Defective Newborns and Section 504 of the Rehabilitation Act: Legislation by Administrative Fiat?

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Medical ethics and social legislation have converged on an issue that has become increasingly controversial over the past decade: treatment decisions for defective newborns. Technological advances in medicine have made it possible for physicians to treat and save the vast majority of infants born each year with birth defects. Yet, these advances have created a moral and ethical dilemma. Often, the lifesaving treatment available does not correct the defect completely, or multiple defects are present. These situations have raised the question whether lifesaving treatment should be provided at all.

Although decisions not to treat have been reported to the general public, and the issue has been hotly debated by legal and medical scholars for several years, no resolution has been reached.[1] Somewhat surprisingly, the courts have been only minimally involved in the discussion and most court decisions have shed very little light on the problem.[2] It may be, however, that courts and legislatures will soon be forced to confront the issue since it appears that a growing social momentum has added a new dimension to the controversy.[3]

While lawyers and doctors have been debating the proper criteria for critical care decisions regarding defective newborns, our society has experienced a growing recognition of the rights of the disabled. Comprehensive federal legislation now provides programs and protection, including an anti-discrimination provision, for the physically and mentally handicapped.[4] The effect of this legislation has been pervasive, and that pervasiveness has contributed significantly to a greater social awareness of the

1. See *infra* notes 10-50 and accompanying text.

2. See *infra* note 27 and accompanying text.

3. The heightened public awareness of the issue has already resulted in legislation which specifically addresses the treatment of severely defective newborns. *E.g.*, LA. REV. STAT. ANN. §§ 40:1299.36.1-.36.3 (West 1983). The Arizona legislature recently passed ARIZ. REV. STAT. ANN. §§ 36-2281 to 36-2283 1983 Ariz. Legis. Serv. 1113-14 (West). Although the Arizona statute raises some of the same issues addressed in the following discussion, a thorough discussion of the new statute is beyond the scope of this Note.

4. *See, e.g.*, The Rehabilitation Act of 1973, 29 U.S.C. §§ 701-794 (1976); for the anti-discrimination provision, see *infra* note 51.

disabled. Given the heightened sensitivity to discrimination against the handicapped, it is not surprising that this major social policy has been superimposed on the controversy surrounding defective newborns.

On May 18, 1982 the Department of Health and Human Services (H.H.S.) issued a Notice to health care providers which indicated that decisions to withhold care from defective newborns might violate section 504 of the Rehabilitation Act.[5] This Notice was followed by an Interim Final Rule which modified existing H.H.S. regulations to encompass the medical care of defective newborns.[6] The new regulations went into effect March 22, 1983; however, the promulgation of these regulations was not in compliance with the Administrative Procedure Act, and on April 14, 1983 the District Court struck them down in *American Academy of Pediatrics v. Heckler*.[7]

The holding of *American Academy of Pediatrics* was only a temporary setback for H.H.S. On July 5, 1983, the Department published a second set of proposed regulations.[8] These most recent regulations appear to respond to the criticisms articulated by the district court in *American Academy of Pediatrics v. Heckler*.[9] They are certain to become final in the very near future.

It is equally certain that, like their predecessors, the new regulations will be challenged in court. The outcome of such a challenge is uncertain because the H.H.S. interpretation of section 504 is debatable on both statutory and constitutional grounds. Even if the courts find the regulations untenable, however, the juxtaposition of the issues of medical care for defective newborns and discrimination against the handicapped compels a reevaluation of both issues.

I. THE DEFECTIVE NEWBORN: THE MEDICAL AND LEGAL IMPLICATIONS

A. *The Medical Perspective*

Approximately 30,000 severely defective infants are born each year.[10] These babies are afflicted with grave handicapping conditions that range from spina bifida[11] to anencephaly.[12] For years, physicians confronted

5. Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice of [sic] Health Care Providers, 47 Fed. Reg. 26027 (1982); for section 504, 29 U.S.C. § 794 (1976), see *infra* text at note 51.

6. Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9630 (1983) (proposed March 7, 1983).

7. 561 F. Supp. 395 (D.D.C. 1983).

8. Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30846 (1983) (proposed July 5, 1983).

9. *See infra* discussion at notes 78 & 83 and accompanying text.

10. Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J. LAW & MED. 393, 393 n.1 (1981).

11. Although spina bifida (myelomeningocele) can cause severe physical disability as well as mental retardation, *see* Ellis, *supra* note 10 at 395, in some cases where the abnormality is low on the spinal cord, the individual can be fitted with braces so that he or she is ambulatory. *See, e.g.*, *In re* Cicero, 101 Misc. 2d 669, 421 N.Y.2d 965 (1979).

12. Anencephaly is a condition involving the total or partial absence of a brain. If the child survives, he or she will suffer severe motor and mental retardation. *See* Ellis, *supra* note 10 at 397.

with infants having such disabilities made the ultimate treatment decisions by themselves.[13] Many times parents were not even consulted when the decision was, in effect, to let a defective newborn die.[14] In the early seventies, however, several decisions to withhold treatment from newborns received national attention.[15] These incidents triggered a plethora of writing in the medical field exploring the ethical considerations involved in passive euthanasia for defective newborns.[16]

The medical debate has focused on numerous issues, including if and when treatment should be withheld,[17] how treatment decisions should be made,[18] and what criteria should be considered when those decisions are made.[19] Although the literature does not reflect a consensus, surveys have indicated that a substantial majority of physicians would acquiesce in a parental decision to withhold lifesaving treatment from a defective newborn.[20] The Judicial Council for the American Medical Association has adopted the position that nontreatment of a severely defective infant is not unethical, although the decision to withhold treatment should be made by

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In this article, Ellis provides a concise summary of some of the more common severe birth defects, including: Myelomeningocele (spina bifida, a birth defect in which the spinal cord is either exposed or deformed, resulting in paralysis); Trisomy 21 or Down's Syndrome (chromosomal abnormality producing mental retardation in various degrees, often accompanied by physical defects); Trisomy 13 (chromosomal abnormality resulting in multiple defects, both physical and mental); Anencephaly (absence of brain); Encephalameningocele (brain protrudes from skull); and severe perinatal trauma (trauma at or near birth resulting in hemorrhage or lack of oxygen and blood supplies to the brain).

13. Ellis, *supra* note 10 at 399.

14. *Id.*

15. *Ellis*, *supra* note 10 at 399-400. As Ellis explains, two of the most notorious cases occurred at Johns Hopkins in 1971 and 1972 respectively. Both cases involved babies born with Down's Syndrome accompanied by a life-threatening physical defect. In both cases, treatment was withheld and the babies were allowed to die. *Id.*

16. *See, e.g.*, Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973); Gustafson, *Mongolism, Parental Desires and the Right to Life*, 16 PERSPECTIVES BIOLOGY & MED. 529 (1973); and Shaw, *Dilemmas of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 885 (1973).

17. *E.g.*, Duff & Campbell, *supra* note 16 (the first article to candidly admit that in certain cases defective infants were being allowed to die); Gustafson, *supra* note 16 (article debating the parents' and physician's decision in one of the highly publicized Johns Hopkins cases); and Diamond, *The Deformed Child's Right to Life* in DEATH, DYING AND EUTHANASIA 127 (D. Horan and D. Mall, eds. 1977).

18. *E.g.*, Duff & Campbell, *supra* note 16 (parents and physician should make the choice); Shaw, *supra* note 16 (parents with help of physician should make choice); Stahlman, *Ethical Dilemmas in Perinatal Medicine*, 94 J. PEDIATRICS 516 (Mar. 1979) (physician should be primary decisionmaker).

19. *E.g.*, Hauerwas, *Selecting Children to Live or Die: An Ethical Analysis of the Debate Between Dr. Lorber and Dr. Freeman on the Treatment of Meningomyelocele*, in DEATH, DYING AND EUTHENASIA 228 (D. Horan and D. Mall, eds. 1977); Fletcher, *Indicators of Humanhood: A Tenative Profile of Man*, 2 HASTINGS CTR. REP. 5:1 (1972); Campbell & Duff, *Author's Response to Richard Sherlock's Commentary*, 5 J. MED. ETHICS 141 (1979).

20. In a 1976 survey, 50% of the California physicians polled said they would do nothing heroic in the way of treatment for a Down's Syndrome baby with a life-threatening intestinal obstruction. *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, 6 HASTINGS CTR. REP. 2 (April 1976). In a 1977 national survey, 85% of the pediatric surgeons and 65% of the pediatricians polled said they would abide by a parental decision not to treat a Down's Syndrome baby with a congenital heart disease. Shaw, Randolph, & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (Supp. 1977).

the parents with the advice of a physician readily available.[21] The President's Commission on Bioethics reached a similar conclusion.[22]

The President's Commission on Bioethics further recommended that hospitals providing care for seriously ill newborns establish explicit procedures for decisionmaking.[23] The Commission felt that these procedures should include internal review as an alternative to the courts, at least whenever the decision is to forego life-sustaining therapy.[24] The Commission recommendation reflects the general resistance of the medical profession to the suggestion that decisions to withhold treatment should be subjected to judicial review.[25] While physicians look to the law for a clarification of their liability, they clearly prefer that the courts leave them with a great deal of discretion in making treatment decisions.

B. *The Legal Perspective*

Not surprisingly, the controversy surrounding the treatment of defective newborns has received a great deal of attention from the legal profession.[26] Although the case law dealing with treatment decisions is relatively sparse,[27] commentators have exhaustively discussed the legal issues.[28]

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21. CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION 9 (AMA, Chicago) (1982). The AMA position is as follows:

> Quality of Life. In the making of decisions for the treatment of seriously deformed newborns . . . the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. *In desperate situations involving newborns, the advice and judgment of the physician should be available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents*. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions.
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> The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected (emphasis added).

Id.

22. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 214-223 (1983). The Commission also expressed concern that the parents receive complete information so that they can make an informed decision. *Id.* at 223.

23. *Id.* at 227.

24. *Id.* at 225-27. The Commission did not offer the internal review mechanism in lieu of resort to the courts, but rather as an initial opportunity to resolve disputes and thus avoid legal proceedings if possible.

25. *Id.* at 225 n.94.

26. *See, e.g.*, Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213-67 (1975); Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice?*, 27 BAYLOR L. REV. 76 (1976); Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645 (1977).

27. In a recent article, Professor Taub advanced three reasons why legal decisions are few. Taub, *Withholding Treatment from Defective Newborns*, 10 LAW, MED. & HEALTH CARE 1:4 (Feb. 1982). According to Taub, in most cases where the physicians believe there is hope, the parents give consent. When parents decline to give their consent, the physicians hesitate to invoke the legal process. Where the parents and physicians concur in a decision to withhold treatment, the

Both courts and commentators frame the primary issue as the right of the parent to withhold treatment versus the right of the state to intervene on behalf of the infant.[29] This formulation of the issue reflects the existing body of case law concerning the rights of parents to withhold medical treatment from their children.

Traditionally, parents refusing to consent to medical treatment for their children have done so on religious grounds.[30] Courts confronted with such cases have recognized the right of parents to make these decisions regarding treatment for their children[31] but have also acknowledged that this right is not absolute.[32] In cases where the medical treatment is necessary to save the child's life, courts have found that the interest of the child in continued life outweighs the religious interests of the parents.[33]

Courts deciding cases regarding birth-defective infants have followed the mode of analysis employed in the religious cases. The cases involving defective newborns or children suffering from birth defects, however, include an element that has not been present in the religious cases: quality of life. Unlike the children in the religious cases, a defective newborn receiving lifesaving treatment does not go on to live a normal, healthy life. This difference, it has been argued, weakens the child/state's interest in continued life.[34] Despite the fact that the anticipated quality of the child's life is often central to the parents' decision to withhold treatment, courts have seemed reluctant to base their decisions, even partially, on such a consideration.[35] Perhaps as a consequence of this reluctance, most courts

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situation usually doesn't come to the attention of the prosecutor and if it does, the prosecutor often chooses not to prosecute. *Id.* at 6.

It should also be noted that a great many of the cases that come before the courts are unreported. *See* Shatten & Chabon, *Decision-Making and the Right to Refuse Livesaving Treatment for Defective Newborns*, 3 J. LEGAL MED. 59, 65 n.30 (1982). In the recently publicized "Baby Doe" case, the Indiana Supreme Court upheld the parent's right to withhold treatment but sealed the case. *Summary and Analysis*, 6 MENTAL DISABILITY REP. 135 (1982).

28. *See supra* note 26.

29. *See, e.g.*, Goldstein, *supra* note 26 at 651 ("state supervention of parental judgment would be justified to provide any proven, nonexperimental medical procedure when its denial would mean *death* for a child who would otherwise have an opportunity for either *a life worth living* or a *life of relatively normal healthy growth* toward adulthood. . . .") (emphasis in original); Shatten & Chabon, *supra* note 27 at 62 ("The issue is, rather, to what extent and under what circumstances the law may intervene to override decisions of parents not to treat their children."); *In re* Cicero, 101 Misc. 2d 699, 702, 421 N.Y.S.2d 965, 968 (1979) ("The argument is made that by granting the petition the parental rights to chose [sic] the treatment, upbringing and welfare of the child is infringed upon by the court [citations omitted]. Parental rights, however, are not absolute.")

30. *See generally* Note, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OHIO ST. L.J. 813 (1981).

31. *See, e.g.*, *In re* Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955) where the court refused to order cosmetic surgery; *In re* Green, 448 Pa. 338, 292 A.2d 387 (1972) where the court refused to order blood transfusions for a 16-year old whose life was not in immediate danger.

32. *In re* Cicero, 101 Misc. 2d 699, 702, 421 N.Y.S.2d 965, 968 (1979), quoted *supra* note 29.

33. *E.g.*, People *ex rel.* Wallace v. Labrenz, 411 Ill. 618, 104 N.E.2d 769 (court ordered blood transfusions for infant suffering from RH blood condition), *cert. denied*, 344 U.S. 824 (1952); State v. Perricone, 37 N.J. 463, 181 A.2d 751 (court ordered blood transfusions), *cert. denied*, 371 U.S. 890 (1962); *In re* Clark, 21 Ohio Op. 2d 86, 185 N.E.2d 128 (C.P. Lucas Cty. 1962) (court ordered blood transfusion for burned three-year old child).

34. *See* Goldstein, *supra* note 26 at 651-53.

35. In some cases the courts have rejected quality of life as a valid consideration, *e.g.*, Maine Medical Center v. Houle, No. 74-145 (1974) *reprinted in* ETHICAL ISSUES IN DEATH AND DYING 185 (R. Weir, ed. 1977) ("In the court's opinion the issue before the court is not the prospective

confronted with the defective newborn dilemma have ruled in favor of the treatment.[36]

Two recent cases have found in favor of parental autonomy in decisions to withhold treatment from birth-defective children.[37] The courts, however, did not publicly articulate these decisions in "quality of life" terms.[38]

In *In re Phillip B.*,[39] parents of a 12-year old Down's Syndrome boy suffering from a congential heart defect refused to consent to corrective heart surgery.[40] Although the boy's life expectancy was substantially reduced without the surgery, the trial court ruled in favor of the parents because the state failed to sustain its petition for court intervention with clear and convincing evidence.[41] In upholding the trial court's decision, the California Court of Appeals enumerated the factors to be considered when the state seeks judicial imposition of medical treatment that the parents have rejected. These factors were: "the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation for the treatment by the medical profession; the risks involved in medically treating the child; the expressed preferences of the child."[42]

In reviewing the trial court's decision, the California appellate court did not address the significance of the parents' reason for withholding treatment or include the parents' reason among the factors to be considered.[43] This omission may have stemmed from the "quality of life" judgment implicit in the parents' decision in this particular case.[44] Regardless of the motive, the California Court of Appeals avoided openly confronting the issue of if and when parents should be allowed to withhold lifesaving treatment on the basis of a child's physical or mental disability.

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quality of life to be preserved, but the medical feasibility of the proposed treatment compared with the almost certain risk of death should treatment be withheld."); *In re* McNulty, No. 1960 (Probate Ct., Essex Cty., Mass., 1978) ("If there is any life-saving treatment available, it must be undertaken regardless of the quality of life that will result.") In other cases the courts have simply avoided the issue; *e.g.*, *In re Phillip B.*, 92 Cal. App. 3d 796; 156 Cal. Rptr. 48 (1978), *cert. denied*, 445 U.S. 949 (1980). See discussion of this case in text, *infra* at notes 39-43. *In re* Cicero, 101 Misc. 2d at 702, 421 N.Y.S.2d at 968 ("There is a hint in this proceeding of a philosophy that newborn, 'hopeless' lives should be permitted to expire without an effort to save those lives. Fortunately, the medical evidence here is such that we do not confront a 'hopeless life.' ").

One commentator, however, advocates consideration of the quality of life factor. Professor Joseph Goldstein reasons that in those difficult cases where there is no societal consensus that life after treatment would be a "life worth living," a quality of life consideration would inhibit state intervention. In other words, the state would have the burden of proving "a life worth living" or "a life of relatively normal, healthy growth" to overcome a presumption of parental autonomy. *See generally*, Goldstein, *supra* note 26 at 654.

36. *E.g.*, *In re* McNulty, No. 1960 (Probate Ct. Essex Cty. Mass. 1978); Maine Medical Center v. Houle, No. 74-145 (Me. 1974); *In re* Cicero, 101 Misc. 669, 421 N.Y.S.2d 965 (1979).

37. *In re* Phillip B., 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1978); "Baby Doe" or the "Bloomington Baby" case sealed, see *infra* text at note 45.

38. See *infra* notes 39-45 and accompanying text.

39. 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979).

40. *Id.* at 799, 156 Cal. Rptr. at 50.

41. *Id.* at 803, 156 Cal. Rptr. at 52.

42. *Id.* at 802, 156 Cal. Rptr. at 51.

43. *Id.*

44. *See* Annas, *Denying the Rights of the Retarded: The Phillip Becker Case*, 9 HASTINGS CTR. REP. 6:18 (1979).

The second case ruling in favor of a parental decision to withhold treatment from a birth-defective child involved a newborn. "Baby Doe" was born in April 1982 with Down's Syndrome and a tracheoesophageal fistula. Although a relatively simple surgical procedure could have connected the esophagus to the stomach, completely correcting the physical defect, the parents chose to withhold treatment. The Indiana courts upheld the parents' decision and the baby died. Unfortunately, the court's reasoning is unknown, because the case was sealed in the apparent interest of protecting the parents' anonymity.[45]

Decisions to withhold treatment from defective newborns have provoked criminal charges against parents and their physicians on at least one occasion.[46] In Illinois, parents of Siamese twins who could not be separated were charged with attempted murder for allegedly instructing the hospital to withhold food from their babies.[47] The charges were eventually dropped because of insufficient evidence to link the parents with a note on the medical chart directing that the babies not be fed.[48] Nonetheless, this case cannot be regarded as an isolated incident. Several commentators have argued that the criminal law can be applied in the area of neonatal passive euthanasia.[49] Given the emotional tenor of this controversy, another attempt at criminal prosecution in the near future seems inevitable.

The most novel development in the law regarding defective newborns has been its interface with existing rehabilitation legislation. In November 1982, the Department of Health and Human Services reinterpreted a broad statute proscribing discrimination against the handicapped applying the statute to medical decisions regarding the treatment of defective newborns.[50] While this interpretation of section 504 may not withstand legal scrutiny, the attempt at application has forced a reexamination of the defective newborn dilemma in light of growing awareness of the rights of the disabled.

II. THE REHABILITATION ACT OF 1973

A. *The History of Section 504*

Section 504 is the anti-discrimination provision of the Rehabilitation

45. Fost, *Putting Hospitals on Notice*, 12 HASTINGS CTR. REP. 4:5, 5 (1982). The "Baby Doe" case was also widely reported by the news media.

46. Taub, *Withholding Treatment from Defective Newborns*, 10 LAW MED. & HEALTH CARE 1:4, 4 (1982).

47. The twins were joined below the waist and shared the lower part of their digestive tracts and three legs. The medical diagnosis indicated that the twins could not be separated and a note on the medical chart read, "do not feed in accordance with parents' wishes." This prompted an anonymous phone call to the Illinois Department of Children and Family Services, which in turn resulted in the prosecution of the parents and physician for attempted murder. *See* Taub, *supra* note 46.

48. *Id.*

49. *E.g.*, Robertson, *supra* note 26 at 217-44; Horan, *supra* note 26 at 77-79; Note, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, TEX. TECH. L. REV. 569, 578-81 (1983).

50. Notice of [sic] Health Care Providers, 47 Fed. Reg. 26027 (1982); for section 504, 29 U.S.C. § 794 (1976), see *infra* note 51.

Act of 1973.[51] Modeled after similar provisions of the Civil Rights Act of 1964[52] and the Education Amendments of 1972,[53] section 504 expresses a broad government policy that programs receiving federal financial assistance shall not discriminate against the handicapped.[54] Although this provision has been law for nearly a decade, the full breadth of its impact is uncertain. A great deal of the uncertainty stems from what could be called its "slow start."

When section 504 was enacted, it was only one provision in a very comprehensive and controversial act.[55] Consequently, very little legislative history pertaining to the anti-discrimination measure exists.[56] Two earlier versions of the act had been subjected to presidential vetoes because they had substantially broadened the existing vocational rehabilitation legislation.[57] To get the new legislation through, Congress was forced to compromise by modifying the proposed Rehabilitation Act so that it had a vocational orientation.[58] This was accomplished by defining "handicapped individual" in vocational terms.[59] Congress amended the Act in 1974, however, redefining "handicapped individual" and thus impliedly extending section 504 to all government programs receiving federal financial assistance.[60]

Subsequent events clarified another ambiguity involving available remedies under section 504. Section 504 itself does not grant any civil or criminal sanctions for the violation of its terms; therefore, in 1978 the act was amended to make all remedies available under the Civil Rights Act of 1964 applicable to section 504 claims.[61] In addition, a substantial majority

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51. Pub. L. No. 93-112, title V, § 504, 87 Stat. 394 (1973). Section 504 reads:

> No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

29 U.S.C. § 794 (1976).

52. The anti-discrimination clause of the Civil Rights Act of 1964 provides: "No person in the United States shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 42 U.S.C. § 2000d (1976).

53. Title IX, § 901(a) provides: "No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance. . . ." 20 U.S.C. § 1681 (1976).

54. See *supra* note 51 for the text of section 504.

55. *See generally* Legislative History, Pub. L. 93-112, 1973 U.S. CODE CONG. & AD. NEWS 2076-2154.

56. *Id.* at 2143.

57. Schoenfeld, *Civil Rights for the Handicapped under the Constitution and Section 504 of the Rehabilitation Act*, 49 U. CIN. L. REV. 580, 581 (1980).

58. Carrick, *Regulating Rehabilitation*, 74 LAW LIB. J. 556, 574 (1981).

59. The Rehabilitation Act of 1973 defined handicapped individuals as: ". . . any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to titles I and III of this Act." Rehabilitation Act of 1973, Pub. L. No. 93-112 § 7(6), 87 Stat. 355 (1973).

60. The amended definition includes: ". . . any 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 an impairment, or (C) is regarded as having such an impairment." 29 U.S.C. § 706(6) (1976).

61. Rehabilitation Comprehensive Services and Developmental Disabilities Amendments of

of the circuit courts have held that private parties aggrieved by a section 504 violation have an implied cause of action.[62]

The above uncertainty was further compounded by the failure on the part of the Department of Health, Education and Welfare (H.E.W.) to promulgate timely regulations under section 504.[63] H.E.W. did not issue proposed regulations until July 16, 1976,[64] and even then only after President Ford had issued an Executive Order[65] and a lawsuit demanding regulations had been filed in federal district court.[66] Final regulations were issued April 21, 1977,[67] more than three years after passage of the provision.

Litigation involving section 504 has focused on several facets of the provision. Cases before the courts have involved claims of employment discrimination,[68] discrimination as a result of inaccessibility,[69] and discrimination in education,[70] as well as several procedural issues.[71] Unfortunately, much of the case law on section 504 is not particularly germane to the issue of the statute's applicability to defective newborns. As a result, any attempt at resolution of that issue must be based on statutory interpretations and tangentially related cases.

1978, Pub. L. No. 95-602, 92 Stat. 2955. For remedies under the Civil Rights Act of 1964, see 42 U.S.C. § 2000d-1 (1976).

62. *See* Pushkin v. Regents of the University of Colorado, 658 F.2d 1372 (10th Cir. 1981); Simon v. St. Louis County, 656 F.2d 316 (8th Cir. 1981), *cert. denied*, 455 U.S. 976 (1982); Kling v. County of Los Angeles, 633 F.2d 876 (9th Cir. 1980); Camenisch v. University of Texas, 616 F.2d 127, 131 (5th Cir. 1980), *vacated on other grounds*, 451 U.S. 390 (1981); Davis v. Southeastern Community College, 574 F.2d 1158, 1159 (4th Cir. 1978), *rev'd on other grounds*, 442 U.S. 397 (1979); Leary v. Crapsey, 566 F.2d 863 (2d Cir. 1977); Lloyd v. Regional Transportation Authority, 548 F.2d 1277, 1284-87 (7th Cir. 1977).

63. Carrick, *supra* note 58, at 557.

64. *Id.*

65. Exec. Order No. 11,914, 3 C.F.R. 117 (1977), *revoked by* Exec. Order No. 12,250, 3 C.F.R. 298, 300 (1981).

66. Cherry v. Mathews, 419 F. Supp. 922 (D.D.C. 1976).

67. Carrick, *supra* note 58 at 557.

68. *See, e.g.*, Coleman v. Dardan, 595 F.2d 533 (10th Cir. 1979) (blind plaintiff claimed he had been discriminated against when he applied for a job as a research analyst), *cert. denied*, 444 U.S. 927 (1979); Drennan v. Philadelphia General Hospital, 428 F. Supp. 809 (E.D. Pa. 1977) (plaintiff claimed denial of employment due to epilepsy); Gurmankin v. Costanzo, 411 F. Supp. 982 (E.D. Pa. 1976) (blind woman brought claim of employment discrimination against Philadelphia School District), *aff'd*, 556 F.2d 184 (3d Cir. 1977), *cert. denied*, 450 U.S. 923 (1981).

69. *See, e.g.*, Ferris v. University of Texas, 558 F. Supp. 536 (W.D. Tx. 1983) (plaintiff brought suit to require university to make its "shuttle buses" accessible to wheelchairs); Bartels v. Biernat, 427 F. Supp. 226 (E.D. Wis. 1977) (court permanently enjoined the defendant transit company from accepting bids or forming binding contracts for buses inaccessible to the handicapped); Snowden v. Birmingham Jefferson County Transit Authority, 407 F. Supp. 394 (N.D. Ala. 1975) (plaintiff brought suit claiming buses that required the wheelchair-bound to provide someone to help them aboard violated Section 504), *aff'd mem.*, 551 F.2d 862 (5th Cir. 1977).

70. *See, e.g.*, Southeastern Comm. College v. Davis, 442 U.S. 397 (1979) (woman with hearing impairment denied admission to nursing program); Camenisch v. University of Texas, 616 F.2d 127 (5th Cir. 1980) (deaf graduate student sought to compel university to provide an interpreter), *vacated*, 451 U.S. 390 (1981).

71. *See supra* note 62 for cases addressing the private cause of action under section 504. Another procedural issue is the necessity of exhaustion of administrative remedies. With respect to exhaustion, the case law is divided. *See, e.g.*, Pushkin v. Regents of the Univ. of Colorado, 658 F.2d 1372 (10th Cir. 1981) (exhaustion not required); Camenisch v. University of Texas, 616 F.2d 127 (5th Cir. 1980) (exhaustion not required), *vacated on other grounds*, 451 U.S. 390 (1981); NAACP v. Wilmington Medical Center, 426 F. Supp. 919 (D. Del. 1977) (exhaustion required).

B. *Application of Section 504 to Defective Newborns*

President Reagan was the first to assert that section 504 applies to treatment decisions regarding defective newborns. Shortly after the "Baby Doe" case in Bloomington, Indiana was reported in the media, President Reagan sent a memorandum to the Attorney General and the Secretary of the Department of Health and Human Services noting both the controversial infant death and the fact that federal law prohibits discrimination against the handicapped.[72] In response to the President's memorandum, the Secretary issued a "Notice of [sic] Health Care Providers" which indicated that section 504 of the Rehabilitation Act makes it unlawful to withhold medical treatment from birth defective infants on the basis of handicap.[73] The H.H.S. Notice further indicated that hospitals could be held accountable for "facilitating discriminatory practices" and that failure to comply with the requirements of section 504 could subject the federal funds recipient to termination of assistance.[74]

In March 1983, H.H.S. took its interpretation of section 504 one step further. The Department issued specific regulations, intended to supplement existing H.H.S. regulations, which addressed the rendering of medical care to defective newborns.[75] These regulations were published on March 7, 1983 as an interim final rule and became effective March 22, 1983.[76]

In April 1983 a United States district court struck down the regulations in *American Academy of Pediatrics v. Heckler*, declaring them arbitrary and capricious.[77] In a thoughtful opinion, the District of Columbia District Court admonished H.H.S. for its failure to consider all of the relevant factors and possible repercussions when it promulgated the new regulations.[78] The court found that the Department's failure in this regard supported the claim that the regulations were arbitrary and capricious and

72. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 397 (D.D.C. 1983).

73. Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of [sic] Health Care Providers, 47 Fed. Reg. 26027 (June 16, 1982).

74. *Id.*

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

76. *Id.*

77. 561 F. Supp. 395, 399 (D.D.C. 1983).

78. *Id.* at 399-400. The court noted that the Department had not considered the disruptive effects of a 24-hour toll-free "hotline." The court was also critical of the fact that, "[t]he Secretary did not appear to give the slightest consideration to the advantages and disadvantages of relying on the wishes of the parents who, knowing the setting in which the child may be raised, in many ways are in the best position to evaluate the infant's best interests." *Id.* Finally the court concluded:

> Not only are these relevant factors not considered but there are other matters lacking in the rulemaking record. It contains no indication that the legal and constitutional considerations which should have guided the Secretary in her decisional process were reviewed. Neither the requirements of the Administrative Procedural Act nor questions as to the scope of section 504 were apparently noted. No alternative means of protecting handicapped infants were reviewed or considered although the Secretary was aware of the imminent release of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavorial Research, which counsels different approaches to the issue. Indeed, the record even fails to suggest a widespread denial of proper newborn care such as would justify the type of regulation selected.

Id. at 400.

as such violated the Administrative Procedure Act (A.P.A.).[79] The court also noted that H.H.S. had failed to comply with A.P.A. procedural requirements for rulemaking.[80] Consequently, even if the regulations had not been found arbitrary and capricious, they would have failed as a result of the procedural noncompliance.[81]

Notwithstanding this initial defeat, H.H.S. has persevered. On July 5, 1983, the Department published proposed regulations substantially the same as those previously struck down in *American Academy of Pediatrics v. Heckler*.[82] The new regulations are buttressed with a significant amount of "Supplementary Information" which reviews the defective newborn controversy and sets forth the legal basis for application of section 504.[83] While this second attempt to regulate the medical treatment of defective newborns may satisfy federal administrative procedural requirements, the question remains whether the statute supports the H.H.S. interpretation.

No court has actually decided whether section 504 applies to defective newborns. In *American Academy of Pediatrics v. Heckler*, the district court declined to reach the issue.[84] The *American Academy of Pediatrics* court did, however, discuss some concerns about application of the statute. On the one hand, the court noted that nothing in the legislative history of section 504 supported the H.H.S. interpretation.[85] On the other hand, the court acknowledged that the broad language of the statute arguably could be construed to include defective newborns.[86] The court concluded that determination of the issue "should await the actual application of the statute to a set of particular circumstances."[87]

As the court noted in *American Academy of Pediatrics*, nothing in the legislative history of section 504 suggests that Congress ever contemplated the application proposed by H.H.S. Yet this fact, by itself, does not warrant a finding that the statute is inapplicable. Legislation is not confined to

79. *Id.* at 399.

80. *Id.* at 400-01. The regulations were promulgated without meeting either the public notice or 30-day delay of effective date requirements of the Administrative Procedure Act. The court found that neither the "procedural" or "interpretative" rule exceptions would apply. *Id.* at 401.

81. *Id.*

82. Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30,846 (1983). The most significant difference is the addition of regulations regarding state child protective agencies, discussed *infra* at notes 160-61, and an Appendix.

83. *Id.* The bulk of this "Supplementary Information" is clearly in response to the criticisms of the district court, discussed *supra* at note 78.

84. 561 F. Supp. at 401.

85. *Id.* The court 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. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were representatives of parents or spokesmen for religious beliefs that would be affected heard. 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.

86. *Id.* at 401-02.

87. *Id.* at 402.

its historical context,[88] and remedial statutes like section 504 are generally given a broad reading.[89]

An examination of the statute on its face makes clear that the language of section 504 could encompass treatment decisions for defective newborns. Section 504 reads: "No otherwise qualified handicapped individual in the United States, as defined in Section 706(6) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ."[90] Thus, two threshold requirements, if met, bring a situation within the statute's purview: 1) the individual allegedly discriminated against must come within the definition of "handicapped," and 2) the party accused of discrimination must be a recipient of federal funds.

The first requirement, that the individual be handicapped, is a relatively unclouded issue in this context. The definition found in the act and referred to in section 504 provides, "the term 'handicapped individual' means . . . any 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, and (C) is regarded as having such an impairment."[91] *Severely* birth-defective newborns clearly have physical or mental impairments which substantially limit major life activities and thus can be termed "handicapped individuals" for section 504 purposes.

The federal funding requirement, however, is not nearly so clear. Some question exists as to whether section 504 applies only to specific programs receiving federal funds or to every program in an institution receiving any federal funding. The court of appeals cases dealing with this question have all involved claims of employment discrimination.[92] Of the seven circuits which have considered the issue, all but one have held that, in order to bring a claim under section 504, a private plaintiff must show that he or she was the intended beneficiary of the federal assistance received by the activity or program accused of discrimination.[93]

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88. *See, e.g.*, United Air Lines, Inc. v. McMann, 434 U.S. 192, 199 (1977) (legislative history is irrelevant to an unambiguous statute); Packard Motor Co. v. National Labor Relations Board, 330 U.S. 485, 492 (1947) (in the absence of ambiguity in a statute, the courts will not resort to legislative history to determine its meaning); Kuehner v. Irving Trust Co., 299 U.S. 445, 449 (1937) (legislative history cannot affect interpretation if language of statute is clear).

89. Jones v. Metro. Atlantic Rapid Transit Auth., 681 F.2d 1376, 1380 (11th Cir. 1982) (citing Peyton v. Rowe, 391 U.S. 54, 65 (1968)).

90. 29 U.S.C. § 794 (1976).

91. 29 U.S.C. § 706(6) (1976).

92. *See infra* note 93.

93. *See* Scanlon v. Atascadero State Hospital, 677 F.2d 1271, 1272 (9th Cir. 1982) (private action under § 794 (504) to redress employment discrimination cannot be maintained unless a primary objective of the federal financial assistance is to provide employment); Brown v. Sibley, 650 F.2d 760, 659 (5th Cir. 1981) ("Plaintiff in a § 504 case must show that the program or activity with which he or she was involved, or from which he or she was excluded itself received or was directly benefitted by federal financial assistance"); United States v. Cabrini Medical Center, 639 F.2d 908, 909 (2d Cir. 1981) ("Hospital's receipt of medicare and medicaid funds does not constitute receipt of financial assistance under the Rehabilitation Act because its primary objective was not to provide employment"); Simpson v. Reynolds Metals Co., Inc., 629 F.2d 1226, 1232 (7th Cir. 1980) ("the discrimination must have some direct or indirect effect on the handicapped persons in

These cases do not necessarily require the same finding in situations involving the rendering of health care. The primary rationale for the "intended beneficiary" rule in the first of these cases, *Trageser v. Libbie Rehabilitation Center*,[94] and in several subsequent cases[95] was the incorporation of section 604 of the Civil Rights Act into the Rehabilitation Act. The *Trageser* court held that Congress' amendment of the Rehabilitation Act in 1978, to include the remedies, procedures and rights of Title VI of the Civil Rights Act of 1964, also incorporated the intended beneficiary limitation found in Section 604.[96] Since section 604 by its very terms applies only to employment discrimination,[97] the *Trageser* holding cannot be directly applied to the health services context.

The Civil Rights Act analysis, however, does not necessarily resolve the question of federal financial assistance. Some of the circuits finding the intended beneficiary requirement have based their decisions on the legislative history of section 504[98] and the case law under Titles VI and IX.[99] Since both of these bases are applicable to all aspects of section 504 protection, the requirement that a plaintiff bringing an action under section 504 be an intended beneficiary of the federal assistance conceivably could extend to claims alleging discrimination on the part of health care providers.

Thus, although the broad language of section 504 appears to encompass defective newborns, the scope of its application may be limited. First, as discussed above, it may be confined to defective newborns found in neonatal programs that receive direct financial assistance from the federal

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the program or activity receiving federal financial assistance"); Carmi v. Metropolitan St. Louis Sewer District, 620 F.2d 672, 675 (8th Cir.) ("Since Carmi was not an intended beneficiary of the federal assistance, he lacks standing to bring suit under section 794"), *cert. denied*, 449 U.S. 892 (1980); Trageser v. Libbie Rehabilitation Center, 590 F.2d 87, 89 (4th Cir. 1978) ("a private action under 504 to redress employment discrimination therefore may not be maintained unless a primary objective of the federal funds is to provide employment"), *cert. denied*, 442 U.S. 947 (1979). *But see* Jones v. Metro. Atlanta Rapid Transit Auth., 681 F.2d 1376, 1380 (11th Cir. 1982) ("[b]ecause the legislative history is devoid of language demonstrating that Congress intended Section 604 of Title VII to apply to suits under the Rehabilitation Act, the remedial nature of the Rehabilitation Act mandates that we reject such an interpretation").

94. 590 F.2d at 89.

95. *See* Scanlon v. Atascadero State Hospital, 677 F.2d 1271 (9th Cir. 1982); United States v. Cabrini Med. Ctr., 639 F.2d 908 (2d Cir. 1981); Carmi v. Metro. St. Louis Sewer Dist., 620 F.2d 672 (8th Cir.), *cert. denied*, 449 U.S. 892 (1980).

96. 590 F.2d at 88-89. *See also* 42 U.S.C. § 2000d-3 (1976). This statute provides: "Nothing contained in this subchapter shall be construed to authorize action under this subchapter by any department or agency with respect to any employment practice of any employer, employment agency, or labor organization except where a primary objective of the Federal financial assistance is to provide employment."

97. *But see* Carmi v. Metro St. Louis Sewer Dist., 620 F.2d 672 (8th Cir.), *cert. denied*, 449 U.S. 892 (1980) where the court stated:

> It is true section 2000d-3 expressly limits only agency enforcement to situations where a primary objective of the federal financial assistance is to provide employment. Nevertheless, the legislative history of title VI lends strong support to our conclusion that Congress did not intend to extend protection under title VI to any person other than an intended beneficiiary of federal financial assistance.

Id. at 674.

98. *See* Brown v. Sibley, 650 F.2d at 767-69 and Simpson v. Reynolds Metals Co., Inc., 629 F.2d at 1323. *But see* Scanlon v. Atascadero State Hosp., 677 F.2d at 1272-77 (Ferguson, J. dissenting); Jones v. Metro. Atlanta Rapid Transit Auth., 681 F.2d at 1380.

99. Brown v. Sibley, 650 F.2d at 767-69.

government. Second, as the following discussion indicates, it may be limited by other statutory and constitutional considerations.

C. *Defining a Violation of Section 504*

1. *The "Otherwise Qualified Handicapped Individual" Requirement*

Assuming that section 504 applies to defective newborns, at least in limited circumstances,[100] what constitutes a violation of section 504 in treatment decisions regarding these infants? The key to this determination in other contexts has been the definition and scope of the words, "otherwise qualified handicapped individual."[101]

The United States Supreme Court interpreted this phrase in *Southeastern Community College v. Davis*.[102] In *Davis*, a hearing-impaired woman who had been denied admission to a nursing program alleged a violation of section 504.[103] The Supreme Court held that no violation had occurred because Davis was not "an otherwise qualified handicapped individual."[104] The Court stated that "otherwise qualified handicapped individual" did not mean qualified in all respects except for being handicapped, but rather qualified "in spite of" the handicap.[105] Thus, according to the Court's interpretation:

> Section 504 by its terms does not compel educational institutions to disregard the disabilities of handicapped individuals . . . . Instead it requires only that an 'otherwise qualified handicapped individual' not be excluded from participation in a federally funded program 'solely by reason of his handicap,' indicating only that mere possession of a handicap is not a permissible ground for assuming an inability to function in a particular context.[106]

Since the *Davis* decision involved a college program, its definition of "an otherwise qualified handicapped individual" arguably can be confined to post-secondary education cases. Yet, if *Davis* is applicable to all programs subject to section 504, the import of its interpretation of "otherwise qualified handicapped individual" in the area of health care has been largely unexplored.

Current H.H.S. regulations regarding section 504 in "Health, Welfare and Other Social Services" omit the word "otherwise" and speak in terms of "qualified handicapped person[s]."[107] This phrase is expressly defined

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100. See discussion *supra* at notes 72-99 and accompanying text.

101. *See* Southeastern Community College v. Davis, 442 U.S. 397 (1979). The phrase "otherwise qualified handicapped individual" comes directly from section 504, see *supra* text at note 90.

102. 442 U.S. at 405-07.

103. *Id.* at 401-02.

104. *Id.* at 406.

105. *Id.*

106. *Id.* at 405.

107. 45 C.F.R. 84.52 (1982) provides:

within the regulations.[108] With respect to health care services, it is interpreted as meaning "a person who meets the essential eligibility requirements for the receipt of such services."[109]

On its face, this definition appears to be broader than that adopted by the *Davis* Court. The language of the H.H.S. definition implies that the presence of a handicapping condition cannot be considered at all in the decision to provide medical services. Eligibility under the program, e.g. due to financial or veteran status, may alone qualify the recipient for treatment. Nonetheless, two strong arguments support an application of the narrower *Davis* definition which would allow providers to consider handicapping conditions.

First, the regulations themselves indicate that handicapping conditions may be considered in treatment decisions. In the Appendix to the regulations, H.H.S. comments on the use of the term "qualified handicapped individual," explaining, "this term is used instead of the statutory term 'otherwise qualified handicapped person' . . . [because] [t]he Department believes that the omission of the word 'otherwise' is necessary in order to comport with the intent of the statute . . . [R]ead literally, 'otherwise qualified handicapped persons' include persons who are qualified except for their handicap, rather than in spite of their handicap."[110] This language was quoted in the *Davis* opinion and was offered as support for the Court's holding.[111] Since the comments in the Appendix apply to all regulations based on section 504, it seems likely that judicial approval of this interpretation would extend to the regulations on health care.

Second, the United States Supreme Court in *Davis* held that section 504 does not compel an educational institution to disregard entirely an applicant's physical disability or condition.[112] Yet, in the educational setting, an applicant's disability would only indirectly affect his or her performance. In contrast, when a health care provider makes a treatment decision, the disability or condition may directly affect the success of the treatment. For example, the presence of a handicap may increase the risk factor such that a particular treatment becomes undesirable. Under these circumstances, it would seem *a fortiori* that the health care provider should be allowed to consider a handicapping condition.

(a) *General*. In providing health, welfare or other social services or benefits, a recipient may not, on the basis of handicap:

(1) Deny a *qualified handicapped person* these benefits or services;

(2) Afford a *qualified handicapped person* an opportunity to receive benefits or services that is not equal to that offered nonhandicapped persons;

(3) Provide a *qualified handicapped person* with benefits or services that are not as effective (as defined in § 84.4(b)) as the benefits or services provided to others;

(4) Provide benefits or services in a manner that limits or has the effect of limiting the participation of *qualified handicapped persons*; or

(5) Provide different or separate benefits or services to handicapped persons except where necessary to provide *qualified handicapped persons* with benefits and services that are as effective as those provided to others. (emphasis added)

108. 45 C.F.R. § 84.3(k) (1982).

109. 45 C.F.R. § 84.3(k)(4) (1982).

110. 45 C.F.R. Appendix A at 296 (1982).

111. 442 U.S. at 407, n.7.

112. *Id.* at 405.

A finding that a health care provider may consider a handicap in making treatment decisions raises a further question of the influence a handicap may have upon an ultimate treatment decision. In *Davis* the Court noted that the respondent's disability would prevent her from performing many of the functions of a registered nurse.[113] The Court then found that refusing admission to Davis on this basis was not discriminatory because Davis was not an "otherwise qualified handicapped individual."[114] The Court did not indicate how attenuated the effect of the handicap must become before denial based on handicap constitutes discrimination; however, this determination is central to the defective newborn question.

The H.H.S. Notice which initially asserted that section 504 applies to defective infants attempted to identify an "otherwise qualified handicapped individual" in terms of whether the handicap that is pivotal in the decision to withhold treatment actually "render[s] the treatment or nutritional sustenance medically contraindicated."[115] This standard was immediately criticized as vague and unintelligible.[116] The Department has attempted to clarify it in the recently published proposed regulations.[117] Through the use of examples and elaboration, H.H.S. has tried to demonstrate how one determines those treatments that are "indicated" and those that are "contraindicated."[118] By way of explanation, the Department purports to distinguish "medical" considerations from nonmedical considerations, and states that physicians may not base decisions to withhold treatment on nonmedical considerations.[119] The Department appears to be saying that the handicap must be directly related to a life-threatening condition before it can properly be considered in making the ultimate treatment decision.

As the court in *American Academy of Pediatrics* noted, the problem with a standard that turns on the relationship of the determinative handicap to the life-threatening condition is that it does not allow for quality of life considerations even in extreme situations.[120] Seemingly in response to this criticism, H.H.S. disclaims this rigidity in its discussion of the regulations and states that "Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies."[121] The Department does not explain why such acts or therapies are not required. Rather,

113. *Id.* at 407.
114. *Id.* at 414.
115. Notice of [sic] Health Care Providers, 47 Fed. Reg. 26,027 (1982).
116. *See* Fost, "Putting Hospitals on Notice," 12 HASTINGS CTR. REP. 4:5, 6 (1982).
117. 48 Fed. Reg. 30,846 (1983).
118. 48 Fed. Reg. 30,846, 30,846-47, 30,851-52 (1983).
119. *Id.* at 30,852.
120. 561 F. Supp. at 402. The district court stated:

> [D]efendants and *amici* in support of defendants read the regulations and thus the statute 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 anacephalic [sic] infant lacking all or part of the brain and with no hope of ever achieving even the most rudimentary form of consciousness.

Id.
121. 48 Fed. Reg. 30,846 (1983).

H.H.S. seems merely to shed the "medical" considerations limitation when it discusses handicaps that are themselves life-threatening.[122] For example, quality of life considerations are tacitly approved under the guise of "legitimate medical judgment" in the case of an anencephalic child.[123]

This inconsistency demonstrates that H.H.S., in its proposed regulations, has really offered no standard whatsoever for treatment decisions. What the Department has offered is its judgment as to where medical practitioners should draw the line. By setting forth numerous examples, the regulations have indicated that it is acceptable to let anencephalic infants die but unacceptable to withhold treatment from infants afflicted with Down's Syndrome. While this result may in fact reflect a general consensus of society, the regulations fail to establish a workable, objective standard for determining when a birth defective newborn is an "otherwise qualified individual," who may not be denied health care on the basis of his handicap. Consequently, they fail to establish what constitutes a section 504 violation for cases not addressed in the specific examples.

2. *Discrimination Against an "Otherwise Qualified Handicapped Individual"*

Once the threshold requirement of "an otherwise qualified handicapped individual" has been met, the question of discrimination remains. Section 504 provides that "[n]o 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."[124] The application of this statute under the proposed H.H.S. regulations clearly contemplates a situation where parents have chosen to withhold treatment from a handicapped child. Consequently, the possible denial of benefits or exclusion from participation in a program need not be addressed. Rather, this inquiry involves the potential culpability of a federally funded program for discrimination, even though it is the parents who decide "discriminatorily" to withhold treatment from a handicapped child.

The H.H.S. Notice acknowledges this element of the section 504 application but states that recipients may violate section 504 by "facilitating discriminatory conduct."[125] The Notice gives examples of such conduct,

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122. *Id.* at 30,852.

123. In the Appendix to the regulations, H.H.S. states:

> For example, a child born with anencephaly will inevitably die within a short span of time; therefore, treatment to correct life-threatening complications may be withheld. *Such withholding is on the basis of legitimate medical judgment that the child would die imminently even with the treatment. The decision to withhold treatment is therefore not based on handicap, and is not prohibited by section 504.* (emphasis added.)

48 Fed. Reg. at 30,852. This excerpt clearly shows the specious reasoning employed by H.H.S. In this example, it is the handicapping condition, anencephaly, that will shorten the infant's life span. It is the shortened life span which in turn allows the physician to withhold treatment—even for complications. Yet, in spite of this causal relationship, the Department concludes that "the decision to withhold treatment is therefore not based on handicap"—a preposterous statement when it is obviously the handicap that is the primary reason for withholding treatment.

124. 29 U.S.C. § 794 (1976).

125. 47 Fed. Reg. 26,027 (1982).

including "encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504," and "aid[ing] a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution."[126] The Notice further states that the health care provider is responsible for the conduct of physicians in cases administered through its facilities.[127]

Putting aside the constitutional implications of this interpretation, we must determine whether a legitimate statutory basis exists for the H.H.S. conclusion that "facilitation" of discriminatory conduct constitutes discrimination under section 504. The Rehabilitation Act itself does not define "discrimination" and no case law directly addresses the question. Because the Rehabilitation Act is remedial in nature, however, courts have held that it should be construed broadly in order to effectuate its purpose.[128] A broad interpretation of the statute would support the definition of discrimination in the H.H.S. regulations. Of particular relevance is subsection 84.4(b)(1)(a), which provides that a recipient may not, on the basis of handicap, "aid or perpetuate discrimination against a qualified handicapped person by providing significant assistance to an agency, organization or *person* that discriminates on the basis of handicap in providing any aid, benefit or service to beneficiaries of the recipient's program."[129] Although this regulation may not be directly applicable where parents choose to discriminate on the basis of their child's handicap, it supports the idea that *indirect* discrimination by a federal funds recipient may violate section 504 under some circumstances.

Even if "facilitation" is within the scope of discrimination under section 504, the H.H.S. application of this principle to defective newborns presents two major problems. First, in this context, avoiding the facilitation of discrimination does not necessarily advance the purposes that underlie section 504. For example, the H.H.S. Notice provides, "[h]ealth care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution."[130] As the court noted in *American Academy of Pediatrics*, "the interests of the child [are not] served by a regulation that contemplates forced removal of the child from a hospital if a parent refuses to allow medical care. . . ."[131]

The second problem with the facilitation of discrimination approach is the dilemma it imposes upon the health professionals. The H.H.S. Notice indicates that a recipient may not counsel parents "to make decisions which, if made by the health care provider, would be discriminatory under section 504."[132] Furthermore, the Notice reminds health care providers

126. *Id.*
127. *Id.*
128. Jones v. Metro. Atlanta Rapid Transit Auth., 681 F.2d 1376, 1380 (11th Cir. 1982) (citing Peyton v. Rowe, 391 U.S. 54, 65 (1968)).
129. 45 C.F.R. § 84.4(b)(1)(v) (1981) (emphasis added).
130. 47 Fed. Reg. 26,027 (1982).
131. 561 F. Supp. at 399.
132. 47 Fed. Reg. 26,027 (1982).

that they are responsible for the conduct of their physicians.[133] Thus, a physician confronted with a defective newborn is only allowed to advise the parents to withhold treatment in those situations where such a decision would not violate section 504. Yet, as discussed above, it is by no means clear when withholding treatment is permissible.[134] Consequently, in order to ensure compliance with the requirements of section 504 as interpreted by H.H.S., a physician is under considerable pressure to recommend treatment in all cases. Again, as the *American Academy of Pediatrics* court noted, this leaves "physicians and hospitals caught between the requirements of the regulation and established legal and ethical guidelines."[135]

In sum, application of section 504 to the medical care of birth-defective infants presents definite problems in determining exactly what will constitute a statutory violation. Despite this uncertainty, the Department's interpretation of section 504 may have merit insofar as it recognizes some sort of applicability to defective newborns. Therefore, the next point for consideration is the manner in which H.H.S. can effect compliance.

D. *Methods of Enforcement and Effecting Compliance Under Section 504*

The novelty of the H.H.S. interpretation of section 504 in relation to defective newborns becomes most apparent in the area of effecting compliance. As has been previously indicated, section 504 does not by its terms specify how it is to be enforced. Although the Rehabilitation Act was amended to incorporate the rights and remedies from the Civil Rights Act of 1964,[136] the uncertainty surrounding available recourse for a section 504 violation still exists. Most of the litigation with respect to available remedies has involved private actions brought by handicapped individuals who have experienced discrimination.[137] The question that arises in the defective newborn context is what action the government can take in the event of a specific section 504 violation. The unique posture of the government in the handicapped infant controversy has led H.H.S. to propose some unusual and, in some cases, unprecedented methods of enforcement.

In its original Notice to Health Care Providers, H.H.S. indicated that noncompliance would result in termination of federal funds.[138] This recourse is authorized by section 602 of the Civil Rights Act of 1964,[139] which is applicable to section 504 by virtue of the 1978 amendments.[140]

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133. *Id.*
134. *See* discussion *supra* at notes 100-123 and accompanying text.
135. 561 F. Supp. at 400.
136. 29 U.S.C. § 794a (1981), quoted *infra* note 140.
137. *See supra* note 62 and accompanying text.
138. 47 Fed. Reg. 26,027 (1982).
139. 42 U.S.C. § 2000d-1 (1976).
140. 29 U.S.C. § 794a (1981). This statute provides:
(2) The remedies, procedures, and rights set forth in title VI of the Civil Rights Act of 1965 shall be available to any person aggrieved by any act or failure to act by any recipient of Federal assistance or Federal provider of such assistance under section 794 of this title.

The funding termination remedy, however, may not be appropriate. The H.H.S. Notice implies that a single incident involving the death of a newborn could result in funding termination.[141] Yet, cases have held that the termination of funds was not intended as a remedy for individual cases of discrimination.[142] Rather, funding termination was perceived as an extreme measure to be used only when voluntary compliance on the part of the recipient is unachievable.[143] The correlative regulations further support this interpretation.[144]

Moreover, under section 602 of the Civil Rights Act of 1964, termination by an agency unable to effect compliance must be limited to the particular program in which noncompliance has been found.[145] Since the 1978 amendments incorporated the remedies, procedures and rights of the Civil Rights Act of 1964, it follows that this limitation is incorporated into section 504. Thus, it can be argued that if a hospital is found to have violated section 504 by improperly letting defective newborns die and if the termination of funds is warranted, the only federal funds that H.H.S. can terminate are those received by the specific hospital program.

Termination of funds is not the only remedy that H.H.S. has proposed. In the interim final rule, published in March 1983, the Department made clear that it intended to ask the Department of Justice to invoke legal proceedings to enforce section 504.[146] In contemplation of such intervention, the regulations required health care providers to post a notice which stated, "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW," and provided that all cases of discrimination should be reported to an H.H.S. "Handicapped Infant Hotline."[147] While

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141. The Notice discusses the withholding of treatment from a defective newborn as a violation of section 504. It then concludes, "[t]he failure of a recipient of Federal financial assistance to comply with the requirement of Section 504 subjects that recipient to possible termination of Federal assistance." 47 Fed. Reg. 26,027 (1982).

142. Fells v. Brooks, 522 F. Supp. 30, 33 (1981) ("cutting off federal funds under § 504 was no more intended to be the remedy for discrimination against individual handicapped people . . . than the same administrative scheme was under Title IX intended to be the remedy for individual victims of sex discrimination") (citing Cannon v. University of Chicago, 441 U.S. 677, 703-08 (1979)).

143. As the United States Supreme Court stated in *Cannon*, "[t]hat remedy [termination of federal funds] is, however, severe and often may not provide an appropriate means of accomplishing the second purpose [providing individual citizens effective protection against discriminatory practices] if merely an isolated violation has occurred." 441 U.S. at 704-5.

144. *See* 45 C.F.R. § 80.8 (1981).

145. 42 U.S.C. § 2000d-1 (1976) provides:

> Compliance with any requirement adopted pursuant to this section may be effected (1) by the termination of or refusal to grant or to continue assistance under such program or activity to any recipient . . . but such termination or refusal shall be limited to the particular political entity, or part thereof, or other recipient as to whom such a finding has been made and, shall be limited in its effect to the particular program or part thereof, in which such noncompliance has been so found. . . .

See also Simpson v. Reynolds Metals Co., Inc., 629 F.2d 1226, 1233 n.12 (7th Cir. 1980).

146. 48 Fed. Reg. 9,630 (1983).

147. *Id.* The entire required notice read:

> 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 participa-

these regulations did not survive *American Academy of Pediatrics v. Heckler*,[148] the same provisions are included in the regulations currently proposed by H.H.S.[149]

Without question, the "hotline" aspect of the H.H.S. regulations has created the most controversy. During the period from March 22, 1983 until April 13, 1983 when the first set of regulations was in effect, hospitals and health professionals expressed resentment at the posting requirement.[150] In striking down the regulations, the *American Academy of Pediatrics* court called the hotline "hasty" and "ill-considered."[151] The *American Academy of Pediatrics* court was also critical of what it called " 'Baby Doe' Squads." In commenting on the H.H.S. emergency terms, the court asserted that their "sudden descent . . . monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant."[152] Significantly, in the four cases where H.H.S. dispatched "Baby Doe" squads, no violations were found.[153] Yet, in at least one case, in Rochester, New York, the hospital in question experienced substantial disruption.[154] Moreover, it is unclear what the "Baby Doe" squad could have done had violations be found.

The general impotence of the "Baby Doe" squads illustrates that the proposed H.H.S. regulations are ill-suited to the statute upon which they are based. The proposed regulations provide that the Department can waive the usual 10-day waiting period from the time a funding recipient is advised of noncompliance to the time the Secretary makes a referral to the

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tion in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminately 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-_____(Available 24 hours a day)

or

Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations 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.

Id. The same notice is required in the proposed regulations. 48 Fed. Reg. 30,846, 30,851 (1983).

148. 561 F. Supp. 395; discussed *supra* at notes 82-85.

149. 48 Fed. Reg. 30,846 (1983).

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

151. 561 F. Supp. at 403.

152. *Id.* at 399.

153. Culliton, *supra* note 150 at 479.

154. *Id.* at 479-80. Siamese twins were flown from southern New York to Strong Memorial Hospital in Rochester for treatment. The newspaper reported this event and quoted the father as saying that no surgery was planned. Someone who had read the article called H.H.S. and the Department dispatched a "baby doe" squad. The squad found that the babies were getting good medical care, but according to the hospital's attorney, the investigation not only caused anquish to the parents of the twins but upset parents of other children at the hospital as well. In fact, the attorney was quoted as saying, "[t]he parents of one critically ill patient signed the child out of the hospital against medical advice for fear their child was not being well cared for. . . ." *Id.* at 480.

Department of Justice, if such waiver is necessary *to save an infant's life*.[155] But section 504 does not authorize the agency to act to save an infant's life. Although authority supports the right of the attorney general to bring suits on behalf of private citizens,[156] and the government may be able to obtain injunctive relief,[157] such relief would not include court-ordered treatment for a defective infant. Noncompliance under section 504 means only discriminatory conduct on the part of a federal funds recipient; therefore, the state cannot, under this statute, prevent a parent from discriminating against his or her child by withholding consent to treatment.[158]

This limited scope of section 504 no doubt led H.H.S., in its second attempt at promulgation, to extend the regulations to encompass state child protective services agencies. The Department noted that those agencies that receive federal funds are subject to section 504 and as such must provide handicapped children with the same protections offered to other children.[159] To ensure that the agencies are in compliance, the proposed regulations set forth specific procedures which must be followed with respect to endangered handicapped children.[160] This approach may be the most appropriate method of achieving the Department's goal. By putting pressure on the hospitals, H.H.S. can hope to prevent discrimination only indirectly, through coercion. Working with the child protective agencies, however, the Department can instigate a direct confrontation with discriminatory nontreatment by utilizing state laws.

While this latter approach is perhaps more palatable than the former, it does not dispel the question whether, by applying pressure to the federal funds recipient via section 504, H.H.S. impermissibly infringes on the constitutional rights of the family. Thus, the constitutional rights involved in treatment decisions regarding defective infants and the extent to which the government can intrude upon those rights must be considered.

III. CONSTITUTIONAL CONSIDERATIONS

In addition to the statutory questions, the application of section 504 to defective newborns raises possible constitutional problems. These problems arise because any government activity in the area of defective newborns implicates the fundamental right of parents to make treatment

155. 48 Fed. Reg. 30,846, 30,851 proposed regulation § 84.61[c].

156. United States v. Marion Cty. School Dist., 625 F.2d 607, 613 (5th Cir.) (held that the United States is entitled to sue to enforce contractual assurances of compliance with Title VI's prohibition against discrimination in federally funded schools), *cert. denied*, 451 U.S. 910 (1980); and United States v. Tatum Indep. School Dist., 306 F. Supp. 285, 288 (E.D. Tex. 1969) (held that the United States is entitled to bring an action under Title VI of the Civil Rights Act of 1964 and its implementing regulations, 45 C.F.R. § 80.8(a)).

157. Injunctive relief was granted in *Tatum*, 306 F. Supp. at 288.

158. Section 504, by definition, applies only to federal funds recipients. *See supra* notes 90, 92-97 and accompanying text.

159. 48 Fed. Reg. 30,846, 30,849. The regulations provide "State child protective agencies that receive federal financial assistance are under the same obligation as other recipients not to provide a qualified handicapped person with benefits or services that are less effective than those provided to others."

160. *Id.* at 30,851, proposed regulation 84.61(e)(1)-(5).

decisions regarding the medical care of their children.[161]

The United States Supreme Court has long recognized as implicit in the Constitution parents' fundamental right to make family decisions without undue government interference.[162] In case law, this principle has translated into the rights of parents to make decisions regarding the education and upbringing of their children,[163] the right to marry and procreate,[164] and the right of a woman to terminate a pregnancy.[165] Given this substantial tradition, if confronted with a case, the United States Supreme Court would probably hold that the right of parents to make decisions regarding the medical care of their children is fundamental.[166] Yet, finding the right fundamental does not make it absolute; it only means that the state must have a compelling interest in order to impinge on the right.[167]

In the case of a defective newborn, the state's interest is in continued life for the child. Generally speaking, continued life would be regarded as a compelling interest.[168] Yet, in *Roe v. Wade*[169] the Supreme Court found that the state's interest in potential life became compelling on a graduated scale, increasing as the woman's pregnancy neared its term.[170]

In the influential New Jersey decision, *In re Quinlan*,[171] the New

161. Other fundamental rights perhaps are also implicated by government regulation in the area of defective newborns. First, language in abortion cases could lend support to a finding of a fundamental right to privacy in the physician-patient relationship. *See, e.g.*, Doe v. Bolton, 410 U.S. 179, 199 (1973). The United States Supreme Court, however, later stated that the physician's right is no greater than that of his patient. *See* Harris v. McRae, 448 U.S. 297, 318 n.21 (1980). *See also infra* note 180 and accompanying text.

Another fundamental right possibly implicated is the right of the child to refuse medical treatment. This right has been acknowledged by state courts, but the United States Supreme Court has never confirmed it. *See, e.g.*, *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976). In the *Quinlan* case the court refused to recognize a constitutional right in Karen's father, as a parent, to terminate her treatment. The court's reason for this refusal was that Karen was no longer a minor. 70 N.J. at 42; 355 A.2d at 664. Assertion of the infant's right to refuse medical treatment in the case of a defective newborn presents the same difficulties encountered in cases involving mental incompetents. See Comment, *Withholding Treatment from Defective Newborns: Substituted Judgment, Informed Consent and the Quinlan Decision*, 13 GONZ. L. REV. 781, 791-95 (1978).

162. Meyer v. Nebraska, 262 U.S. 390, 339 (1923) (the liberty guaranteed by the fourteenth amendment encompasses "the right of the individual to . . . marry, establish a home and bring up children").

163. Wisconsin v. Yoder, 406 U.S. 205 (1972); Pierce v. Society of Sisters, 268 U.S. 510 (1925); Meyer v. Nebraska, 262 U.S. 390 (1923).

164. Loving v. Virginia, 388 U.S. 1 (1967); Skinner v. Oklahoma, 316 U.S. 535 (1942).

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

166. Several state courts have so held. *In re* Phillip B., 156 Cal. Rptr. 48, 50-51, *cert. denied*, 445 U.S. 949 (1980); State v. Perricone, 37 N.J. 463, 470, 181 A.2d 751, 756, *cert. denied*, 371 U.S. 890 (1962); Matter of Hoffauer, 47 N.Y.2d 648, 655, 393 N.E.2d 1009, 1013, 419 N.Y.S.2d 936, 940 (1979). *See also* Note, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OHIO ST. L.J. 813 (1981).

In the supplementary information to the recently proposed regulations, H.H.S. acknowledged, "The Department recognizes that parents retain the fundamental right, coupled with the high duty, to nuture and direct the destiny of their children." 48 Fed. Reg. 30,846, 30,848 (1983).

167. "Where certain 'fundamental rights' are involved, the Court has held that regulation limiting these rights may be justified only by a 'compelling state interest,'. . ." *Roe* 410 U.S. at 155.

168. In *Roe v. Wade* the Court found the state's interest in the preservation of the lives of the mother and a viable fetus "compelling." 410 U.S. at 163.

169. 410 U.S. 113 (1973).

170. 410 U.S. at 163.

171. 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

Jersey Supreme Court employed a similar sliding scale in its constitutional analysis. After finding a constitutional right to refuse medical treatment, the court held that the state's interest in continued life weakened as the medical prognosis dimmed.[172] Conceivably, the same type of approach would be appropriate in the defective newborn situation, so that the state's interest in continued life, counterbalanced against the parent's right to make the treatment decision, becomes progressively less compelling as the physical and mental handicaps become more severe.

If this "sliding scale" view of the state's interest were adopted, the application of section 504 to the defective newborn dilemma might encounter constitutional obstacles. Any statutory impringement on a fundamental right must be "narrowly drawn to express only legitimate state interests at stake" even when the state interest is compelling.[173] As the court noted in *American Academy of Pediatrics*, "to the extent that the regulation is read to eliminate the role of the infant's parents in choosing an appropriate course of medical treatment, its application may in some cases infringe upon the interests outlined in cases such as . . . *Roe v. Wade*. . . ."[174] The Department's interpretation of section 504 does not clearly differentiate between those cases where the state has a compelling interest in preserving the infant's life and those where the state's interest is less than compelling.[175] Thus, the possibility exists that parents exercising a constitutionally protected right to withhold treatment from a severely defective infant will be pressured to consent to further medical care.

The application of section 504 to defective newborns, as contemplated by H.H.S., does not directly impinge on a parent's right to choose the course of medical care for his or her child. The federal government can only require that a federal funds recipient not discriminate against handicapped infants.[176] Consequently, any intrusion on the fundamental rights of parents by virtue of this interpretation will be indirect. The fact that the H.H.S. interpretation does not directly prevent the parents from exercising their right, however, is not constitutionally significant. In *Shapiro v. Thompson*, the United States Supreme Court stated, "[i]f a law has no other purpose . . . than to chill the assertion of constitutional rights by penalizing those who choose to exercise them, it [is] patently unconstitutional."[177]

Arguably, the principle of *Shapiro* would apply to the H.H.S. interpretation of section 504, which requires parents who choose to forego medical treatment for their severely defective child to remove the child from a federally funded hospital.[178] If, under these circumstances, the child is so severely defective that the state does not have a compelling interest in pre-

172. "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." *Id.* at 41, 355 A.2d at 664.

173. *Roe v. Wade*, 410 U.S. at 155.

174. 561 F. Supp. at 403.

175. *See supra* notes 115-123 and accompanying text.

176. *See supra* note 158.

177. 394 U.S. 618, 631 (1969) (quoting United States v. Jackson 390 U.S. 570, 581 (1968)).

178. 47 Fed. Reg. 26,027 (1982); this requirement is discussed *supra* at notes 130-31.

serving its life, the H.H.S. interpretation will, in effect, penalize those parents for exercising a constitutional right.

The H.H.S. interpretation which requires a physician in a federally funded facility to refrain from counseling parents to withhold treatment from their defective newborn presents a similar problem.[179] Again, this restriction may prevent a physician from recommending the withholding of treatment even in cases where the state's interest is not compelling. In such a case, the state would impermissibly encumber the parents' exercise of a constitutional right "by placing obstacles in the path of the doctor upon whom [they were] entitled to rely for advice in connection with [their] decision."[180]

These constitutional attacks on the H.H.S. interpretation, however, could be countered by using the reasoning of *Harris v. McRae*.[181] In *Harris*, the United States Supreme Court upheld a statute proscribing government funding of abortions. The Court held that, "although government may not place obstacles in the path of a woman's exercise of her freedom of choice, it need not remove those not of its own creation."[182] Thus, "whether freedom of choice that is constitutionally protected warrants federal subsidization is a question for Congress to answer, not a matter of constitutional entitlement."[183] Arguably, the same reasoning can be applied to the situation involving defective newborns. If the state can encourage childbirth by subsidizing those health care costs, while refusing to subsidize abortion, then the state can also encourage treatment for defective newborns by subsidizing infant health care only when it is consonant with promoting the child's life.

A significant difference exists, however, between the situation in *Harris v. McRae* and that covered by the H.H.S. interpretation. The constitutional amendment at issue in *Harris* limited only the direct funding of abortions.[184] It prevented neither the institution from administering nor a physician from advising a patient to seek an abortion. In this respect, the impact and intent of the H.H.S. defective newborn stance is much more severe. As the Department's counsel acknowledged in oral argument in *American Academy of Pediatrics*, the H.H.S. interpretation is "intended, among other things, to change the course of medical decisionmaking in these cases by eliminating the parents' right to refuse to consent to life-sustaining treatment of their defective newborn."[185]

If this admission is an accurate reflection of the regulation's impact, and if the court were to find that in some instances parents have a right to refuse lifesaving medical treatment for their defective infant, section 504 as applied by the Department of Health and Human Services seems to impinge on constitutional rights in an impermissible manner.

179. 47 Fed. Reg. 26,027 (1982). *See also* discussion at notes 132-35.
180. Whalen v. Roe, 429 U.S. 589, 604 n.33 (1977).
181. 448 U.S. 297 (1980).
182. *Id.* at 316.
183. *Id.* at 318.
184. *Id.* at 301.
185. 561 F. Supp. at 401.

IV. CONCLUSION

The Department of Health and Human Services appears intent upon applying section 504 to the defective newborn controversy. As the foregoing analysis indicates, the government may be able to regulate health care decisions regarding defective newborns to some extent, but it must do so with precision. Clearly, the H.H.S. reinterpretation of section 504 paints with too broad a brush in an area involving fundamental rights. Furthermore, there is something inherently offensive in an administrative agency's manipulation of existing law via its rulemaking powers to create, in effect, new legislation. This is especially true when the regulations are directed at such a critical and difficult issue.[186]

Despite these objections, the H.H.S. application of section 504 to the newborn controversy serves as a reminder that the physically and mentally disabled continue to be the target of a great deal of discrimination. It may well be that able-bodied physicians and parents of normal intelligence often misperceive the "quality of life" of one with a handicap.[187] In such instances it may be entirely appropriate for the government to protect a disabled infant from his or her own parents. The problem with the H.H.S. approach is that it does not account for the complexity of the moral issues involved in many cases. Surely a dilemma that has challenged the legal and medical professions for more than a decade cannot and should not be resolved by administrative fiat.

186. *See* Office of Consumers' Counsel v. Federal Energy Regulatory Commission, 655 F.2d 1132, 1152 (D.C. Cir. 1980) ("It is not for an administrative agency, however, to preempt Congressional action or to 'fill in' where it believes some federal action is needed. It goes without saying that appropriate respect for legislative authority requires regulatory agencies to refrain from the temptation to stretch their jurisdiction to decide questions of competing public priorities whose resolution properly lies with Congress.")

187. This same concern was expressed by the President's Commission Report, *supra* note 22, at 223.