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Medical Treatment Decisionmaking for Seriously Handicapped Infants: Is There a Role for the Federal Government?

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MEDICAL TREATMENT DECISIONMAKING FOR SERIOUSLY HANDICAPPED INFANTS: IS THERE A ROLE FOR THE FEDERAL GOVERNMENT?

In 1982, a Down's Syndrome baby in Indiana focused public and governmental attention on the problems involved in making treatment decisions for seriously handicapped infants.[1] This baby, known as Baby Doe, died after his parents decided not to consent to surgery to correct his blocked esophagus.[2] The public outcry over this case led the U.S. Department of Health and Human Services and ultimately Congress to seek ways to ensure that medical treatment decisions are based only on the likelihood that treatment will be medically beneficial rather than on subjective assessments of the quality of life deemed possible for an infant who is likely to suffer from permanent disabilities.[3]

Before this case, the parents and doctors of a disabled infant made these difficult decisions regarding medical treatment primarily on their own.[4] Although state child protective services agencies and state courts protected infants from treatment decisions which violated state homicide and neglect statutes, the federal government was not involved.[5] After 1982, however, the federal government decided that the existing framework for decisionmaking had not worked in the Indiana Baby Doe case.[6] As a result, the government sought, under two different federal statutes, to give the Department of Health and Human Services (HHS) a role in infant treatment decisions.[7]

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[1] *See* Ellman, *Baby Doe: Problems and Legislative Proposals — Legislative Workshop*, 1984 ARIZ. ST. L.J. 601, 601–02.

[2] *See* R.F. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE, 128–29 (1984).

[3] *See* Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101–5103 (1982 & Supp. III 1985); 45 C.F.R. § 84.55 (1986) (Final Rules issued under Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982)). The Supreme Court invalidated portions of these Final Rules in Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101 (1986). *See infra* notes 117–143 and accompanying text.

[4] *See* R.F. WEIR, *supra* note 2, at 39. For a discussion of the incidence of parental decisions not to treat and physician attitudes towards nontreatment, see Turnbull, *Incidence of Infanticide in America: Public and Professional Attitudes*, 1 ISSUES IN L. & MED. 363 (1986). After emphasizing the diversity of opinion among physicians and the difficulty of making generalizations, Professor Turnbull concludes that public and professional attitudes "are largely negative and incidence is greater than reported." *Id.* at 383. Another survey of physician attitudes indicates that over 80% of pediatric surgeons and pediatricians do not believe that "the life of each and every newborn infant should be saved if it is within [their] ability to do so." Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588, 589 (1977). Doctors at an Oklahoma hospital have been sued for allegedly using various nonmedical criteria in determining how to treat infants born with spina bifida. Johnson v. Sullivan, No. Civ. 85-2434 A (W.D. Okla., filed Oct. 3, 1985), *described in* 1 ISSUES IN L. & MED. 321, 321 (1986). In determining how to treat infants born with spina bifida, the doctors considered nonmedical factors including the financial and intellectual resources of the infant's family and the financial support available from support agencies. *Id.* at 323.

[5] *See* Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 222, 233 (1975).

[6] *See* 49 Fed. Reg. 1622, 1622–23 (1984).

[7] *See* Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982); Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101–5103 (1982 & Supp. III 1985).

The federal government responded initially to the Baby Doe case by issuing and amending a series of HHS regulations[8] under the authority of section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against the handicapped in federally funded programs.[9] The section 504 regulations generally empowered HHS officials to intervene directly in individual cases by conducting on-site investigations when HHS received reports alleging that a handicapped infant was not receiving appropriate medical care.[10] In addition, the regulations authorized HHS to recommend that the U.S. Justice Department take action in individual cases where HHS deems it necessary to ensure that an infant is not discriminatorily denied medical treatment.[11]

In the 1986 case of *Bowen v. American Hospital Association*, the United States Supreme Court struck down the section 504 regulations which gave HHS officials a role in individual medical treatment decisions.[12] The Supreme Court in *Bowen* found that HHS failed to establish that the incidence of discrimination against handicapped infants justified the intrusive federal agency involvement in medical treatment decisions contemplated by the section 504 regulations.[13] The Court, however, did not decide whether section 504 permitted any HHS involvement in these medical treatment decisions.[14]

The federal government's second response to the Indiana Baby Doe case was to amend the Child Abuse Prevention and Treatment Act in 1984.[15] Congress amended the definition of child neglect to include the "withholding of medically indicated treatment" from seriously disabled infants.[16] The Child Abuse Amendments require states to implement documented procedures to respond to reports of such medical neglect.[17] Congress also authorized HHS to issue regulations generally implementing the provisions of these amendments.[18]

Despite the federal government's regulatory and legislative responses to the Indiana Baby Doe case, its role in the process of making medical treatment decisions for seriously handicapped infants has, in the final analysis, remained essentially unchanged. The Supreme Court has declared that the federal government's efforts to involve itself in

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[8] *See* 45 C.F.R. § 84.55 (1986) (Final Rules issued Jan. 12, 1984); 48 Fed. Reg. 30,846 (1983) (Proposed Rules, proposed July 5, 1983); 48 Fed. Reg. 9630 (1983) (Interim Final Rule, proposed Mar. 7, 1983). HHS has the authority to issue regulations implementing the provisions of the Rehabilitation Act. *See* S. REP. No. 1297, 93d Cong., 2d Sess. 40, *reprinted in* 1974 U.S. CODE CONG. & ADMIN. NEWS 6373, 6391.

[9] 29 U.S.C. § 794 (1982). For the text of § 504, see *infra* note 54.

[10] *See* 45 C.F.R. § 84.55 (1986).

[11] 45 C.F.R. §§ 80.8(2), 84.55(e) (1986). For a general discussion of the objections to the § 504 regulations, see Mathieu, *The Baby Doe Controversy*, 1984 ARIZ. ST. L.J. 605, 607–11; Meyer, *Protecting the Best Interests of the Child: Is The State the Necessary Blunt Instrument?*, 1984 ARIZ. ST. L.J. 627, 633–35.

[12] 106 S. Ct. 2101, 2123 (1986).

[13] *See id.* at 2122.

[14] *See id.* at 2124–25 (White, J., dissenting).

[15] *See* 42 U.S.C. §§ 5101–5103 (1982 & Supp. III 1985). The Child Abuse Prevention and Treatment Act, originally passed in 1974, generally provides for federal grants to the states and public and private organizations for the purpose of identifying, preventing, and treating child abuse and neglect. *See* 50 Fed. Reg. 14,878 (1985).

[16] 42 U.S.C. §§ 5102(3) (Supp. III 1985).

[17] 42 U.S.C. § 5103(b)(2)(K) (Supp. III 1985).

[18] 42 U.S.C. § 5103 note (Supp. III 1985) (Procedures and Programs for Responding to Reports of Medical Neglect).

treatment decisions under section 504 are unwarranted.[19] In addition, the Child Abuse Amendments leave to the states the task of ensuring that treatment decisions are not based on discriminatory considerations related to an infant's likely disabilities.[20]

While the potential exists for further federal regulation under both statutory schemes, the government has thus far refrained from further intrusion into the medical decisionmaking process. Currently, the infant's parents and doctors still have primary responsibility for deciding when to withhold treatment,[21] although the Child Abuse Amendments require state agencies to intervene if they receive a report that treatment is being withheld wrongfully.[22] The federal government thus seems to have recognized that the problem of making treatment decisions for handicapped infants is not one which is best resolved by federal government action, but rather is a matter best left to the more flexible judgment of parents, doctors, and, in exceptional cases, state agencies.[23]

This note will explore the changing role of the federal government in medical treatment decisionmaking for handicapped infants. Section I will describe briefly the framework in which treatment decisions were made prior to the recent federal responses to the "Baby Doe" problem.[24] Section II will discuss the HHS regulations promulgated and amended under the nondiscrimination provisions of section 504 of the Rehabilitation Act, and how lower courts responded to those regulations.[25] This section also will examine the Supreme Court's decision in *Bowen v. American Hospital Association* and its effect on HHS's ability to regulate treatment decisions under section 504.[26] Section III will describe the Child Abuse Amendments enacted by Congress and regulations issued thereunder by HHS.[27] Finally, section IV will analyze the role the federal government could still play in medical treatment decisions for handicapped infants and conclude that federal government involvement in the decisionmaking process is unwarranted.[28]

I. Regulation of Medical Decisionmaking for Infants Before 1982

Prior to the recent activity in the federal arena, no uniform law governed medical treatment decisionmaking for handicapped infants and regulation of this process was left to the states.[29] Individual state homicide laws, and, in some states, child abuse and neglect laws, provided some limitations within which parents and doctors made treatment

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[19] Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101, 2123 (1986).

[20] 42 U.S.C. § 5103(b)(2)(K) (Supp. III 1985).

[21] *See* 50 Fed. Reg. 14,878, 14,880 (1985).

[22] 42 U.S.C. § 5103(b)(2)(K) (Supp. III 1985).

[23] For a discussion of the advisability of regulating treatment decisions, *compare* Goldstein, *Not for Law to Approve or Disapprove — A Comment on Professor Mnookin's Paper*, 1984 Ariz. St. L.J. 685, 691–92 (concluding that legislation is inappropriate because society does not agree on what treatment decisions are "right" or "wrong") *and* Shapiro, *Medical Treatment of Defective Newborns: An Answer to the "Baby Doe" Dilemma*, 20 Harv. J. on Legis. 137, 150 (1983) (concluding that legislation is needed to "establish a legal framework to guide the activities and the decisions of health care personnel and others").

[24] *See infra* notes 29–49 and accompanying text.

[25] *See infra* notes 54–116 and accompanying text.

[26] *See infra* notes 117–59 and accompanying text.

[27] *See infra* notes 160–87 and accompanying text.

[28] *See infra* notes 188–235 and accompanying text.

[29] *See generally* Robertson, *supra* note 5, at 217–35.

decisions.[30] Yet despite the apparent applicability of these state laws, as several commentators noted, whether a decision to withhold treatment from a handicapped infant would result in civil or criminal liability for the parents or doctors was an open question.[31]

The intentional killing of an infant clearly violates state homicide laws.[32] A parent or doctor who deliberately withholds or withdraws lifesaving medical care from an infant for the purpose of causing the infant's death could be subject to criminal liability for murder, as well as for violating state child abuse and neglect laws.[33] Criminal sanctions, however, are rarely, if ever, applied to parents or doctors who decide to withhold treatment from severely handicapped newborns.[34] In some cases states have instituted neglect proceedings which result in courts ordering that a child be taken from his or her parents for purposes of treatment.[35] In general, however, most parental decisions to withhold treatment are not challenged because parents and doctors make these decisions privately and state prosecutors, even if informed, generally respect the difficult nature of these decisions.[36]

In the early 1970s, articles began to appear in medical journals publicizing the fact that parents and doctors were withholding or withdrawing medical treatment from some severely handicapped infants.[37] Nevertheless, parents and doctors continued to make treatment decisions for severely handicapped infants privately, except in rare cases when hospital personnel disagreed with a decision strongly enough to intitiate neglect proceedings.[38] Despite the problem's increased exposure, no substantive change occurred in doctor and parental discretion concerning treatment decisions for disabled infants until nearly ten years later, when the Baby Doe case came to the public's attention and sharply focused public debate and criticism on these medical treatment decisions.[39]

Baby Doe was born in Bloomington, Indiana with Down's Syndrome and esophageal atresia, a condition in which the esophagus is separated from the stomach and the result of which is that food cannot be taken orally.[40] Although this condition is surgically

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[30] *Id.* (discussing criminal liability of parents and doctors under existing laws). *See also* R.F. WEIR, *supra* note 2, at 99.

[31] *See, e.g.*, R.F. WEIR, *supra* note 2, at 98.

[32] *Id.* at 92.

[33] *See* Mnookin, *Two Puzzles*, 1984 ARIZ. ST. L.J. 667, 668–69; Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J.L. & MED. 393, 402 (1982).

[34] R.F. WEIR, *supra* note 2, at 98. In fact, Weir asserts that no parent or doctor in this country has ever been successfully prosecuted for neonatal euthanasia. *Id.*

[35] Mnookin, *supra* note 33, at 670 & n.10. Professor Mnookin gives several examples, including *Weber v. Stony Brook Hospital*, discussed *infra* at notes 89–91 and accompanying text, of cases where states have become involved in parental nontreatment decisions through state child abuse and neglect laws. *Id.* at 670 n.10.

[36] *See* R.F. WEIR, *supra* note 2, at 101.

[37] Mnookin, *supra* note 33, at 670 n.8. *See, e.g.*, Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973) (reporting that 43 out of 299 consecutive deaths of infants admitted to the special care nursery during 1970–72 resulted from decisions to withhold treatment).

[38] *See* Mnookin, *supra* note 33, at 670–71.

[39] *See id.* at 671–72. Weir explains that possible reasons for the infrequent prosecution of parents and doctors who decide to withhold treatment from handicapped infants include the private nature of the decision, general agreement among those involved about the action taken, and respect for the parents' autonomy in making a very difficult decision. R.F. WEIR, *supra* note 2, at 100–02.

[40] R.F. WEIR, *supra* note 2, at 128 & 141 n.29 (describing the Indiana Baby Doe case).

correctible, the doctors involved in this case disagreed about the operation's chance of success. The parents decided not to consent to surgery or to intravenous feedings.[41]

The hospital administration brought suit seeking to overrule the parents' decision. At an emergency hearing, the judge held that the parents had a right to withhold consent to the surgery even though it meant that the child would die.[42] Although the county welfare agency, appointed as the child's guardian ad litem, did not appeal the court's decision, county prosecutors intervened and unsuccessfully sought to have the appeals court take custody of the child.[43] The prosecutors then appealed to the Indiana Supreme Court which refused to intervene.[44] Baby Doe died six days after his birth while the prosecutors were seeking a stay in the United States Supreme Court.[45]

The parents' decision in the Baby Doe case received a great deal of publicity and criticism.[46] Before this controversial case, parents and doctors generally made difficult treatment decisions for seriously disabled infants without interference from government agencies.[47] After the Baby Doe case, however, HHS promulgated a series of regulations under section 504 of the Rehabilitation Act intended to regulate the decisionmaking process regarding medical treatment for handicapped infants.[48] The Supreme Court ultimately invalidated these regulations in its 1986 decision in *Bowen v. American Hospital Association*.[49]

II. The Government's First Response — The Regulations Under Section 504 of the Rehabilitation Act

A. *HHS Regulations Issued Under Section 504 and Lower Court Responses*

As a result of the publicity over the Baby Doe case, President Reagan issued a memorandum directing the Secretary of HHS to remind health care providers that section 504 of the Rehabilitation Act of 1973 applied to them.[50] The Rehabilitation Act of 1973 extended and amended the Vocational Rehabilitation Act.[51] As the name implies, the Act is geared towards assisting the states, through federal grants, in providing vocational rehabilitation programs to help handicapped individuals gain employment and participate more fully in society.[52] Although in general the act focuses on providing

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[41] *Id.* Weir reports that some of the doctors involved believed the operation had an 85–90% chance of success, while others believed the chance of success was 50–50. *Id.*

[42] *Id.*

[43] *Id.* at 128–29 (referring to *In re* Infant Doe, No. GU 8204-004A (Monroe County Cir. Ct., Apr. 12, 1982), *cited in* Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101, 2108 n.5 (1986)).

[44] *Id.* (referring to State *ex rel.* Infant Doe v. Baker, No. 482 S 140 (May 27, 1982), *cited in Bowen*, 106 S. Ct. at 2108 n.5).

[45] *Id.* at 129. Certiorari was denied. Infant Doe v. Bloomington Hosp., 464 U.S. 961 (1983).

[46] *See* Mnookin, *supra* note 33, at 671–72.

[47] *See id.* at 669–70.

[48] *See* 49 Fed. Reg. 1622 (1984).

[49] 106 S. Ct. 2101, 2123 (1986).

[50] 49 Fed. Reg. 1622 (1982).

[51] 29 U.S.C. § 790 (1982).

[52] S. Rep. No. 318, 93d Cong., 1st Sess. 18–19, *reprinted in* 1973 U.S. Code Cong. & Admin. News 2076, 2092. *See also* 29 U.S.C. § 701 (1982), which contains the following "congressional declaration of purpose": "The purpose of this chapter is to develop and implement, through

vocational training to the handicapped, the act also establishes groups to study architectural and transportation barriers impeding the handicapped, and to monitor the federal government's progress in hiring and placement of handicapped individuals.[53] Section 504, the act's last section, makes it unlawful for programs or activities that receive federal funding to discriminate against an otherwise qualified handicapped individual solely because of the individual's handicap.[54] Under section 504, the federal government's executive agencies are authorized to issue regulations prohibiting discrimination against handicapped individuals in federally funded programs.[55] Thus, section 504 provides a mechanism for the federal government to institute procedures to eliminate handicap discrimination in federally funded programs.[56]

In May of 1982, the Secretary of HHS responded to the Indiana Baby Doe case and the President's memorandum by sending a notice to 7,000 health care providers reminding them that section 504 applied to medical treatment decisions involving handicapped infants.[57] In March of 1983, the Secretary published an Interim Final Rule (the "Interim Rule") which required hospitals to post in a conspicuous place a notice titled: "DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW."[58] The Interim Rule established a confidential "Handicapped Infant Hotline" for persons who wished to report suspected discriminatory treatment of handicapped infants, and provided for immediate HHS on-site investigations, including access to medical records, parents, and doctors, when HHS officials believed it necessary to protect a handicapped infant.[59]

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research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living."

[53] 29 U.S.C. §§ 791, 792 (1982).

[54] *See* Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982). Section 504 provides: "[n]o otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his [or her] 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 . . . ." *Id.*

29 U.S.C. § 706(7)(B) defines handicapped individual as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

[55] 29 U.S.C. § 794 (1982).

[56] S. REP. NO. 1297, 93d Cong., 2d Sess. 24, *reprinted in* 1974 U.S. CODE CONG. & ADMIN. NEWS 6373, 6390.

[57] 49 Fed. Reg. 1622, 1622–23 (1984). The notice stated:

> Under section 504, it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:
>
> (1) The withholding is based on the fact that the infant is handicapped;
>
> (2) The handicap does not render the treatment or nutritional sustenance medically contraindicated.

47 Fed. Reg. 26,027 (1982). The notice also recommended that "[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." *Id.*

HHS later changed its position on this latter point, stating that "a recipient hospital may not blindly implement improper and discriminatory parental decisions. Rather, the hospital should resort to the system provided by state law to determine whether a parental decision should be implemented." 49 Fed. Reg. 1622, 1631 (1984).

[58] 48 Fed. Reg. 9630, 9631 (1983) (proposed Mar. 7, 1983).

[59] *Id.* at 9630–31.

Shortly after its publication, a group of children's medical organizations challenged the Interim Rule, alleging, among other things, that the regulation was issued in violation of the Administrative Procedure Act's (APA's) notice requirements.[60] In *American Academy of Pediatrics v. Heckler*, the United States District Court for the District of Columbia struck down the Interim Rule.[61] The court found that the Interim Rule violated the APA in two respects: first, it was arbitrary and capricious because HHS ignored several important factors involved in medical treatment decisionmaking;[62] and second, it violated the specific APA procedural requirements for a public comment period[63] and publication of the regulation at least thirty days before its effective date.[64]

The court found that the Interim Rule failed to satisfy the APA's substantive requirements in that HHS failed to present evidence that it considered several critical factors involved in applying section 504 to medical treatment decisions for handicapped infants.[65] The court noted HHS's failure to consider the disruption of hospital routine and infant care that the Handicapped Infant Hotline and the so-called "Baby Doe squads" would cause in hospital nurseries.[66] While the regulations encouraged doctors to think in terms of the medical risks and benefits to the handicapped infant, the court was concerned that the regulations did not give sufficient consideration to the parents' wishes, commenting that it is the parents who know what decision will be in their child's best interests.[67]

The court further criticized HHS's failure to consider the proper course of treatment in futile cases, failure to consider other ways to protect handicapped infants, failure to consider the proper scope of section 504, and failure to show that the problem is of sufficient magnitude to warrant the proposed regulation.[68] The court also faulted the text of the rule, citing particularly the provision that it is unlawful to deny to a handicapped infant "customary medical care."[69] On reviewing the evidence submitted, the court found that no customary standard of medical care existed for treating severely handicapped infants, and, therefore, the regulation was meaningless "beyond its intrinsic *in terrorem* effect."[70]

In addition to finding that HHS violated the APA in failing to consider all relevant factors, the court found that HHS failed to meet the APA's procedural requirements because it did not provide the required public comment period or publish the regulation at least thirty days before its effective date.[71] Because the Interim Rule proposed substantial changes in the process of medical treatment decisionmaking, the court found

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[60] American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 396 (D.D.C. 1983). The plaintiffs also argued that the regulation unconstitutionally invaded the parents' and doctors' privacy rights, and that HHS did not have statutory authority to issue the regulations. *Id.*

[61] *Id.* at 403.

[62] *Id.* at 398–99 (citing Administrative Procedure Act, 5 U.S.C. § 706(2)(A) (1982)).

[63] *Id.* at 400 (citing Administrative Procedure Act, 5 U.S.C. § 553(b) (1982)).

[64] *Id.* (citing Administrative Procedure Act, 5 U.S.C. § 553(d) (1982)).

[65] *Id.* at 399.

[66] *Id.*

[67] *Id.* at 400.

[68] *Id.*

[69] *Id.* (citing Interim Rule, 48 Fed. Reg. 9630, 9631 (1983)).

[70] *Id.*

[71] *Id.*

that it was not a mere procedural or interpretive rule.[72] Instead, the court found, the Interim Rule affected substantive rights and therefore was subject to the APA's comment and delayed effective date requirements.[73] The court dismissed HHS's argument that the APA's procedural requirements should be waived in order to save infant lives, finding no evidence of an emergency that justified waiving the public comment period.[74]

Because it determined that the Interim Rule was invalid under the APA, the court did not decide the issue of section 504's general applicability to medical treatment of seriously handicapped newborns.[75] In dicta, however, the court observed that although the legislative history does not evidence a specific congressional intent to apply section 504 to sensitive medical treatment decisions for handicapped newborns, the language is similar to that of other civil rights statutes which have been applied broadly to fight racial discrimination.[76] The court therefore speculated that section 504 might authorize some regulation of medical treatment decisions for handicapped infants,[77] but noted that a specific case would provide a better basis for determining the statute's proper scope.[78]

After the *American Academy of Pediatrics* decision, HHS issued and requested comment on a new Proposed Rule.[79] This Proposed Rule contained a slightly revised notice requirement and an added provision requiring federally funded *state* child protective services agencies to use their authority under *state* law to fight discrimination against handicapped infants.[80] HHS gave several examples of treatment decisions that would violate section 504, including, for example, denying treatment to a child with spina bifida when the denial is based on the likelihood that the child will suffer mental impairment, paralysis, or incontinence throughout his or her life.[81] After the Proposed Rule was issued, a case involving facts similar to the HHS example entered the public spotlight and eventually led to two lawsuits.[82]

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[72] *Id.* at 401.

[73] *Id.* One purpose of the APA, the court noted, is to ensure rational consideration of the potential impact of regulatory action by allowing persons the opportunity to comment on proposed regulations. *Id.* at 398–99.

[74] *Id.* at 401.

[75] *Id.*

[76] *See id.* at 401–02.

[77] *See id.* at 402. The court stated, however:

> 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.
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> Many would argue that had Congress intended section 504 to reach so far into such a sensitive area of moral and ethical concerns it would have given some evidence of that intent.

Id.

[78] *Id.* The plaintiffs also argued that the § 504 regulations invaded various constitutional rights. *Id.* at 402–03. The court found that resolution of the constitutional issues was better left to specific cases in which the regulations had been applied to individual plaintiffs. *Id.* at 403.

[79] *See* 48 Fed. Reg. 30,846 (1983) (proposed July 5, 1983).

[80] *Id.* at 30,851.

[81] *Id.* at 30,852.

[82] *See* United States v. University Hosp., 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984); Weber v. Stony Brook Hosp., 95 A.D.2d 587, 467 N.Y.S.2d 685 (*per curiam*), *aff'd per curiam on other grounds*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983).

On December 11, 1983, Baby Jane Doe was born in New York with spina bifida[83] and other serious complications.[84] Her parents decided not to consent to surgery that would close the lesion in her back and correct her hydrocephalus, and decided instead to treat her condition with antibiotic therapy.[85] Their decision was challenged first by a person unrelated to Baby Jane Doe or her family,[86] and later by the United States government acting on an anonymous telephone call to the HHS hotline alleging that the hospital was discriminating against Baby Jane Doe based on her handicap.[87]

In the first action, a Vermont attorney named A. Lawrence Washburn challenged the parents' decision by petitioning the court to appoint a guardian ad litem for Baby Jane Doe.[88] The Supreme Court of Suffolk County initially appointed a guardian ad litem and authorized him to consent to surgery to preserve Baby Jane Doe's life, but the Appellate Division of the Supreme Court reversed this decision the next day.[89] The Appellate Division found no cause to interfere with the parents' informed choice of one reasonable course of medical treatment over another for their daughter.[90] The New York Court of Appeals affirmed and emphasized that it found no basis for interfering when the party challenging the parents' decision had no relationship with any of the concerned parties and apparently did not notify the New York Department of Social Services of Baby Jane Doe's supposed neglect.[91]

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[83] Weir defines spina bifida as most commonly involving:

> an opening in the . . . back that exposes both membrane tissue and nerve tissue and often leaks cerebrospinal fluid. Caused by the failure of the neural tube to close during the first trimester of pregnancy spina bifida with meningomyelocele differs in its severity depending on the size of the lesion, the location of the defect along the spinal column, and the associated congenital anomalies present (hydrocephalus, neurological dysfunction, sensory loss below the lesion, paralysis or muscle weakness below the defect, incontinence of bowel and bladder).

R.F. WEIR, *supra* note 2, at 43.

[84] *Weber*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686. The court described Baby Jane Doe's other medical problems as including "microcephaly, a small head circumference, bespeaking increased pressure in the cranial cavity, and hydrocephalus, a condition in which fluid fails to drain from the cranial areas." *Id.*

[85] *Id.* at 588–89, 467 N.Y.S.2d at 686.

[86] *Weber*, 60 N.Y.2d at 211, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.

[87] *University Hosp.*, 729 F.2d at 147.

[88] *See id.* at 146.

[89] *Weber*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686. *See also University Hosp.*, 729 F.2d at 147.

[90] *Weber*, 95 A.D.2d at 589, 467 N.Y.S.2d at 687. The court specifically found:

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

Id., 467 N.Y.S.2d at 686–87.

There are instances, however, where courts do not find the parents' decision to be reasonable. *See, e.g.*, Matter of Cicero, 101 Misc. 2d 699, 702, 421 N.Y.S.2d 965, 967–68 (N.Y. Sup. Ct. 1979) (court granted petition to appoint guardian to consent to surgery for infant with spina bifida whose parents had refused consent "without justification").

[91] *Weber*, 60 N.Y.2d at 212–13, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65. The Court of Appeals

During these state court proceedings, HHS received a complaint alleging that doctors were denying Baby Jane Doe medical treatment because of her handicap.[92] The government brought suit in federal district court under section 504 and the HHS regulations promulgated thereunder when the hospital, at the parents' behest, refused to release the infant's medical records to HHS.[93] The United States District Court for the Eastern District of New York held, in *United States v. University Hospital*, that although Medicare and Medicaid payments do constitute federal financial assistance and thus subject the hospital to section 504's prohibitions,[94] the hospital had not in fact violated section 504.[95] Because the court found that the hospital's failure to perform the surgery on Baby Jane Doe was based solely on the parents' refusal to consent, and the hospital could not legally operate without this consent, the court concluded that the hospital had not discriminated against Baby Jane Doe based on her handicap.[96] The court further noted that the parents' decision to refuse consent was reasonable and in the child's best interests; in following the parents' decision, therefore, the hospital's actions could not violate section 504.[97]

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found that the petitioner had not complied with the New York Family Court Act, which provided that child protective proceedings could be brought only by a child protective agency or by a person appointed by a court. *Id.* at 212, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64 (citing N.Y. FAM. CT. ACT § 1032). The court expressed its disapproval of the entire matter:

> There are overtones to this proceeding which we find distressing. Confronted with the anguish of the birth of a child with severe physical disorders, these parents, in consequence of judicial procedures for which there is no precedent or authority, have been subjected in the last two weeks to litigation through all three levels of our State's court system. We find no justification for resort to or entertainment of these proceedings.

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

[92] *University Hosp.*, 575 F. Supp. at 611.

[93] *Id.* The regulations which HHS relied on in this case were not the new Proposed Rules issued after the Indiana Baby Doe case, as they had not yet become effective. *See University Hosp.*, 729 F.2d at 146. The regulations involved in this case required that recipients of federal financial assistance allow HHS officials access, during normal business hours, to such records as HHS deemed necessary to determine that the recipient was in compliance with section 504. *See id.* at 147–48 (citing 45 C.F.R. § 84.61 (1982)).

[94] 575 F. Supp. 607, 612 (E.D.N.Y. 1983). The courts have not fully addressed the issue of whether hospitals are recipients of federal financial assistance within the meaning of § 504. Although the court here decided that Medicaid and Medicare reimbursements do constitute federal financial assistance, other courts that have examined the issue in this context have not reached any conclusions. *See* Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101, 2111 n.9 (1986) (Court had "no reason to review" the issue); *University Hosp.*, 729 F.2d at 151 (court "bypassed" the issue "[i]n the interest of justice"); American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 403 n.8 (1983) (court found it was not necessary to reach this issue).

[95] *University Hosp.*, 575 F. Supp. at 614.

[96] *Id.*

[97] *Id.* at 614–15. The court relied on both the state court findings in this case, and the decision of the New York State Child Protection Service, to whom HHS initially referred the complaint, which supported the parents' decision. *Id.* at 615.

The court commented in dicta that the argument based on the parents' constitutional right to privacy was an "extremely weak" one where the government had reason to believe that the parents were not acting in the best interests of the handicapped infant, and where the records were confidential. *Id.* at 615–16. The court noted that the language, legislative history, and judicial interpretation of § 504 all indicated that it was not intended to authorize federal government involvement in the choice between reasonable medical alternatives, although the court found it

On appeal, the United States Court of Appeals for the Second Circuit affirmed the *University Hospital* decision.[98] In contrast to the district court's holding, however, the Second Circuit determined that section 504 did not apply to medical treatment decisions for handicapped infants.[99] The court reasoned that neither section 504's language nor its legislative history indicated a congressional intention to get involved in decisions which had traditionally been regulated by the states.[100] In determining whether Congress intended section 504 to apply in this area, the Second Circuit first examined the evolution of HHS's current view that Congress did intend section 504 to apply to medical treatment decisions for handicapped infants.[101] The court noted that, from 1976 through the recent issuance of the Final Rules, HHS's view of whether section 504 authorized investigating these decisions had changed considerably.[102] The court therefore found that it could not rely on HHS's "longstanding, consistent interpretation" of section 504 for guidance.[103]

The court next examined section 504's language and found that although Baby Jane Doe was a "handicapped individual," she was not "otherwise qualified" within the meaning of the statute.[104] The court reasoned that section 504 only prohibits discrimination where the individual's handicap is not a proper consideration because the individual is qualified in spite of his or her handicap.[105] In the context of medical treatment decisions, however, the court emphasized the difficulty of separating the handicap from the resulting need for medical services, and, therefore, determined that it was appropriate to consider the infant's handicaps in deciding on a course of medical treatment.[106] Thus, section 504's prohibition against discrimination could not be applied meaningfully to a medical treatment decision for an infant with multiple birth defects, the court explained, because the infant's medical problems are likely to be interrelated and because, in the "fluid context" of medical treatment decisions, it would be difficult to determine whether any given medical judgment was bona fide or discriminatory.[107] The court further

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"quite possible" that § 504 authorized federal challenges to unreasonable choices. *Id.* at 616. For a discussion of possible constitutional arguments in this area, see Bopp, Jr., *Protection of Disabled Newborns: Are There Constitutional Limitations?*, 1 ISSUES IN L. & MED. 173 (1985). Bopp concludes: "[n]one of the asserted constitutional rights would prevent the government from acting to protect handicapped infants denied beneficial medical care necessary to treat a life-threatening condition." *Id.* at 199–200.

[98] 729 F.2d 144, 161 (2d Cir. 1984).

[99] *Id.*

[100] *Id.* at 160.

[101] *See id.* at 151–54. Although the court discussed HHS's Final Rules issued on January 12, 1984, the court did not apply the Rules because they were issued after this litigation commenced. *See id.* at 154. See *supra* note 93 for the regulations the court applied in this case.

[102] *Id.* at 157. The court found that the Department of Health, Education and Welfare — the predecessor to HHS — had emphasized making services equally available to handicapped individuals in its initial § 504 regulations. *Id.* at 152. The court noted that "[i]t was not until five years later that HHS first took the position that section 504 made it unlawful for hospitals receiving 'Federal financial assistance' to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition." *Id.*

[103] *Id.* at 154.

[104] *Id.* at 156.

[105] *Id.* at 156–57 (citing Doe v. New York Univ., 666 F.2d 761 (2d Cir. 1981)).

[106] *See id.*

[107] *See id.* at 156–57. The court found:

> [T]he phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not

reasoned that Congress would have spoken more clearly to this issue if it had intended section 504 to apply to these decisions.[108] After reviewing section 504's legislative history and commenting on the federal government's traditional reluctance to get involved in medical treatment decisions, the court concluded that Congress had not intended section 504 to impose a duty on the defendant hospital either to perform the surgery without the parents' consent or to attempt through the state court system to circumvent the parents' decision.[109]

Writing in dissent, Judge Winter stated that the lack of legislative history specifically addressing section 504's application to medical treatment decisions for handicapped infants did not overcome the plain language of the statute.[110] The dissent emphasized that the statute's language purposefully mirrored the broad antidiscrimination language of the Civil Rights Act of 1964.[111] The dissent argued, therefore, that Congress intended to establish a broad policy prohibiting discrimination based on handicap just as it had for discrimination based on race and that it was appropriate to examine whether a given medical judgment was made because of an infant's handicap.[112] While conceding the possibility that handicap is not fully analogous to race, the dissent argued that the courts should not question the reasonableness of Congress's decision to draw that analogy.[113]

Additionally, the dissent characterized the majority's reading of section 504 as ambiguous. The majority holding, the dissent argued, could be read either to prohibit section 504's application to all medical treatment decisions or only to treatment decisions involving certain "kinds" of handicapped persons.[114] Determining the statute's proper scope on a case-by-case basis, as the majority now requires, the dissent argued, leads to

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> ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents. If congress intended section 504 to apply in this manner, it chose strange language indeed . . . .
>
> . . . Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory."

Id. at 156–57.

[108] *Id.* at 157.

[109] *Id.* at 157–60.

[110] *Id.* at 161 (Winter, J., dissenting).

[111] *Id.* at 162 (Winter, J., dissenting) (citing S. REP. No. 1297, 93d Cong., 2d Sess. 39, *reprinted in* 1974 U.S. CODE CONG. & ADMIN. NEWS 6373, 6390). Section 601 of the Civil Rights Act of 1964 provides: "No person in the United States shall, on the ground 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 (1982).

[112] *University Hosp.*, 729 F.2d at 162 (Winter, J., dissenting). The dissenting judge illustrated this point with an example:

> A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent.

Id.

[113] *Id.* (Winter, J., dissenting).

[114] *Id.* at 162–63 (Winter, J., dissenting).

the same intrusive federal inquiry into the facts of individual cases that the majority claimed Congress never intended.[115]

In summary, over a year after Baby Jane Doe was born, the Second Circuit finally settled the controversy concerning her parents' decision not to consent to surgery. The court found that federal government involvement under section 504 was not warranted in this particular case.[116] In the *University Hospital* decision, in contrast, the court left unanswered the general question of federal involvement in treatment decisions under section 504, as well as the question of the validity of HHS's Final Rules.

B. *The Government's Section 504 Response Invalidated — The* Bowen *Decision*

In *Bowen v. American Hospital Association*,[117] a plurality of the United States Supreme Court invalidated portions of the section 504 Final Rules relating to medical treatment decisions for handicapped infants.[118] In *Bowen*, various medical organizations brought suit to determine whether section 504 properly authorized these regulations.[119] The Court found that the administrative record failed to show a need for such federal intervention under section 504.[120]

The *Bowen* plurality examined only the four provisions of HHS's Final Rules which required health care providers to take certain actions under section 504.[121] These four mandatory sections required that: (1) recipients of federal financial assistance post, in a

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[115] *Id.* at 163 (Winter, J., dissenting).

[116] *Id.* at 161.

[117] 106 S. Ct. 2101 (1986).

[118] *Id.* at 2123. The Final Rules which the *Bowen* Court invalidated were those issued by HHS in January 12, 1984 during the *University Hospital* litigation. *See supra* note 101.

Justices Marshall, Blackmun, and Powell joined in the plurality opinion by Justice Stevens. *Id.* at 2105. Chief Justice Burger concurred in the judgment without opinion. *Id.* at 2123 (Burger, C.J., concurring). Three Justices dissented and Justice Rehnquist took no part in the decision. *Id.*

[119] *Id.* at 2105 & n.2. The *Bowen* case consolidated two actions, one filed by the American Hospital Association after HHS issued the Interim Rules, and one filed by the American Medical Association after HHS issued the Final Rules. *See id.* at 2108, 2109. The district court, basing its decision on the court of appeals decision in *University Hospital*, found that the regulations were not authorized by § 504. American Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (1984) (citing Administrative Procedure Act, 5 U.S.C. § 706(2)(C) (1982)). The section of the APA cited by the *Heckler* court provides that reviewing courts shall "(2) hold unlawful and set aside agency action, findings, and conclusions found to be — . . .

(C) in excess of statutory jurisdiction, authority, or limitations, or short of statutory right . . . ." 5 U.S.C. § 706(2)(C) (1982).

The United States Court of Appeals for the Second Circuit affirmed without opinion based on its own opinion in *University Hospital*. American Hosp. Ass'n v. Heckler, No. 84-1529 (2d Cir. Dec. 27, 1984). *See Bowen*, 106 S. Ct. at 2124 n.2 (White, J., dissenting). Although the government did not appeal the *University Hospital* decision, that decision forms the basis for the Supreme Court's decision in *Bowen*. *See Bowen*, 106 S. Ct. at 2111.

[120] *Bowen*, 106 S. Ct. at 2117.

[121] *Id.* at 2111. In addition to the four mandatory provisions, the Final Rules contained non-mandatory sections recommending that health care providers establish Infant Care Review Committees (ICRCs) and describing a Model ICRC to help "in the development of standards, policies and procedures for providing treatment to handicapped infants." *Id.* §§ 84.55(a), (f).

An Appendix to the Final Rules contained HHS's interpretative guidelines for applying § 504 to health care decisions for handicapped infants and guidelines that describe how HHS should investigate § 504 complaints. *Id.* pt. 84, app. C.

place accessible to medical personnel, an informational notice indicating that section 504 prohibited discrimination against handicapped infants and containing telephone numbers for HHS and state child protective services agencies;[122] (2) state child protective services agencies implement procedures to prevent discriminatory medical treatment of handicapped infants;[123] (3) federal assistance recipients give HHS officials round-the-clock access to their records and facilities when HHS deemed it necessary in order to protect a handicapped infant;[124] and (4) HHS be permitted to initiate court action to effect compliance without prior notice to recipient hospitals when HHS deemed it necessary.[125]

In examining whether section 504 authorizes the federal government to intervene in treatment decisions as contemplated by the Final Rules, the *Bowen* plurality determined that the agency must show a factual basis supporting the need for federal regulation.[126] The plurality emphasized that such treatment decisions had in the past been considered matters governed by parental authority, except in extreme cases when state law could be invoked to protect an infant.[127] Furthermore, the plurality reasoned, because Congress, when it enacted section 504, did not indicate an intent to involve the federal government in medical treatment decisions which state law governed in the past, HHS must "clearly" show that federal intervention was justified.[128]

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[122] 45 C.F.R. § 84.55(b) (1986). Although HHS originally required that the notice be placed at nurses' stations where parents might see it, HHS changed this requirement in response to critical comments which suggested that the notice would upset parents. 49 Fed. Reg. 1622, 1626 (1984).

[123] 45 C.F.R. § 84.55(c) (1986).

[124] *Id.* § 84.55(d).

[125] *Id.* § 84.55(c).

[126] *Bowen*, 106 S. Ct. at 2113. The plurality stated:

> Our recognition of Congress' need to vest administrative agencies with ample power to assist in the difficult task of governing a vast and complex industrial Nation carries with it the correlative responsibility of the agency to explain the rationale and factual basis for its decision, even though we show respect for the agency's judgment in both.

Id. Although the plurality opinion does not specifically mention the Administrative Procedure Act section relied on by the district court, 5 U.S.C. § 706(2)(C) (1982), the Court's general discussion of administrative law principles, as well as the cases cited, demonstrate that the plurality interpreted the Final Rules under 5 U.S.C. § 706. *See Bowen*, 106 S. Ct. at 2112–13.

[127] *Id.* at 2113. The plurality quoted from the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in describing the pattern of decisionmaking for handicapped infants:

> First, there is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants. Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents. Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervene parental decisions before they become operative to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.
>
> . . . [A]s long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervened.

Id. at 2113 n.13 (quoting REPORT OF THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH: DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 212–13 (1983)).

[128] *Id.* at 2121–22 (quoting Florida v. United States, 282 U.S. 194, 211–12 (1931)).

The plurality considered the two possible section 504 violations that HHS indicated justified federal involvement in this area: first, where a hospital withholds medically beneficial treatment solely because of an infant's handicap even where the parents have consented to treatment; and second, where a hospital fails to report possible medical neglect to state child protective services agencies when parents refuse consent for treatment of a handicapped infant.[129] The plurality found that HHS had failed to demonstrate that either problem justified the federal intervention envisioned by the Final Rules.[130]

The plurality dismissed HHS's first justification for federal involvement because of a lack of evidence that hospitals ever refuse to treat infants when parents have given their consent.[131] Where the parents do consent to treatment and the hospital refuses to treat their child, the plurality found, the parents themselves would contact appropriate authorities. Thus, the plurality determined that federal intervention under the Final Rules is unnecessary in cases where the parents consent to treatment.[132]

In those cases where the parents withhold consent to treatment, the plurality found that the infant is not "otherwise qualified" and thus, the hospital that complies with the parents' decision has not denied the infant treatment "solely by reason of his handicap" within the meaning of section 504.[133] The plurality was not persuaded by the government's Civil Rights Act analogy and stated that, in the case of either a black or a handicapped infant, when the parents have refused consent, a *hospital's* decision not to treat cannot be discriminatory no matter what motivates the *parental* decision.[134] The plurality therefore found that cases involving parental nonconsent to treatment do not provide the necessary factual support for federal intervention under section 504.[135]

The plurality also found no factual support for HHS's second argument that hospitals do not report to state agencies cases of parental refusal to consent to treatment for their handicapped infants.[136] The plurality noted that a hospital's failure to report a parental decision not to treat a handicapped infant would violate section 504 only if the hospital would report the decision in the case of a similarly-situated nonhandicapped infant.[137] The plurality observed, however, that a hospital's failure to report nontreatment decisions for both handicapped and nonhandicapped infants does not violate section 504's nondiscrimination principle.[138] Because HHS did not demonstrate that

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[129] *Id.* at 2113. The plurality limited its discussion to these two bases for intervention under § 504 because "an agency's action must be upheld, if at all, on the basis articulated by the agency itself." *Id.* at 2121 (quoting Motor Vehicle Mfrs. Ass'n v. State Farm Mut., 463 U.S. 29, 50 (1983)).

[130] *Id.* at 2117, 2118.

[131] *Id.* at 2115.

[132] *Id.* The plurality was not persuaded by the dissent's theory that the regulations address the problem of discriminatory advice given by doctors to parents in the process of making treatment decisions. *See id.* at 2117 n.22. The plurality found that the regulations are not directed to the advice which physicians can give to parents. *Id.* Moreover, because § 504 does not apply to parental decisions not to treat, the plurality observed that § 504 cannot prohibit "the giving of advice to do something which § 504 does not itself prohibit." *Id.* The plurality suggested that such a prohibition might violate the constitutional doctrine of free speech. *Id.*

[133] *Id.* at 2114.

[134] *Id.*

[135] *Id.* at 2116.

[136] *Id.* at 2118.

[137] *Id.* at 2118 n.23.

[138] *Id.* at 2118. The plurality noted, however, that failure to report medical neglect might violate state law reporting obligations. *Id.*

hospitals discriminatorily observed their reporting obligations, therefore, the plurality found that HHS had not justified federal intervention under section 504.[139]

Lastly, the plurality criticized the Final Rules' requirement that state agencies use their full authority under state law to prevent discriminatory medical neglect of handicapped infants.[140] The plurality found unjustifiable the Final Rules' imposition of an "absolute obligation" on state agencies to investigate reports of medical neglect of handicapped infants when the Final Rules imposed no similar requirement on the level of services provided to nonhandicapped infants.[141] In the plurality's view, section 504 only authorizes HHS to require state agencies to make the same services available to handicapped infants as are available to similarly situated nonhandicapped infants. Thus, the plurality concluded that section 504, with its focus on equality of treatment between handicapped and nonhandicapped individuals, did not authorize HHS to impose such an "affirmative-action obligation" on state agencies with regard to handicapped infants.[142] In fact, the plurality noted, HHS seemed more concerned with ensuring that handicapped infants receive life-saving medical treatment than with applying section 504's principle of equal treatment for both handicapped and nonhandicapped individuals.[143]

The dissent in *Bowen* criticized the plurality's narrow focus on the validity of the Final Rules' four mandatory provisions.[144] The dissent argued that the Court should have decided the more fundamental question left open by *University Hospital* of whether section 504 authorizes HHS to regulate medical treatment decisions for handicapped infants in any way.[145] Whereas the *University Hospital* court struck down the section 504 regulations, the dissent would have found that handicapped infants with multiple birth defects can be "otherwise qualified" to receive medical treatment.[146]

The dissent reasoned that section 504's "otherwise qualified" language on which the *University Hospital* court relied, did not necessarily prevent section 504's application to treatment decisions regarding handicapped infants.[147] Where an infant has a medically correctable condition which is unrelated to his or her handicap, the dissent argued, the infant would be "otherwise qualified" to receive medical treatment.[148] The dissent thus

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[139] *Id.* In contrast to HHS's contentions, the plurality observed that in both the Indiana Baby Doe case and the Baby Jane Doe case, the hospitals had initiated proceedings in the courts to override the parents' decisions. *Id.* at 2118 n.24.

[140] *Id.* at 2119 (citing 45 C.F.R. § 84.55(c)(1) (1985)).

[141] *Id.* at 2120.

[142] *Id.* at 2119 (quoting Southeastern Community College v. Davis, 442 U.S. 397, 411 (1979)).

[143] *Id.* at 2123. The plurality commented that "[s]ection 504 does not authorize [HHS] to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children." *Id.*

[144] *Id.* at 2124 (White, J., dissenting). Justice Brennan joined Justice White's dissent, and Justice O'Connor joined in all but one section. *Id.* at 2123 (White, J., dissenting). See *infra* note 150 and accompanying text explaining the section Justice O'Connor did not join.

[145] *Id.* at 2124–25 (White, J., dissenting).

[146] *Id.* at 2127 (White, J., dissenting).

[147] *Id.*

[148] *Id.* Justice White illustrated this point with an example:

> An esophageal obstruction, for example, would not be part and parcel of the handicap of a baby suffering from Down's Syndrome, and the infant would benefit from and is thus otherwise qualified for having the obstruction removed in spite of the handicap. . . .
>
> It would not be difficult to multiply examples like this. And even if it is true that in the great majority of cases the handicap itself will constitute the need for treatment,

concluded that the *University Hospital* court's holding that section 504 may never apply to medical treatment decisions for handicapped infants was incorrect.[149]

The dissent also addressed the plurality's finding that HHS failed to support factually a need for the regulations under section 504.[150] The dissent criticized the plurality for examining only two instances in which discrimination that violates section 504 could occur, that is, when a hospital refuses to treat an infant whose parents have consented to treatment, or when a hospital, solely because of an infant's handicap, does not report to appropriate state agencies a case of parental nonconsent.[151] Citing the medical studies on which HHS relied, the dissent contended that there is evidence that handicapped infants are discriminatorily denied medical treatment and suggested that physician and hospital attitudes might discriminatorily influence parental decisions.[152] Thus, the dissent concluded that these general studies provided the factual support for HHS's intervention under section 504.

Lastly, the dissent criticized the plurality for failing to delineate clearly what authority HHS *does* have under section 504.[153] On the one hand, the dissent pointed out, the plurality purported to limit itself only to an evaluation of the four mandatory regulations.[154] On the other hand, the dissent observed, the plurality seemed to conclude that HHS could not issue other regulations similar to those found invalid in this case, thus implying that HHS could not regulate treatment decisions for handicapped infants at all under section 504. In short, the dissent concluded, the plurality opinion "gives no guidance to the Secretary or the other parties as to the proper construction of the governing statute, and fails to explain adequately the precise scope of the holding or how that holding is supported under the plurality's chosen rationale."[155]

In conclusion, a plurality of the Court in *Bowen* invalidated those portions of HHS's section 504 regulations which authorized federal intervention in individual treatment decisions where HHS deemed the life of a handicapped infant to be in danger.[156] The plurality found that HHS had failed to demonstrate the need for such intrusive federal intervention in an area previously governed by parental discretion and, in extreme cases, state law.[157] The dissent criticized the plurality's narrow focus on the validity of only the

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> I doubt that this consideration or any other mentioned by the Court of Appeals justifies the wholesale conclusion that § 504 never applies to newborn infants with handicaps. That some or most failures to treat may not fall within § 504, that discerning which failures to treat are discriminatory may be difficult, and that applying § 504 in this area may intrude into the traditional functions of the State do not support the categorical conclusion that the section may never be applied to medical decisions about handicapped infants.

Id.

[149] *Id.* at 2127–28 (White, J., dissenting). Having determined that *University Hospital* was wrongly decided, the dissent would have remanded to the court of appeals for determination of the scope of HHS's authority under section 504. *Id.* at 2128 (White, J., dissenting).

[150] *Id.* at 2128–31 (White, J., dissenting). Justice O'Connor did not join in this section of the dissent because she found "no need at this juncture to address the details of the regulations . . . ." *Id.* at 2132 (O'Connor, J., dissenting).

[151] *Id.* at 2128 (White, J., dissenting).

[152] *Id.* at 2128, 2129–30 (White, J., dissenting).

[153] *Id.* at 2132 (White, J., dissenting).

[154] *Id.* at 2131 (White, J., dissenting).

[155] *Id.* (White, J., dissenting).

[156] *Id.* at 2123.

[157] *Id.* at 2113.

four mandatory regulations and their narrow reading of the evidence concerning discrimination against handicapped infants.[158]

The *Bowen* decision does not decide the ultimate question of whether section 504 can ever apply to medical treatment decisions for handicapped infants. The plurality's decision to consider only the mandatory sections of the Final Rules not only leaves open the possibility that other regulations under section 504 might be upheld but it also leaves intact the nonmandatory recommendations contained in the Final Rules.[159] It is thus unclear whether *Bowen* or the prior lower court decisions have settled the question of federal involvement in the treatment of handicapped infants under section 504's nondiscrimination mandate.

III. The Government's Second Response — The Child Abuse Amendments of 1984

In another federal government response to the Indiana Baby Doe case, Congress began in 1982 to consider amending the Child Abuse Prevention and Treatment Act to include provisions dealing with medical treatment decisions for handicapped newborns.[160] The Child Abuse Amendments, enacted in 1984, constitute another federal attempt to influence treatment decisions for severely handicapped newborns.[161] The Child Abuse Amendments, however, place the ultimate responsibility for ensuring that these infants are not neglected medically in the hands of state child protective services agencies rather than in the hands of any federal agency.[162]

In the Child Abuse Amendments, Congress added the term "withholding of medically indicated treatment" to the existing statutory definition of child neglect.[163] The amendments provide, in substance, that failure to treat all of an infant's correctable life-threatening conditions constitutes neglect except in three specific instances.[164] The three exceptions include those cases where, in the physician's "reasonable medical judgment," the infant is irreversibly comatose, the treatment would be futile in saving the infant's life, or the treatment would be virtually futile and therefore inhumane.[165]

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[158] *See id.* at 2124, 2128–30 (White, J., dissenting).

[159] *See id.* at 2106 & n.4 (describing 45 C.F.R. §§ 84.55(a), (f) (1986)). See *supra* note 125 for a description of the recommendations contained in the Final Rules.

[160] *See Treatment of Infants Born with Handicapping Conditions: Hearing on H.R. 6492 Before the Subcomm. on Select Education of the House Comm. on Education and Labor*, 97th Cong., 2d Sess. 1 (1982) (opening statement of Austin J. Murphy, Chairman, Subcomm. on Select Education).

[161] 42 U.S.C. § 5101–5103 (1982 & Supp. III 1985).

[162] *Id.* § 5103(b)(2)(K) (Supp. III 1985).

[163] *Id.* § 5102(3) (Supp. III 1985). The definition of child abuse and neglect also includes physical or mental injury, sexual abuse and negligent treatment. *Id.* § 5102(1) (Supp. III 1985).

[164] *See id.* § 5102(3) (Supp. III 1985).

[165] *Id.* The amendments provide that:

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

The amendments require the states to ensure that hospitals report cases of suspected medical neglect to state child protective services agencies.[166] The amendments also make these state agencies responsible for implementing procedures to respond to reports that parents or doctors are withholding medically indicated treatment from an infant.[167] In addition, states must grant state child protective services agencies authority to bring suit to ensure that medically indicated treatment is not withheld.[168] The amendments further authorize HHS to issue regulations and to provide funding to help implement these new requirements.[169]

On April 15, 1985, HHS issued Final Rules implementing the Child Abuse Amendments (the CAA Rules).[170] In the CAA Rules, HHS provided that these regulations should not be construed to affect any regulation issued under section 504 of the Rehabilitation Act.[171] This provision reflected congressional and HHS policy to remain neutral in the *Bowen* litigation involving section 504, which was then pending before the Supreme Court.[172]

In its discussion of the CAA Rules, HHS recognized the general similarity of purpose underlying the regulations it proposed under both section 504 and the Child Abuse

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terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id. § 5102(3) (Supp. III 1985).

[166] *Id.* § 5103(b)(2)(K)(ii).

[167] *Id.* § 5103(b)(2)(K)(i).

[168] *Id.* § 5103(b)(2)(K)(iii). Congress ensures state enforcement of the amendments by conditioning federal grant money for state child abuse programs on states' implementing these procedures within one year of the amendments' enactment date. *Id.* § 5103(b)(2)(K). This section of the statute provides:

> (2) In order for a State to qualify for assistance under this subsection, such State shall —
>
> (K) within one year after [the date of the enactment of the Child Abuse Amendments of 1984], have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Id. § 5103(b)(2).

[169] *See id.* § 5103 note (Supp. III 1985) (Procedures and Programs for Responding to Reports of Medical Neglect).

[170] *See* 45 C.F.R. pt. 1340. After Congress enacted the amendments, HHS issued a Notice of Proposed Rulemaking. 49 Fed. Reg. 48,160 (1984) (proposed Dec. 10, 1984). After receiving over 116,000 comments on its Proposed Rules, 50 Fed. Reg. 14,878, 14,879 (1985), HHS issued the CAA Rules in 1985. *See* 45 C.F.R. § 1340.15 (1985).

[171] 45 C.F.R. § 1340.15(e)(1) (1986). The CAA Rules also provide that they are not to be construed to create any requirement for specific medical treatment for particular medical conditions. *Id.* § 1340.15(e)(2).

[172] 50 Fed. Reg. 14,878, 14,885 (1985).

Amendments: to assure the provision of medically indicated treatment to disabled infants within the bounds of reasonable medical judgment.[173] HHS expressed the hope that if the government prevailed in the section 504 litigation, HHS would be able to coordinate the two sets of regulations to achieve their common purpose.[174] While the CAA Rules rely on state agencies for enforcement, HHS commented, the section 504 regulations provide the additional benefit of a direct federal enforcement mechanism.[175]

In promulgating the CAA Rules, HHS made several general comments regarding the application of the Child Abuse Amendments to medical treatment decisionmaking for infants.[176] In response to requests for clarification by those commenting on the proposed CAA rules, HHS stated unequivocally that parents and their doctors, "except in highly unusual circumstances," are responsible for making medical treatment decisions.[177] HHS emphasized, however, that such decisions should not be based on the anticipated quality of life of the handicapped infant.[178] HHS anticipated that when a state child protective services agency receives a report of suspected medical neglect, the

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[173] *Id.* In issuing the CAA Rules, HHS stated that it attempted to preserve the Child Abuse Amendments' carefully constructed compromise between competing concerns: the need to prevent unnecessary interference in medical and parental decisionmaking on the one hand, and the need to protect disabled infants from unreasonable decisions not to provide treatment on the other. *Id.* at 14,879. The CAA Rules' definitional terms, therefore, either reflect the language of the amendments themselves or derive from their legislative history. *See id.* at 14,880, 14,881. In its Proposed Rule, HHS had specifically defined the terms contained in the amendments' new provision regarding "withholding of medically indicated treatment." 49 Fed. Reg. 48,160, 48,166–48,167 (1984) (proposed Dec. 10, 1984) (defining the terms "life-threatening condition," "treatment," "merely prolong dying," "not be effective in ameliorating or correcting all of the infant's life-threatening conditions," "virtually futile," "the treatment itself under such circumstances would be inhumane"). HHS removed these definitions from the text of the CAA Rules in response to comments from medical organizations which criticized the inclusion of rigid definitions as part of the Rules. 50 Fed. Reg. 14,878, 14,880 (1985). Because HHS wanted to inform health care professionals of its interpretation of these key terms, however, HHS included the definitions in an appendix to the CAA Rules. 45 C.F.R. pt. 1340, app. C (1986).

In addition to the requirements the amendments impose on states, *see supra* note 168, the CAA Rules require states to have documented programs and procedures in place which show that the child protective services system has a contact at each health care facility with whom the agency will coordinate its activities. 45 C.F.R. § 1340.15(c)(3) (1986). The procedures must specify how the agencies, consistent with state law, will obtain medical records and a court order for an independent medical examination of the infant when necessary in investigating reported instances of medical neglect. *Id.* § 1340.15(c)(4) (1986).

[174] 50 Fed. Reg. 14,878, 14,885 (1985).

[175] *Id.*

[176] *See id.* at 14,880–14,881. HHS commented that the Child Abuse Amendments had developed out of cooperation among many medical and disability advocacy organizations. 49 Fed. Reg. 48,160, 48,160 (1984) (proposed Dec. 10, 1984).

The American Medical Association (AMA), however, opposed the Child Abuse Amendments. *Treatment of Infants Born with Handicapping Conditions: Hearings on H.R. 6492 Before the Subcomm. on Select Education of the House Comm. on Education and Labor*, 97th Cong., 2d Sess., 56–58 (1982) (statement of the American Medical Association) [hereinafter, Statement of the AMA]. See *infra* note 234 for a discussion of the AMA's position.

[177] 50 Fed. Reg. 14,878, 14,880 (1985).

[178] *Id.* The AMA, however, has expressed the contrary view: "[q]uality of life is a factor to be considered in determining what is best for the individual." Statement of the AMA, *supra* note 176, at 57.

agency, in conjunction with the hospital, should provide all available information to the parents and work with them in making their decision.[179]

HHS also commented on the CAA Rules' potential economic impact on state child protective services agencies.[180] The impact would not be too burdensome, HHS believed, because although the aggregate costs of treating infants with severe birth defects might be significant, HHS felt that it was customary even before the amendments' passage to provide aggressive and costly treatment for such infants.[181] Thus, HHS believed that the amendments and regulations would influence treatment decisions in only a "very small fraction" of cases.[182] HHS acknowledged that the possibility of legal action might cause inhumane defensive treatment practices, such as trying to treat infants whose death is inevitable, but found that the statute's reliance on reasonable medical judgment would protect against inappropriate treatment decisions.[183]

In summary, the Child Abuse Amendments and the CAA Rules issued thereunder emphasize the role of the states in dealing with the perceived problem of parents, doctors, and hospitals intentionally withholding life-saving medical treatment from handicapped infants. Although the amendments do provide a new definition of medical neglect which emphasizes the federal government's commitment to providing treatment to all infants except in extreme cases,[184] the amendments do not give the federal government a direct role in overseeing individual treatment decisions. Rather, the federal government's role under the Child Abuse Amendments currently is limited to threatening to withdraw federal funds in order to motivate state agencies to ensure that handicapped infants receive adequate medical care.[185]

While the *Bowen* decision and the Child Abuse Amendments presently do not appear to give the federal government an active role in individual treatment decisions, the potential for federal intervention still exists both under section 504 of the Rehabilitation Act and under the Child Abuse Prevention and Treatment Act. The *Bowen* plurality specifically did not decide whether section 504 could ever apply to medical treatment decisions for handicapped infants.[186] Furthermore, under the Child Abuse Amendments,

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[179] 50 Fed. Reg. 14,878, 14,880 (1985).

[180] *Id.* at 14,886.

[181] *Id.* HHS also pointed out that health insurance pays for health care for most infants. *Id.*

[182] *Id.* HHS stated:

> In some unknown but very small fraction of infants, medically indicated treatment may have been or would have been withheld but for the response to the "Baby Doe" cases (including not only the law and this rule, but also public awareness and prior rules). However, the great majority of expensive interventions would occur — and are already occurring at annual costs in the range of several billion dollars — regardless of this change.

Id.

Regarding the economic impact of the new procedural and administrative costs to state child protective services agencies, HHS commented that Congress intended the states to implement the new requirements through existing child protective services systems. *Id.* at 14,883. Because the systems are in place already, and because HHS increased the federal grants to states in order to offset the costs of implementing the new requirements, HHS felt that the economic impact on state agencies would not be unmanageable. *Id.* at 14,887.

[183] *Id.* at 14,886.

[184] *See* 42 U.S.C. §§ 5102, 5103 (Supp. III 1985).

[185] *See id.* § 5103 (Supp. III 1985).

[186] *Bowen*, 106 S. Ct. at 2111.

HHS is authorized to issue regulations to implement the new state requirements and thus can influence what the states must do to comply with the amendments.[187] Thus the extent to which the federal government can still influence medical treatment decisions for handicapped infants is still uncertain, as is the question of whether it should exercise that influence.

IV. Potential for Future Federal Role in Treatment Decisions for Handicapped Infants

Six years after the Indiana Baby Doe case, two related questions remain unanswered: first, to what extent can the federal government still influence these treatment decisions either under section 504 of the Rehabilitation Act or under the Child Abuse Amendments; and second, to what extent should the federal government exercise this influence. The courts' treatment of the section 504 regulations and the history of the Child Abuse Amendments, however, both argue against an increased role for the federal government in the decisionmaking process. That process is best left in the hands of the infant's parents and doctors.

A. *Possibility of Future Federal Government Involvement*

The federal government first sought to play a role in medical treatment decisions for severely disabled infants under section 504 of the Rehabilitation Act, which prohibits discrimination based on handicap.[188] Courts uniformly defeated HHS's repeated attempts to regulate individual treatment decisions under section 504.[189] The courts primarily were concerned with HHS's failure to demonstrate a need for regulations which authorize federal officials to intervene in individual cases to ascertain whether nontreatment decisions complied with section 504.[190] Because section 504 merely prohibits recipients of federal financial assistance from discriminating against handicapped individuals,[191] section 504 is not the appropriate vehicle for an HHS campaign to save the lives of all handicapped infants, regardless of how nonhandicapped infants are treated.

In order for HHS to promulgate any regulations under section 504, it would have to gather factual support showing that recipients of federal financial assistance make different treatment decisions for handicapped versus nonhandicapped infants.[192] The dissent in *Bowen* argued that the influence that doctors, nurses, and other hospital personnel have on parents as they deliberate about whether to consent to treatment for their handicapped infant may violate section 504.[193] As the *Bowen* dissent contended, if hospital personnel influence parents not to treat a medically correctable condition for a handicapped infant, but advocate treating the same condition for a nonhandicapped

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[187] 42 U.S.C. § 5103 note (Supp. III 1985) (Procedures and Programs for Responding to Reports of Medical Neglect).

[188] 29 U.S.C. § 794 (1982). *See* 49 Fed. Reg. 1622, 1622–23 (1984).

[189] *See Bowen*, 106 S. Ct. at 2123; American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 404 (D.D.C. 1983).

[190] *See Bowen*, 106 S. Ct. at 2122; *American Academy of Pediatrics*, 561 F. Supp. at 399. *See also University Hosp.*, 729 F.2d at 161.

[191] Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982). *See Bowen*, 106 S. Ct. at 2123.

[192] *See supra* text accompanying notes 136–143.

[193] *Bowen*, 106 S. Ct. at 2129 (White, J., dissenting).

infant, then discrimination is shown and would provide a basis for HHS to intervene under section 504.[194]

While this argument appears plausible at first glance, it is flawed in at least two respects. First, it assumes that an infant's multiple handicaps are unrelated and therefore can be medically evaluated as separate problems.[195] As the *University Hospital* court suggested, however, it is often impossible to consider an infant's multiple impairments separately when deciding on the best course of medical treatment.[196] Thus, the existence of one handicap may create new risks in treating a second, correctable condition, or may decrease the likelihood that the treatment will be successful.

Second, even if it were possible to show in some cases that an infant's multiple handicaps are unrelated when deciding whether treatment will be beneficial,[197] it is the parents who decide whether to consent to the treatment.[198] A parental decision not to consent to treatment does *not* violate section 504 because section 504 only prohibits discrimination on the basis of handicap in federally funded programs.[199] Therefore, even if a health care professional's discriminatory attitude towards handicapped infants influences the parents, section 504 does not cover the parental decision not to provide medical treatment and thus does not support federal intervention under the Rehabilitation Act.[200]

Moreover, although HHS cited several studies that indicate that doctors often discriminatorily influence these decisions,[201] this evidence does not support section 504's application in this area because section 504 does not cover the parents' decision regarding medical treatment for their infant.[202] As the *Bowen* plurality indicated, section 504 does not prohibit health care professionals from giving advice to parents who are not covered by section 504.[203] In fact, the *Bowen* plurality observed, such a prohibition would violate the constitutional doctrine of free speech.[204]

The courts' uniform rejection of the section 504 regulations demonstrates their decided hostility towards using section 504 to implement such intrusive measures as hotlines and investigative "Baby Doe squads" without better evidence that federal intervention is necessary in an area previously governed by state law.[205] The dissenting judge in *University Hospital* argued that because section 504's language mirrored that of the civil rights statutes, this indicated a congressional intent to apply section 504 broadly to combat discrimination against the handicapped.[206] As the *Bowen* plurality observed, however, section 504's language does not support a mandate for federal agencies to

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[194] *Id.*

[195] *See University Hosp.*, 729 F.2d at 156–57.

[196] *See id.*

[197] *See Bowen*, 106 S. Ct. at 2127 (White, J., dissenting). *See supra* notes 147–48 and accompanying text.

[198] Even the dissent in *Bowen* recognized that it is "the parental decision to consent or not [that] is obviously the critical one." *Bowen*, 106 S. Ct. at 2129 (White, J., dissenting).

[199] 49 Fed. Reg. 1622, 1631 (1984).

[200] *See Bowen*, 106 S. Ct. at 2117 n.22.

[201] *See* 48 Fed. Reg. 30,846, 30,847–30,848 (1983) (proposed July 5, 1983). *See also Bowen*, 106 S. Ct. at 2129 (White, J., dissenting).

[202] *See* 49 Fed. Reg. 1622, 1631 (1984).

[203] *See Bowen*, 106 S. Ct. at 2117 n.22.

[204] *Id.*

[205] *See, e.g.*, United States v. University Hosp., 729 F.2d 144, 160 (2d Cir. 1984).

[206] *Id.* at 162 (Winter, J., dissenting).

require that handicapped infants receive special services not applicable to nonhandicapped infants.[207] Because Congress did not expressly indicate that section 504 should apply to medical treatment decisions previously governed by state law,[208] and because Congress has not amended the Rehabilitation Act to clarify whether it should apply to these treatment decisions, HHS must present more compelling evidence than it has done of discriminatory treatment of handicapped infants to justify the kind of federal intervention which the Final Rules contemplated.

Although the *Bowen* decision clearly stated that section 504 does not authorize the federal intervention into individual treatment decisions that the Final Rules contemplated, the decision is ambiguous concerning what sort of federal intervention the statute *does* authorize.[209] *Bowen*'s plurality opinion was extremely narrow, addressing only the four mandatory provisions of the section 504 Final Rules.[210] Thus, HHS still may be able to influence medical treatment decisions and encourage nondiscriminatory provision of health care to handicapped infants by implementing further nonmandatory recommendations under section 504. To the extent that such recommendations focus on equality of treatment for handicapped and nonhandicapped infants in federally funded programs, and to the extent that they do not ignore the states' traditional role in protecting all children, it is unlikely that such recommendations would encounter the same objections from medical groups and the courts.

Although HHS retains some authority to regulate medical treatment decisions under section 504 after *Bowen*, the Child Abuse Amendments provide a better framework for effecting the goal of ensuring that handicapped infants receive adequate medical care.[211] Through the Child Abuse Amendments, Congress stated that medical treatment must be provided unless it would be virtually futile in saving the infant's life.[212] Although the amendments' procedural requirements make the states responsible for enforcing the new provisions regarding withholding medical treatment from handicapped infants,[213] the amendments also authorize HHS to regulate implementation of these new state requirements.[214] Thus, HHS has some power to influence treatment decisions through its role in determining what state actions constitute compliance with the amendments.

Although HHS potentially can influence the way states enforce the Child Abuse Amendments, it has thus far declined to do anything which might upset the amendment's "careful balance between the need to establish effective protection of the rights of disabled infants and the need to avoid unreasonable governmental intervention into the practice of medicine and parental responsibilities."[215] In its proposed version of the CAA Rules, for example, HHS had specifically defined several key terms within the statute's definition of "withholding of medically indicated treatment."[216] After receiving a great

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[207] *See Bowen*, 106 S. Ct. at 2120 & n.28.

[208] *See id.* at 2121. The plurality noted that "unless Congress conveys its purpose clearly, it will not be deemed to have significantly changed the federal-state balance." *Id.* at 2121 n.33 (quoting United States v. Bass, 404 U.S. 336, 349 (1971)).

[209] *See id.* at 2132 (White, J., dissenting).

[210] *See id.* at 2106 & n.4.

[211] 42 U.S.C. §§ 5101–5103 (1982 & Supp. III 1985).

[212] *Id.* § 5102(3) (Supp. III 1985).

[213] *Id.* § 5103(b)(2)(K).

[214] *Id.* § 5103 note (Supp. III 1985) (Procedures and Programs for Responding to Reports of Medical Neglect).

[215] 50 Fed. Reg. 14,878, 14,879 (1985).

[216] 49 Fed. Reg. 48,160, 48,166–48,167 (1984) (proposed Dec. 10, 1984).

deal of criticism about including rigid definitions of medical neglect in the mandatory regulations, however, HHS moved these definitions to an Appendix to the CAA Rules.[217] As a result of this restructuring, the CAA Rules implement only procedural requirements that direct the states to ensure that they have adequate mechanisms in place to respond to reports of medical neglect.[218] The CAA Rules thus do not go beyond the Child Abuse Amendments themselves in defining when medical treatment is inappropriately withheld.[219] Nevertheless, HHS retains the authority to change its position on this issue if it sees a need to do so, as well as to implement other regulations determining what states must do to comply with the Child Abuse Amendments.

B. *Desirability of Future Federal Government Involvement*

Given that HHS retains some authority to further regulate treatment decisions for handicapped infants under both section 504 and the Child Abuse Amendments, the question becomes whether it is necessary, practical, or desirable for HHS or Congress to do so. Currently, because *Bowen* invalidated the mandatory section 504 regulations, HHS does not have an active role in individual treatment decisions for handicapped infants. HHS has emphasized, however, that treatment decisions are the responsibility of the infant's parents and doctors "except in highly unusual circumstances."[220] It is only in exceptional cases, therefore, that the current scheme envisions even state involvement.

Moreover, HHS has acknowledged that the regulations already in place will not affect a great number of individual treatment decisions.[221] HHS estimated that of the two and one half percent of births that involve serious medical problems, federal action under section 504 and the Child Abuse Amendments would influence treatment decisions in only a "very small fraction" of cases.[222] Because HHS views the parents as the primary decisionmakers, with state agencies and courts available to correct inappropriate decisions that may occur in these few cases, increased federal involvement is both unwarranted and unnecessary.[223]

HHS had expressed the hope, before the *Bowen* decision was announced, that the section 504 regulations and those promulgated under the Child Abuse Amendments would complement one another in working toward the goal of ensuring proper medical care to disabled infants.[224] Perhaps HHS believed it advantageous to have a federal enforcement mechanism in addition to a state enforcement mechanism to foster uni-

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[217] 50 Fed. Reg. 14,878, 14,880 (1985). *See* 45 C.F.R. pt. 1340 app. C (1986).

[218] *See* 45 C.F.R. § 1340.15 (1986).

[219] *See* 50 Fed. Reg. 14,878, 14,880 (1985).

[220] *See id.*

[221] *See id.* at 14,886–14,887.

[222] *Id.* at 14,886.

[223] Not only is increased federal intervention unwarranted, but as one commentator has asked:

> [H]ow did it come to pass that the Reagan Administration, elected under the banner "Get the Government Off our Backs," proposed the Baby Doe Hotline, and has gone to the wall to protect the rights of handicapped newborns with the one hand, while reducing maternal and child health appropriations with the other?

Meyer, *supra* note 11, at 627. If the government is going to interfere in the parents' treatment decision for their child, then the government must be responsible to some degree, both financially and physically, for helping to care for that child. Goldstein, *supra* note 23, at 689–90. *See also* Mathieu, *supra* note 11, at 610, 625.

[224] 50 Fed. Reg. 14,878, 14,885 (1985). *See supra* notes 227–30 and accompanying text.

formity regarding when decisions not to treat might be appropriate. It is likely, however, that uniform standards are neither possible nor desirable in the context of medical treatment decisions for handicapped infants.

The promotion of uniform standards for decisionmaking implies that there is some medical or societal consensus regarding how to decide when it is appropriate to withhold treatment from a seriously handicapped infant.[225] Even medical and ethics experts, however, do not agree on the appropriate response to the dilemmas posed by these infants.[226] Some commentators believe that legislation is needed to provide guidance to doctors and parents regarding what actions society accepts so that parents need not be forced into the courts for answers.[227] Other commentators, however, recognize that all medical treatment decisions are based on complex medical variables with unpredictable outcomes and believe that legislation, by its very nature, is unable to address all the subtleties involved in these difficult decisions.[228]

Against this background of conflicting views, the federal government attempted to impose uniform standards on medical treatment decisions for handicapped infants.[229] Yet in the two highly publicized Baby Doe cases which fueled the federal government's actions, the highest courts which heard the cases, as well as the respective state child protective services agencies, ratified the parents' decision in each case.[230] Therefore, although the federal government appears to have objected to the parents' treatment decisions in these cases, the state agencies and courts which investigated the allegations of unlawful medical neglect found the parents' decisions to be reasonable.[231] This incongruity is not surprising in light of the lack of any medical or societal consensus concerning the correct treatment decision under any given set of medical facts.

Given the difficulty of the medical determinations and the variety and severity of medical conditions that may be involved in each individual case, the Child Abuse Amendments' general reliance on reasonable medical judgment may be as specific and appropriate a standard as any legislature can enact.[232] Although medical organizations led the fight against HHS's mandatory regulations under section 504,[233] many medical groups

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[225] *See generally* Mnookin, *supra* note 33, at 677–81 (describing the disagreement among ethicists concerning the proper approach to medical treatment decisions for handicapped infants). *See also* R.F. WEIR, *supra* note 2, at 59; Ellis, *supra* note 33, at 412.

[226] *See, e.g.*, R.F. WEIR, *supra* note 2, at 59–90 (describing views of seven pediatricians); *id.* at 143–87 (describing five approaches taken by ethicists).

[227] *See* Shapiro, *Medical Treatment of Defective Newborns: An Answer to the "Baby Doe" Dilemma*, 20 HARV. J. ON LEGIS. 137, 148 (1983); Ellis, *supra* note 33, at 413–18.

[228] R.F. WEIR, *supra* note 2, at 139; Mathieu, *supra* note 11, at 624.

[229] The government attempted first to investigate and judge individual treatment decisions under § 504, 45 C.F.R. § 84.55 (1986), and, when this failed, to impose uniform standards for withholding treatment under the Child Abuse Amendments. 42 U.S.C. §§ 5101–5103 (1982 & Supp. III 1985).

[230] *See* United States v. University Hosp., 729 F.2d 144, 147 (2d Cir. 1984); *See* R.F. WEIR, *supra* note 2, at 128–29 (describing the Indiana Baby Doe case).

[231] *See University Hosp.*, 729 F.2d at 147; R.F. WEIR, *supra* note 2, at 128–29 (describing the Indiana Baby Doe case).

[232] *See generally* Burt, *The Treatment of Handicapped Newborns: Is There a Role for Law?*, 1 ISSUES IN L. & MED. 279, 281–283 (1986).

[233] *See* Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101 (1986); American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (1983).

supported the Child Abuse Amendments.[234] The explanation lies in the careful drafting of the amendments.

The amendments establish a broad policy that medical treatment should be provided to seriously handicapped infants except when it will be futile or inhumane.[235] Whether the exceptions apply to treatment in a specific case depends on the reasonable medical judgment of the health care professionals involved. The scope of the exceptions, therefore, is subject to the individual physician's interpretation of the medical risks and benefits in each case. Thus, health care professionals supported the amendments because the reasonable medical judgment standard allows them to maintain the flexibility they need when deciding how to advise parents about treatment for their handicapped infants.[236] Health care professionals need this flexibility in order to respond appropriately to the "myriad of real-life problems in intensive care nurseries,"[237] even though the result reached in any one case might vary depending on the decisionmaker's assessment of the medical risks and benefits involved.

The federal government's responses to the Indiana Baby Doe case, while they did not ultimately alter the federal role in individual treatment decisions significantly, served instead to publicize the issues and possibly make nontreatment decisions less likely to occur.[238] HHS's recommendations to form Infant Care Review Committees, the Child Abuse Amendments' requirements regarding state action, and perhaps most significantly, the public attention that has been generated, all serve to minimize the likelihood that decisions to withhold treatment from a handicapped infant will be made without careful consideration of the possible legal consequences.[239] While such considerations may help some parents in reaching a decision, it also seems clear that the parents' decision will be depersonalized and that parents will have to be constantly looking over their shoulders fearing interference from someone who disagrees with the course of treatment they have chosen.

Perhaps, in the face of the public outcry over the Indiana Baby Doe case, the government's efforts to formulate a federal standard constituted an important statement affirming a nondiscriminatory commitment to life for all infants, disabled or not. If it was desirable for the federal government to respond to the Indiana Baby Doe case in order to clarify its position, however, it was also desirable that the federal government's efforts in the end amounted to very little substantive change. The government's response left intact the framework that makes parents, doctors, and state agencies, in that order, responsible for making these difficult decisions, but it publicized both the weaknesses in that framework and established review methods for when decisions improperly are based on concerns about the infant's future handicaps.

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[234] *See* 49 Fed. Reg. 48,160, 48,160 (1984) (proposed Dec. 10, 1984). *But see* Statement of the AMA, *supra* note 208, at 57 (AMA opposed amending the Child Abuse Prevention and Treatment Act because it would "substitute a statutory prohibition for the case-by-case medical judgment of the attending physician and the judgment of the parents").

[235] 42 U.S.C. § 5102(3) (Supp. III 1985).

[236] *See* 50 Fed. Reg. 14,878, 14,879 (1985).

[237] *Id.*

[238] *See id.* at 14,886.

[239] In fact, some commentators have criticized the federal response to the Baby Doe problem because it could lead to *overtreatment* in futile cases as doctors practice defensive medicine. Meyer, *supra* note 11, at 634. *But see* 50 Fed. Reg. 14,878, 14,886 (1985) (HHS commenting that the Child Abuse Amendments' reliance on "reasonable medical judgment" protects against overtreatment).

Conclusion

In 1982, the Indiana Baby Doe case focused the attention of the media, the public, the President, the Department of Health and Human Services, and ultimately Congress on the problem of withholding medical treatment from seriously handicapped infants. HHS responded to the Baby Doe case by attempting to issue regulations which authorized HHS officials to investigate individual cases of suspected medical neglect under the nondiscrimination provisions of section 504 of the Rehabilitation Act. Courts repeatedly struck down these regulations, finding no clear showing that federal intervention was necessary in this area. Congress responded to the Baby Doe problem with the Child Abuse Amendments of 1984, which require that states, not the federal government, institute procedures to respond to reports of nontreatment of handicapped infants. Thus, the federal government's responses to the Baby Doe problem did not result in any significant change in the federal government's role in individual cases of suspected medical neglect.

While HHS retains some general power to influence medical treatment decisions under both section 504 and the Child Abuse Amendments, the history of the section 504 regulations in the courts, and the implementation of the Child Abuse Amendments demonstrate that an intrusive federal government role in individual treatment decisions is unwarranted. The impossibility of formulating uniform treatment standards, the rarity of cases where treatment is inappropriately withheld, and the existence of state agencies and courts to handle the cases that do occur all indicate that the federal government has no role in medical treatment decisionmaking for handicapped infants. As a result of the federal government's actions, courts and Congress affirmed that these decisions are appropriately left to the infant's parents, guided by reasonable medical judgment, and, only in exceptional cases will state agencies and courts review these decisions.

Kate H. Lind