the original enactment to reflect fairly its goals.¹¹⁶

Furthermore, the current Congress approves of including handicapped infants within the coverage of section 504. Congress has not objected to the promulgation of the rules under section 504, nor has it attempted to alter the rules. Congressional acquiescence in administra-

112. For an extensive discussion concerning the status of Medicaid and Medicare as programs of federal financial assistance, see Final Rule, *supra* note 63, at 1638-40. For relevant legislative history of Medicaid and Medicare, see 111 CONG. REC. 15803, 15813 (1965).

For case precedent on the proposition that Medicaid and Medicare reimbursements constitute "federal financial assistance," see, e.g., *United States v. Baylor University Medical Center*, 564 F. Supp. 1495 (N.D. Tex. 1983), *stay granted pending appeal*, 711 F.2d 38 (5th Cir. 1983); *NAACP v. Wilmington Medical Center, Inc.*, 453 F. Supp. 280 (D. Del. 1978); *NAACP v. Wilmington Medical Center, Inc.*, 453 F. Supp. 330 (D. Del. 1978); *United States v. Cabrini Medical Center*, 497 F. Supp. 95, 96 n.1 (S.D.N.Y. 1980), *rev'd on other grounds*, 639 F.2d 908, 910-11 (2d Cir. 1981); *Bernard B. v. Blue Cross and Blue Shield*, 528 F. Supp. 125, 132 (S.D.N.Y. 1981), *aff'd*, 679 F.2d 7 (2d Cir. 1982); *Flora v. Moore*, 461 F. Supp. 1104, 1115 (N.D. Miss. 1978); *Bob Jones University v. Johnson*, 396 F. Supp. 597, 603 n.21 (D.S.C. 1974), *aff'd*, 529 F.2d 514 (4th Cir. 1975).

However, on February 28, 1984, the Supreme Court gave a narrow interpretation to "program or activity receiving Federal financial assistance" in *Grove City College v. Bell*, 52 U.S.L.W. 4283 (U.S. Feb. 28, 1984). If this narrow interpretation is extended to the receipt of Medicaid and Medicare funds by health care providers, any direct application of section 504 to hospitals could be vitiated. The author believes, however, that the congressional intent and long case precedent for Medicaid and Medicare constituting "Federal financial assistance" precludes extension of the *Grove City College* rationale to this situation.

113. CAPPALLI, *supra* note 90, § 20:01.

Section 504 was approved without a murmur because it had no visible costs. It simply granted equality to the handicapped in federally-assisted programs, leaving the problem and expense of implementation to grantees. So, a congressional committee report was able to estimate a budgetary impact of zero.

114. See S. REP. NO. 318, 93d Cong., 1st Sess., *reprinted in* 1973 U.S. CODE CONG. & AD. NEWS 2091, 2123, 2143.

115. S. REP. NO. 1297, *supra* note 103 (emphasis added).

116. CAPPALLI, *supra* note 90, § 20:05.

tive practice may be inferred from silence and presumed knowledge of the rules as well as from failure to alter with actual knowledge of the administrative interpretation.¹¹⁷ Hence Congress originally intended, and continues to acquiesce in, the inclusion of handicapped infants within section 504's coverage.

Therefore, the HHS has properly utilized its constitutional and statutory authority in creating the final rules. As *Pennhurst* requires, section 504 is sufficiently specific to authorize HHS to promulgate the final rules.

Substantive Provisions of the Final Rules

Section 504 of the final rules essentially creates an equal-treatment, nondiscrimination standard.¹¹⁸ It is not a right-to-life statute. Section 504 simply protects handicapped individuals from being treated differently than nonhandicapped individuals. The HHS final rules have the difficult task of ensuring that this standard is adhered to when dealing with handicapped infants. The HHS has two alternatives to properly enforce this standard. First, section 504's standard is clearly enforced if the HHS final rules prohibit *any* withholding of treatment from handicapped infants. Second, absent such a prohibition, the standard is enforced only if the rules set forth firm requirements that ensure the equal protection of handicapped infants in withholding treatment decisions. The HHS has opted for the latter. Unfortunately, the final rules do not *guarantee* equal protection in *all* withholding treatment decisions.

Compared to the proposed rule,¹¹⁹ the final rules seem to have taken a step backwards in protecting handicapped infants. Whereas the proposed rule prohibited health care providers from causing death by starvation or dehydration,¹²⁰ the final rules do not take such a definitive stance. They seem to allow at least some denial of intravenous feeding to be decided on a case by case basis.¹²¹ The final rules have

117. *Norwegian Nitrogen Products Co. v. United States*, 288 U.S. 294 (1933); *Costanzo v. Tillinghast*, 287 U.S. 341 (1932); *Long v. Dick*, 87 Ariz. 25, 347 P.2d 581 (1959). Moreover, courts generally give great weight to an agency's statutory interpretation. *Zenith Radio Corp. v. United States*, 437 U.S. 443 (1978).

118. Proposed Rule, *supra* note 50, at 30,851.

119. See *supra* notes 50-57 and accompanying text.

120. The proposed rule stated:

At the same time, the basic provision of nourishment, fluids, and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment. Even if a handicapped infant faces imminent and unavoidable death, no health care provider should take upon itself to cause death by starvation or dehydration. Routine nursing care to provide comfort and cleanliness is required to respect the dignity of such an infant. To deny these forms of basic care to handicapped individuals would constitute discrimination contrary to Section 504.

Proposed Rule, *supra* note 50, at 30,852.

121. Paraphrasing the final rule:

There are few definitive statements on the various dimensions of the applicability of handicapped discrimination law. Hence, it would be imprudent to speculate on the outcome of applying section 504 in a wide variety of specific factual circumstances. The law and government cannot prospectively and unequivocally answer every hypothetical question. Thus, in many cases, "the law, like medical treatment, can only be applied on a case-by-case

also shifted the major responsibility for policing infant neglect from federal agencies to hospitals and state agencies.¹²²

These policy changes would be of minor significance for enforcement of section 504 if the final rules mandated standards and procedures that *guarantee* defective infants equal protection in decisions about whether to withhold life-sustaining treatment. Unfortunately, the final rules lack mandates providing for impartial decisionmaking. The recommendations and guidelines advancing an infant's equal protection within the decisionmaking process remain wholly voluntary. The final rules, therefore, cannot *guarantee* the equal protection of handicapped infants.¹²³

The mandatory aspects of the final rules "deal only with several discreet points"¹²⁴ and include:

First, hospitals must post an informational notice. Second, the normal 10-day notice before initiating action to effect compliance can be waived when immediate access is necessary. Third, access by the Department to pertinent records and facilities can be obtained after "normal business hours" when immediate access is necessary. Fourth, state child protection services agencies must establish procedures to utilize their full authority under state law to prevent medical neglect of handicapped infants.¹²⁵

Admittedly, these mandates are important. Ultimately, they advise people about legal requirements concerning handicapped infant discrimination, provide mechanisms for reporting section 504 violations, ensure prompt access to medical records,¹²⁶ require "reasonable assurance of compliance"¹²⁷ with state standards, and allow for swift remedial action for non-compliance. The mandates, however, have little bearing on the critical issue of ensuring impartial decisionmaking in denial of treatment cases.

In comparison, the voluntary aspects of the final rules can assure

basis with a full appreciation for the facts presented." Final Rule, *supra* note 63, at 1632. Thus, by implication the HHS rule will allow some denials of intravenous feeding to be decided case by case.

122. See *supra* notes 72-80 and accompanying text.

123. A caveat may be necessary. Since the HHS proposed these guidelines, it is fair to assume that the HHS will follow those guidelines applicable to itself. Consequently, the HHS will normally take the following procedure:

If a hospital has an ICRC, federal investigators, 'unless impractical,' will wait 24 hours after receiving reports of withheld treatment to allow the ICRC to consider the case and make its analysis and recommendations. An HHS medical consultant will contact the Committee. After receiving the Committee's report and input from the medical consultant, the investigators will determine whether an on site visit is necessary. The HHS will carefully review the complaints to prevent unnecessary on site investigations. If an investigation is authorized, the investigators first meet with the ICRC.

Final Rule, *supra* note 63, at 1631-32.

124. *Id.* at 1628.

125. *Id.*

126. This requirement has been successfully challenged in court. See *supra* notes 21-28 and accompanying text.

127. Final Rule, *supra* note 63, at 1627.

impartial decisionmaking. The final rules recommend that health care providers establish Infant Care Review Committees (ICRC's).¹²⁸ The purpose of such committees is to "assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases."¹²⁹ The rules suggest that these committees operate under very strict standards.¹³⁰ If health care providers voluntarily implement and adhere to the recommendations and guidelines, the final rules will offer equal protection to handicapped infants.

By establishing an ICRC, health care providers can improve the ability of parents and physicians to decide whether to withhold treatment from defective infants. An ICRC can ensure that the best and most current information is available and used by parties making decisions about life-sustaining treatment.¹³¹ For example, parents will be fully informed of the infant's condition and prognosis and will also be provided with names of and access to various public and private agencies which provide services to infants with similar conditions.¹³² This information may afford parents and physicians a better context in which to make treatment decisions. Moreover, an ICRC could correct communication problems that often exist between health care providers and parents.¹³³

Furthermore, an ICRC can ensure that the infant's rights and interests are fully considered. The final rules provide for a model ICRC¹³⁴ which calls for broad representation of differing backgrounds and perspectives within the committee's membership.¹³⁵ This broad representation will likely prevent decisions to withhold treatment from being made solely by those parties whose interests may conflict with those of the infants.¹³⁶ The model ICRC also designates one committee member as "special advocate" for the infant to ensure that all considerations favoring life-sustaining treatment are fully evaluated and regarded by the ICRC.¹³⁷ Since a child's best interests usually depend on who de-

128. *Id.* at 1651. This position is consistent with the recommendation by the President's Commission. See PRESIDENT'S COMMISSION, *supra* note 3, at 227.

129. Final Rule, *supra* note 63, at 1651.

130. Quoting from "Principles of Treatment of Disabled Infants," the final rule states:
Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

Id. at 1652.

131. PRESIDENT'S COMMISSION, *supra* note 3, at 224.

132. Final Rule, *supra* note 63, at 1653.

133. PRESIDENT'S COMMISSION, *supra* note 3, at 224.

134. Final Rule, *supra* note 63, at 1652.

135. See Final Rule, *supra* note 77.

136. Parents and the infant's treating physician generally fall into this category. For a good discussion of these conflicting rights and interest, see Longino, *supra* note 5, at 383-92. See also *supra* notes 32-38 and accompanying text.

137. Final Rule, *supra* note 63, at 1653. The full consideration of the child's best interests seems

finest what those interests are, the presence of a "special advocate" will provide the infant with a "voice" to defend its interests against those who might fail to take its interest into account. Moreover, the presence of a "special advocate" can prevent a committee, which may be generally sympathetic to parents or physicians, from merely rubber stamping parents'¹³⁸ or treating physicians'¹³⁹ decisions to withhold treatment from a defective infant.

An ICRC can also ensure appropriate review of these cases to provide full protection of the infant's interests. The rules state: "[t]he hospital will, to the extent possible, require in each case that life-sustaining treatment be continued, until the ICRC can review the case and provide advice."¹⁴⁰ Should the ICRC disagree with a family's refusal to consent to continued treatment, the ICRC can recommend to the hospital board that the case be referred immediately to an appropriate court or child protection agency, and that every effort be made to continue treatment and maintain the infant's condition throughout the process.¹⁴¹

The ICRC and accompanying guidelines provide an effective means to promote equal protection of handicapped infants by ensuring improved conditions for decisionmaking as well as providing a detached but passionate inquiry into the decisionmaking process. Therefore, the final rules have provided an effective means to advance the equal-treatment, nondiscrimination standards of section 504 towards handicapped infants.

The ICRC and accompanying guidelines are not mandatory, however, but advisory.¹⁴² Consequently, like the final rules' mandatory aspects, the recommended procedures cannot *guarantee* the equal protection of handicapped infants. Health care providers may opt for alternative review procedures or may establish an ICRC, but do so according to their own guidelines.¹⁴³ Admittedly, some health care prov-

to conform with the conception of social policy that since a child's life is at stake, reason requires that his interests should prevail.

138. The shock of having a defective infant can overwhelm parents with grief, guilt, personal blame, and hopelessness. See Fletcher, *Attitudes Toward Defective Newborns*, 2 HASTINGS CENTER STUDIES 21 (1974). No sensitive person can fail to sympathize with the parents' situation or can casually condemn their decision. Therefore, a "special advocate" can ensure that the infant's interests are considered during these difficult times.

139. The standard of care in treating defective newborns is the provision of "medically beneficial" treatment, as determined by "reasonable medical judgments," which cannot be withheld solely because of the infant's present or anticipated physical or mental impairment. Final Rule, *supra* note 63, at 1653. Consequently, the degrees of section 504 protection afforded to handicapped newborns depends in part on the construction of "medically beneficial" treatment and the allowable latitude of "reasonable medical judgments." See AMERICANS UNITED FOR LIFE, SUMMARY ANALYSIS OF FINAL "BABY DOE" RULES WITH RECOMMENDATIONS FOR ACTION 6-7 (1984). Therefore, the "special advocate" can advance section 504 protection by ensuring that medical judgments are not based upon the infant's present or anticipated impairments.

140. Final Rule, *supra* note 63, at 1653.

141. *Id.*

142. *Id.* at 1652.

143. Once a particular review procedure is adopted, it will be difficult to assess whether the basis

iders may implement procedures providing as much or more protection to handicapped infants than the guidelines require. With no required elements, however, nothing ensures that health care providers will implement procedures that provide equal protection.

Since the final rules have shifted the responsibility of reviewing treatment decisions to local entities,¹⁴⁴ the lack of any required guidelines will likely result in an extensive variation of review procedures throughout the United States. In a nation comprised of diverse interests and beliefs,¹⁴⁵ this variation in review procedures does not guarantee equal protection for defective infants. For example, if a hospital should establish a review committee with no "special advocate,"¹⁴⁶ the handicapped infant has no guarantee that his or her rights and interests will be fully considered,¹⁴⁷ that the reviewing body will not merely rubber stamp the decisions of parents and physicians,¹⁴⁸ or that any member of the committee will even feel personally responsible for the choices made.¹⁴⁹ Furthermore, since pediatricians frequently acquiesce to parents' decisions refusing consent,¹⁵⁰ a review committee consisting primarily of pediatricians rather than a diverse membership will fail to ensure that the handicapped infant's rights and interests are fully considered.

Therefore, the final rules lack effective mandatory guidelines to ensure equal protection of handicapped infants in decisions to forego life-sustaining treatment and in the procedures for review of these decisions. The decisionmaking process can be emotional¹⁵¹ and filled with conflicting interests¹⁵² that overcome equal protection considerations. Thus, the final rules do not effectively promote the equal treatment, nondiscrimination standard of section 504.

RECOMMENDATIONS

The United States Senate is currently considering a bill¹⁵³ that spe-

for the reviewing body's decisionmaking is indeed medical indications or whether it involves biased quality of life considerations.

144. See *supra* notes 72-80 and accompanying text.

145. For example, many views are espoused concerning the nature and extent of a handicapped infant's rights. See *supra* notes 138-140 and accompanying text.

146. See *supra* notes 120-26 and accompanying text.

147. See, e.g., *Infant Doe*, *supra* notes 9-14 and accompanying text.

148. See *supra* notes 139-40 and accompanying text.

149. See Annas, *In re Quinlan: Legal Comfort for Doctors*, 6 HASTINGS CENTER REP. 29, 30-31 (1976).

150. For a list and explanation of surveys soliciting physicians' views on acquiescing, see PRESIDENT'S COMMISSION, *supra* note 3, at 208.

151. See discussion, *supra* note 139.

152. For a review of these conflicting rights, see discussion *supra* note 36. See also Longino, *supra* note 5, at 383-92.

153. See S. 1003, 98th Cong., 1st Sess., 129 CONG. REC. S4284 (daily ed. April 7, 1983). Also, on February 2, 1984, the House of Representatives passed H.R. 1904, 98th Cong., 1st Sess., 129 CONG. REC. H878 (daily ed. Mar. 3, 1983), to extend and improve the provisions of the Child Abuse Prevention and Treatment Act and the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978. American Bar Association, Washington Summary, Jan. 30-Feb. 3, 1984, at 1, col. 1. The Act directs, *inter alia*, the HHS to establish guidelines for

cifically incorporates protection of handicapped infants into the Child Abuse Prevention and Treatment and Adoption Reform Act.¹⁵⁴ The bill would require studies of existing procedures and the legal, medical, and ethical issues involved in treating defective infants, and would require that the Secretary of the HHS, based on these studies, recommend procedures and regulations to deal with such situations.

The Secretary should encourage the statutory incorporation of the HHS final rules¹⁵⁵ as amended by the following recommendations:¹⁵⁶

1. mandate the use of "special advocates" in all review procedures;
2. establish the denial of medical treatment in a situation like the *Bloomington Infant Doe* case as a violation of section 504; and
3. select medical consultants that support the HHS final rules.

First, mandating the use of "special advocates"¹⁵⁷ in all review procedures furthers the policy and goal of the final rules. Special advocates would ensure that the health care provider fully evaluates all considerations favoring life-sustaining treatment.¹⁵⁸ Such a mandate guarantees that at least one person reviewing the case feels personally responsible for the decisions made and that the infant's rights and interests are considered as thoroughly as other competing rights and interests.¹⁵⁹

This recommendation does not constitute excessive federal intervention. The final rules do not require the establishment of ICRC's in order to grant health care providers flexibility to establish review procedures that are best-suited for themselves.¹⁶⁰ Since the use of special advocates is the only requirement, this recommendation maintains flexibility in establishing review procedures and does not promote excessive federal interference with local health care.

Second, by specifically finding the medical situation in the Bloom-

advisory committees to provide advice on the care and treatment of seriously ill newborns.
Id.

154. Child Abuse Prevention and Treatment Act of 1974, Pub. L. No. 93-247, 88 Stat. 4, *amended by* Child Abuse Prevention and Treatment and Adoption Reform Act of 1978, Pub. L. No. 95-166, 92 Stat. 205; Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357, 488-89 (codified at 42 U.S.C. §§ 5101-5115 (Supp. II 1976)).

155. By adopting the HHS regulation within its bill, Congress will indirectly grant its approval of HHS's interpretation of section 504. *Great Northern R. Co. v. United States*, 315 U.S. 262 (1942). By approving HHS's interpretation of section 504, Congress will have provided the congressional action which the Second Circuit Court of Appeals felt was lacking in *United States v. University Hospital*, No. 83-6343. See discussion *supra* note 28. The author, however, agrees with the dissent in *University Hospital*, which stated, "[o]nce section 504's legislative heritage is acknowledged, the 'void' in the legislative history is eliminated and the many issues raised by the defendants with regard to medical decisions, parental judgments, and state authority simply evaporate." *Id.* at 1941. By adopting HHS's regulation, Congress will have protected handicapped infants' fairly won political victory.

156. These recommendations are suggested with the hope that the Federal Government continues its protection of handicapped infants with increased concern for programs that aid parents with the burdens and responsibilities of caring for these infants.

157. See *supra* notes 137-40 and accompanying text.

158. Final Rule, *supra* note 63, at 1653.

159. See *supra* note 137 and accompanying text.

160. Final Rule, *supra* note 63, at 1624.

ington *Infant Doe* case¹⁶¹ violative of section 504, the HHS could demonstrate its intent to enforce section 504 standards. Although the *Infant Doe* decision is almost universally condemned,¹⁶² the final rules fail to prohibit medical decisions in cases substantially similar to the *Infant Doe* case. While the guidelines to the final rules condemn such decisions,¹⁶³ the guidelines remain merely illustrative.¹⁶⁴ Finding that *Infant Doe* type medical decisions violate section 504 will further the equal protection rights of infants while allowing continued case by case analysis in other more severe cases.

This recommendation will also establish a minimum standard to which all state child protection agencies will be held responsible. State agencies which fail to challenge such a medical decision will be held to have violated section 504.¹⁶⁵ Such a standard is essential since, if section 504 is held inapplicable to hospitals,¹⁶⁶ only state agencies would be subject to this section.

Third, selecting medical consultants who support the final rules will increase the rules' effectiveness.¹⁶⁷ Once notified of potential section 504 violations, an HHS medical consultant will review the health care provider's report. Use of medical consultants who are indifferent or opposed to the final rules fails to guarantee the rights of handicapped infants. Therefore, the HHS Secretary should establish an advisory committee,¹⁶⁸ comprised of physicians nominated by organizations committed to the implementation of the final rules, designed to recommend medical consultants for each federal region. Only in that manner can the rights of handicapped infants be guaranteed.

CONCLUSION

Achieving consistent decisions about withholding medical care from handicapped infants is essential if these children are to receive full equal protection as guaranteed by the Constitution. Consistency can only be achieved by either requiring that all defective infants be medically treated or by allowing case by case analysis based on firm

161. See *supra* notes 9, 10 and accompanying text.

162. AMERICANS UNITED FOR LIFE, *supra* note 139, at 10. For example, Dr. Harry Jenison, executive director of the American Academy of Pediatrics, stated: "[T]he decision made in Bloomington, Ind., was wrong. . . . No child should ever be denied treatment on the basis that he is also retarded and handicapped." Chi. Tribune, Jan. 15, 1984, at E-1, col.4. The President's Commission concluded that "the handicaps of Down's Syndrome . . . do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract." PRESIDENT'S COMMISSION, *supra* note 3, at 212.

163. Final Rule, *supra* note 63, at 1654.

164. *Id.* at 1653.

165. The Monroe County Department of Public Welfare declined to appeal *Infant Doe*'s case. See discussion, *supra* note 12. The author suggests that this agency be cited for violating section 504 to enhance the standard established by this recommendation.

166. See discussion *supra* notes 28, 112.

167. AMERICANS UNITED FOR LIFE, *supra* note 139, at 12.

168. Such a committee could be established by legislation, Executive Order, or the HHS Secretary pursuant to the Federal Advisory Committee Act, 5 U.S.C. App. 263-65 (1979).

standards that ensure the full consideration of an infant's rights and interests during the decisionmaking process. While the HHS has opted for the latter alternative, it has failed to provide the necessary mandatory guidelines to *guarantee* that equal protection considerations enter the decisionmaking process.

Ironically, failure to ensure equal protection of handicapped infants exists contemporaneously with society's desire to advance the rights and respectability of handicapped individuals. Tolerating less than full equal protection for defective infants makes folly of the rights accorded all handicapped individuals. Until the rules assure that the rights and interests of handicapped infants are fully represented in determining whether to withhold treatment, the HHS final rules will not meet the equal treatment, non-discrimination standard of section 504.

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