Bowen v. American Hospital Association: Federal Regulation Is Powerless to Save Baby Doe

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I. Introduction

On April 9, 1982, an infant boy, afflicted with Down's syndrome[1] and an esophageal obstruction which prevented oral feeding, was born in a Bloomington, Indiana hospital.[2] Although the esophageal obstruction was correctable with surgery,[3] the infant's parents refused to consent to any life-saving treatment.[4] On April 10, the hospital sought a court order to override the parents' decision, but a trial court denied the requested relief.[5] On April 12, the trial court permitted the local Child Protection Committee to review its decision, and after a hearing, the Committee did not disagree with the court's decision.[6] On April 14, the Indiana Court of Appeals denied a request for an immediate hearing.[7] Thereafter, the Indiana Supreme Court denied a petition for a writ of mandamus.[8]

Six days after his birth, the infant, known only as Baby Doe, died while a stay was being sought in the United States Supreme Court.[9] The treatment or, more precisely, the non-treatment of Baby Doe received national media coverage and sparked heated public debate.[10] Not only was an infant denied food, water, and surgical aid, but the decision to do so was also approved by a court of law.

Immediately following the death of Baby Doe, the federal government responded with its plan to protect other handicapped infants from passive euthanasia.[11] The Director of the Office of Civil Rights, Depart-

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[1]Bowen v. American Hosp. Ass'n, 106 S. Ct. 2101, 2107 (1986). Down's syndrome is a chromosomal abnormality which produces various degrees of mental retardation. *See infra* notes 25-28 and accompanying text.

[2]*Bowen*, 106 S. Ct. at 2107.

[3]Fost, *Putting Hospitals on Notice*, 1982 Hastings Center Report 5.

[4]*Id.*

[5]*Bowen*, 106 S. Ct. at 2107.

[6]*Id.*

[7]*Id.* at 2107-08, n.5.

[8]*Id.*

[9]*Id.* The Supreme Court later denied certiorari. Infant Doe v. Bloomington Hosp., 464 U.S. 961 (1983).

[10]Fost, *supra* note 3, at 5.

[11]Passive euthanasia is the term used when life-sustaining medical treatment is withdrawn

ment of Health and Human Services, following a directive from President Reagan, sent a letter on May 18, 1982, to 6,800 hospitals receiving federal aid, "reminding" them that denial of medical services to handicapped infants would violate section 504 of the Rehabilitation Act of 1973.[12] The letter warned that a violation of section 504 would result in the termination of federal financial assistance to participating hospitals.[13]

The Department of Health and Human Services (Department) thereafter promulgated an "Interim Final Rule" to enforce its position that section 504 prohibited the discriminatory failure to feed and care for handicapped infants.[14] The regulations required hospitals receiving federal financial assistance to post in a conspicuous place in delivery, maternity, and pediatric wards and nurseries, including intensive care nurseries, a notice stating that section 504 prohibits the discriminatory withholding of medical care from handicapped infants.[15] In addition, the notice was required to advise of the availability of a telephone "hotline" to report violations to the Department.[16] Finally, the Interim Final Rule also provided for expedited compliance actions and expedited access to hospital records and facilities whenever the Department determined that access was "necessary to protect the life or health of a handicapped individual."[17]

After the Interim Final Rule was invalidated by a federal district court,[18] the Department issued new "Proposed Rules," upon which it invited public comment.[19] The Proposed Rules mirrored the Interim Final Rules, except that the new rules required federally-assisted state child protective service agencies to implement their "full authority pursuant to State law to prevent instances of medical neglect of handicapped infants."[20] The Final Rules became effective on February 13, 1984.[21]

The United States Supreme Court, in *Bowen v. American Hospital*

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or withheld from a terminally ill patient by one other than the patient. *See* Perlman, Koulack & Tinney, *Developmental Defects*, in 1C R. GRAY, ATTORNEYS' TEXTBOOKS OF MEDICINE ¶ 17.53(5e) (3d ed. 1981).

[12]*Bowen*, 106 S. Ct. at 2108. Section 504 of the Rehabilitation Act of 1973 provides: "No otherwise qualified handicapped individual . . . shall, solely by reason for his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal Financial assistance . . . ." 29 U.S.C. § 794 (1985).

[13]*See infra* note 29.

[14]48 Fed. Reg. 9,630 (1983).

[15]*Id.* at 9,631.

[16]*Id.*

[17]*Id.* at 9,632.

[18]American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983). *See infra* notes 40-41 and accompanying text.

[19]48 Fed. Reg. 30,846 (1983).

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

[21]*Bowen*, 106 S. Ct. at 2109.

Association,[22] by a plurality vote, ruled that the regulations were not authorized by section 504 of the Rehabilitation Act of 1973.[23] The Final Rules represented an attempt by the executive branch of the federal government to regulate a highly complex and sensitive area of state law that was not previously subject to federal regulation.

This Article will briefly examine the nature and frequency of congenital infant birth defects and will examine the development and requirements of the Department's Final Rules. After analyzing the Supreme Court's decision in *Bowen*, the Article concludes that the Final Rules, although commendable in purpose, were properly invalidated because the Department has no authority to promulgate regulations interfering with the decisional process in the emergency medical treatment of newborn infants with severe birth defects.

II. The Nature and Frequency of Infant Birth Defects

The primary wish of expectant parents is that their infants are normal and healthy at birth. Unfortunately, there are thousands of severely deformed infants born in this country every year.[24] Despite modern medical technology, most of these infants can expect no more than a harshly limited and severely impaired life.

Infant birth defects vary in both the nature and degree of abnormality. The decision whether to withhold life-saving or life-sustaining medical treatment from impaired newborns is most often made in the case of a severe impairment. A severely impaired newborn is "one who is not likely to survive without surgical and medical intervention and whose prognosis, even assuming this intervention, may be poor in terms of cognitive life and minimal functioning."[25]

Baby Doe was born with one of the most common types of severe birth defects: Trisomy 21, or Down's syndrome, which is a chromosomal defect that causes varying degrees of mental retardation. At birth, it is impossible to predict accurately the potential degree of retardation, but the highest I.Q. that can be expected is 60.[26] Down's syndrome is usually accompanied by heart or bowel defects requiring immediate surgical treatment.[27] If such life-saving treatment is successfully performed, Down's

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[22]106 S. Ct. 2101 (1986).

[23]*Id.* at 2123.

[24]Two commentators have estimated that 30,000 infants are born in this country each year with severe birth defects. Brown & Truitt, *Euthanasia and the Right to Die*, 3 Ohio N.U.L. Rev. 615, 630-35 (1976).

[25]Ellis, *Letting Defective Babies Die: Who Decides?*, 7 Am. J. Law & Med. 394 (1982).

[26]*Id.* at 396.

[27]*Id.*

syndrome babies can expect a shorter than average life span of forty to sixty years.[28]

III. Federal Response to the Baby Doe Incident

The widely publicized story of Baby Doe did not fall on deaf ears in the nation's capital. The Department of Health and Human Services, following a directive from President Reagan, issued a letter on May 18, 1982, to 6,800 hospitals which receive federal financial assistance, such as Medicaid or Medicare.[29] The letter

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[28]*Id.* Other types of severe birth defects include anencephaly, a condition in which there is a partial or total absence of the brain; myelomeningocele (spina bifida cystica), a condition in which the baby's spinal cord is malformed and exposed; and encephalomeningocele, a condition in which an infant's brain protrudes from its skull. For an excellent, non-technical discussion of these and other severe birth defects, see *id.* at 395.

[29]The full text of the letter is as follows:

May 18, 1982

NOTICE TO HEALTH CARE PROVIDERS

SUBJECT: Discriminating Against the Handicapped by Withholding Treatment or Nourishment

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

This notice is intended to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). Section 504 provides that "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ." Implementing regulations issued by the Department of Health and Human Services make clear that this statutory prohibition applies in the provision of health services (45 C.F.R. 84.52) and that conditions such as Down's syndrome are handicaps within the meaning of section 504 (45 C.F.R. 84.3(j)).

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; and

(2) The handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, a recipient may not lawfully decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

We recognize that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another per-

reminded[30] hospitals of the federal government's position that section 504 of the Rehabilitation Act of 1973[31] prohibits the withholding of life-saving nutrition or medical treatment from handicapped infants.[32]

Although the letter recognized that a hospital does not have full control over the treatment of handicapped infants when parental consent to treatment has been refused, it warned hospitals to discharge the infant from the institution when the infant's parents refused consent to such treatment.[33] The letter also intimated that the discriminatory withdrawal of medical treatment or nourishment from handicapped infants would result in the termination of federal financial assistance to the hospital.[34]

The May 18, 1982, letter was not an idle threat. On March 7, 1983, the Department, contemplating a "vigorous federal role", promulgated an "Interim Final Rule," pursuant to section 504, to enforce its position with respect to the non-treatment of handicapped infants.[35] The Interim Rule required hospitals to post an informational notice "in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery . . . ."[36] The notice

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son or organization. 45 C.F.R. 84.4(b)(1)(v). Recipients must accordingly insure that they do not violate section 504 by facilitating discriminatory conduct.

In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.
- Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.
- Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance. Moreover, section 504 does not limit the continued enforcement of State laws prohibiting the neglect of children, requiring medical treatment, or imposing similar responsibilities.

Betty Lou Dodson
Director, Office for Civil Rights.

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

[30]Although the letter purported to "remind" hospitals of the applicability of section 504 to medical treatment decisions, the letter was actually the first indication given by the government that it intended to enforce section 504 in that manner.

[31]29 U.S.C. § 794 (1985).

[32]*See supra* note 12.

[33]*See supra* note 29; *see also* 49 Fed. Reg. 1,631 (1984) (section 504 does not mandate hospital to overrule parental decision of non-treatment); *infra* note 96.

[34]*See supra* note 29.

[35]48 Fed. Reg. 9,630 (1983).

[36]*Id.* at 9,631.

was required to state that the "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law."[37] The notice was also to advise of the availability of a twenty-four hour telephone "hotline" to report violations to the Department.[38] Finally, the Interim Final Rule authorized expedited compliance actions and access to hospital records when "in the judgment of the responsible Department official," such access was "necessary to protect the life or health of a handicapped individual."[39]

In April of 1983, the United States District Court for the District of Columbia, in *American Academy of Pediatrics v. Heckler*,[40] struck down the Interim Final Rule as "arbitrary, capricious and promulgated in violation of the Administrative Procedure Act."[41] Undaunted by the court's decision, the Department issued a somewhat amended version of the Interim Final Rule as new "Proposed Rules" on July 5, 1983, and invited public comment.[42]

After the period for public comment had passed, the Department promulgated the Final Rules, which became effective February 13, 1984.[43] The new rules contained four mandatory provisions.[44] Like the Interim Final Rule, they required hospitals to post an informational notice which was to contain a statement either that section 504 prohibits discrimination on the basis of handicap,[45] or that "nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments."[46] In addition, the notice was to provide the telephone number of a 24-hour

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[37] *Id.*

[38] *Id.*

[39] *Id.* at 9,632.

[40] 561 F. Supp. 395 (D.D.C. 1983). The plaintiffs, American Academy of Pediatrics, National Associations of Children's Hospitals and Related Institutions and the Children's Hospital National Medical Center, brought suit to challenge the validity of the Interim Final Rule.

[41] *Id.* at 404. The District Court concluded that "haste and inexperience has resulted in agency action based on inadequate consideration" of a number of crucial factors. *Id.* at 399-401. Alternatively, the court ruled that the Department had improperly failed to solicit public comment in violation of the Administrative Procedure Act. *Id.*

[42] 48 Fed. Reg. 30,846 (1983).

[43] *Bowen*, 106 S. Ct. at 2109.

[44] The adopted code section already contained two other, non-mandatory subsections. Subsection (a) encouraged hospitals to establish Infant Care Review Committees (ICRC) to develop treatment standards for handicapped infants. 45 C.F.R. § 84.55(a) (1985). Subsection (f) provided that "[t]he activities of the ICRC will be guided by . . . the interpretive guidelines of the Department. . . ." 45 C.F.R. § 84.55(f)(1)(ii)(A) (1985). The Guidelines were only illustrative and set forth the Department's interpretation of Section 504.

[45] 45 C.F.R. § 84.55(b)(3) (1985).

[46] 45 C.F.R. § 84.55(b)(4) (1985).

"hotline" to the Department or the telephone number of the appropriate child protection agency.[47]

A second mandatory provision delineated the responsibilities of state child protective services agencies. This provision required these state agencies to adopt and enforce procedures utilizing their "full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants."[48] This provision also mandated (1) health care providers to report "known or suspected instances of unlawful medical neglect of handicapped infants;"[49] (2) a procedure so that state agencies receive timely reports;[50] (3) "on-site investigation" of hospitals, where appropriate;[51] (4) protection of infants by seeking legal action to obtain "timely court order[s] to compel the provision of necessary nourishment and medical treatment;"[52] and (5) timely notification to the Department of every complaint of "suspected unlawful medical neglect" of handicapped infants.[53]

The final mandatory sections authorized expedited access to records and expedited action to insure compliance.[54] Immediate access to patient records was authorized on a twenty-four hour basis, even in the absence of parental consent.[55] The Department was also clothed with authority to implement immediate action to effect compliance when "necessary to protect the life or health of a handicapped individual."[56] When a handicapped infant was in "imminent danger of death," the government was authorized to seek a temporary restraining order to sustain its life.[57]

The message conveyed in the Final Rules was clear and unequivocal. It was unlawful for hospitals receiving federal financial assistance to withhold or withdraw life-sustaining medical treatment from handicapped infants, regardless of whether parental consent was given or refused.

Not surprisingly, both sets of regulations met with immediate opposition. Several organizations filed lawsuits to enjoin enforcement of both the Interim Final Rule and the Final Rules.[58] These lawsuits progressed

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[47]45 C.F.R. § 84.55(b)(3)-(4) (1985).

[48]45 C.F.R. § 84.55(c)(1) (1985).

[49]45 C.F.R. § 84.55(c)(1)(i) (1985).

[50]45 C.F.R. § 84.55(c)(1)(ii) (1985).

[51]45 C.F.R. § 84.55(c)(1)(iii) (1985).

[52]45 C.F.R. § 84.55(c)(1)(iv) (1985).

[53]45 C.F.R. § 84.55(c)(1)(v) (1985). This subsection even applies "where a refusal to provide medically beneficial treatment is a result, not of decisions by a health care provider, but of decisions by parents." 49 Fed. Reg. 1,627 (1984).

[54]45 C.F.R. § 84.55(d)-(e) (1985).

[55]Access was authorized "when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual." 45 C.F.R. § 84.55(d) (1985).

[56]45 C.F.R. § 84.55(e) (1985).

[57]49 Fed. Reg. 1,628 (1984).

[58]*See infra* notes 59-64 and accompanying text.

through the federal courts and gave the Supreme Court the opportunity to rule on the validity of the regulations in *Bowen v. American Hospital Association*.

IV. *Bowen v. American Hospital Association*

A. Prior Litigation

On April 6, 1983, the American Hospital Association, along with two other organizations,[59] filed suit in federal court to restrain the enforcement of the Interim Final Rules.[60] In March, 1984, the parties amended their complaint and filed a motion to enjoin the enforcement of the Final Rules.[61] This action was consolidated with a separate, but related suit filed by the American Medical Association and other organizations.[62] The district court granted summary judgment in favor of the petitioners and enjoined enforcement of the Final Rules.[63] On appeal, the United States Court of Appeals for the Second Circuit summarily affirmed the ruling of the district court.[64]

The district court granted the requested relief solely on the authority of the Second Circuit decision in *United States v. University Hospital*,[65] which was also the authority upon which the Second Circuit summarily affirmed the judgment of the District Court.[66] Because *University Hospital* was found to be controlling, it is helpful to examine that case.

After the Department's Interim Final Rule was invalidated, but before the promulgation of the Final Rules, an infant, known as "Baby Jane Doe," was born with multiple congenital birth defects.[67] Baby Jane Doe was "transferred to University Hospital for dual surgery to correct her spina bifida and hydrocephalus."[68] Although the surgery was likely to prolong the infant's life, it would not have improved her handicapped conditions, including probable mental retardation.[69] After consulting with several physicians and other advisers, her parents decided to forgo the

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[59]Also party plaintiffs were the Hospital Association of New York State and Strong Memorial Hospital of the University of Rochester.

[60]American Hosp. Ass'n v. Heckler, 585 F. Supp. 541 (S.D.N.Y. 1984); *see also* Ahern, *Baby Doe: AHA Prevails in Supreme Court*, Health Law Vigil, June 20, 1986, at 1.

[61]Ahern, *supra* note 60.

[62]*Id.*

[63]American Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (S.D.N.Y. 1984).

[64]*Bowen*, 106 S. Ct. at 2109.

[65]729 F.2d 144 (2d Cir. 1984).

[66]*Bowen*, 106 S. Ct. at 2109.

[67]*Id.* She suffered from myelomeningocele (spina bifida), microencephaly (an abnormally small head), and hydroencephalus (fluid in the cranial vault). United States v. University Hosp., 729 F.2d 144, 146 (2d Cir. 1984).

[68]*University Hosp.*, 729 F.2d at 146.

[69]*Id.*

corrective surgery, and instead opted for "conservative" medical treatment.[70]

Five days after Baby Jane Doe's birth, an unrelated Vermont attorney filed suit in the New York State Supreme Court requesting the appointment of a *guardian ad litem* and an order directing the hospital to perform the surgery for the infant.[71] The trial court granted the requested relief, but was promptly reversed by the New York Appellate Division on the ground that the " 'concededly concerned and loving parents' "[72] chose a course of appropriate medical treatment which was "in the best interest of the infant."[73] The New York Court of Appeals affirmed the decision of the Appellate Division on the different ground that the trial court had no jurisdiction to entertain a child neglect proceeding by a stranger who had not requested aid from the appropriate state agency.[74]

During the course of the state proceedings, the Department received an anonymous complaint "that Baby Jane Doe was being discriminatorily denied medical treatment on the basis of her handicaps."[75] The Department referred the complaint to the New York State Child Protective Service, which investigated and concluded that there was no basis for state intervention.[76] Before the state agency reached its conclusion, however, the Department made several requests to the hospital for inspection of the medical records to enable it to decide whether section 504 had been violated.[77] The hospital refused to comply on the grounds that Baby Jane Doe's parents had not consented to a release of her medical records and that the Department's jurisdiction was doubtful.[78]

The Department thereafter filed suit in federal court pursuant to a regulation that authorized Departmental access to information necessary to ascertain compliance with section 504.[79] After the parents were allow-

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[70] *Id.* The treatment consisted of "good nutrition, the administration of antibiotics, and the dressing of the baby's exposed spinal sac." *Id.*

[71] *Id.*

[72] *Id.* at 147 (quoting the Appellate Division of the New York Supreme Court).

[73] *Id.*

[74] *Id.* (quoting the New York Court of Appeals).

[75] *Id.*

[76] *Id.*

[77] *Id.*

[78] *Id.* at 148.

[79] *Id.* The pertinent regulation provided:

> (c) *Access to sources of information.* Each recipient [of Federal financial assistance] shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part. . . . Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part.

45 C.F.R. § 80.6(c) (1985), *as incorporated by* 45 C.F.R. § 84.61 (1985).

ed to intervene, the district court ruled that the government had no right of access to the records because the hospital had not violated section 504.[80] According to the court, the hospital " 'failed to perform the surgical procedures in question, not because Baby Jane Doe [was] handicapped, but because her parents ha[d] refused to consent . . . .' "[81]

The court of appeals agreed with the district court that the attempt by the Department to gain access to Baby Jane Doe's medical records was beyond the authority granted to it by Congress.[82] The court of appeals went further than the district court, however, by ruling that section 504 was never meant to apply to treatment decisions involving impaired newborns.[83] In the court's view, Baby Jane Doe was not "otherwise qualified" within the meaning of section 504 because "where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to the need for services."[84] Because "the handicapping conditions 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'."[85] The court of appeals concluded that until Congress indicates otherwise, "it would be an unwarranted exercise of judicial power to approve the type of investigation that ha[d] precipitated this lawsuit."[86]

The Department did not seek certiorari in *University Hospital*. The Supreme Court granted certiorari in *Bowen v. American Hospital Association*.[87]

B. The Supreme Court Decision in Bowen

The plurality[88] opinion began by narrowly circumscribing the scope of review. According to the plurality, the only issue before the Court was whether the four mandatory provisions of the Final Rules were authorized by section 504.[89] The plurality expressly refused to decide

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[80]*University Hosp.*, 729 F.2d at 148-49.

[81]*Id.* at 148 (quoting United States v. University Hosp., 575 F. Supp. 607, 614 (S.D.N.Y. 1983)).

[82]*Id.* at 161.

[83]*Id.*

[84]*Id.* at 156. The court stated that "the phrase 'otherwise qualified' is geared toward relatively static programs or activities such as education, . . . employment, . . . and transportation systems. . . . As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning." *Id.* (citations omitted). The court noted that the phrase " 'refers to a person who is qualified *in spite of* her handicap . . . .' " *Id.* (quoting Doe v. New York Univ., 666 F.2d 761 (2d Cir. 1981)).

[85]*Id.* at 157. The court noted that the hospital was always willing to perform the surgery if Baby Jane Doe's parents consented. *Id.* at 160.

[86]*Id.* at 161.

[87]105 S. Ct. 3475 (1985).

[88]The opinion was authored by Justice Stevens, in which Justices Marshall, Blackmun and Powell joined. Chief Justice Burger concurred in the judgment. Justices White, Brennan and O'Connor dissented. Justice Rehnquist took no part in the consideration or decision of the case.

[89]*Bowen*, 106 S. Ct. at 2111. The District Court's ruling, summarily affirmed by the

whether section 504 "ever applies to individual medical treatment decisions involving handicapped infants."[90]

The validity of the mandatory components of the Final Rules depended upon whether the Department's explanation of the need for the rules "included a 'rational connection between the facts found and the choice made.' "[91] Although the plurality recognized that the Department was entitled to some deference with respect to its reasoning, the plurality cautioned that an agency regulation will not be upheld merely because "it is possible to 'conceive a basis' for administrative action."[92]

The plurality applied this standard to the two justifications offered by the Department for the promulgation of the Final Rules.[93] The Depart-

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Second Circuit, declared " '[t]he Final Regulation . . . invalid and unlawful as exceeding' " Section 504, enjoined the Department from "any further implementation of the Final Regulation," and declared invalid and enjoined "[a]ny other actions" of the Department "to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions." *Id.* at 2111, n.11 (quoting American Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (S.D.N.Y. 1984)).

[90]*Id.* at 2111. In footnote 11, the plurality narrowly construed the language of the injunction by noting that the complaints filed by the plaintiffs challenged only the validity of the Final Rules, not the Department's authority to regulate all treatment decisions. The plurality also was of the opinion that the Court of Appeals intended only to enjoin the current regulations, not all possible activity that might involve the medical treatment of handicapped infants. The dissent took exception with this narrow construction. *See infra* notes 120-125 and accompanying text.

[91]*Bowen*, 106 S. Ct. at 2112 (quoting Motor Vehicles Mfrs. Ass'n v. State Farm Mut., 463 U.S. 29, 43 (1983) (quoting Burlington Truck Lines, Inc. v. United States, 371 U.S. 156, 168 (1962))).

[92]*Id.*

[93]Before examining the Department's two justifications, the plurality reviewed the pre-existing state law mechanisms that governed the provision of medical care to handicapped infants:

> In broad outline, state law vests decisional responsibility in the parents, in the first instance, subject to review in exceptional cases by the State acting as *parens patriae.* Prior to the regulatory activity culminating in the Final Rules, the federal government was not a participant in the process of making treatment decisions for newborn infants. We presume that this general framework was familiar to Congress when it enacted § 504.

Id. at 2113 (footnote omitted). The plurality also cited a 1983 government report:

> "The paucity of directly relevant cases makes characterization of the law in this area somewhat problematic, but certain points stand out. First, there is a presumption, strong but rebuttable, that parents are the appropriate decision-makers 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.
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> ". . . [A]s long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervened.

ment's first argument was that a hospital discriminates within the meaning of section 504 by failing to furnish a handicapped infant with medically beneficial treatment "solely by reason of his handicap."[94] Second, the Department contended that a hospital may violate section 504 by failing to report incidents of medical neglect to a state child protective agency.[95] Both justifications were rejected by the plurality.

The plurality first ruled that as a matter of law, a hospital cannot violate section 504 by withholding medical treatment from a handicapped newborn when the infant's parents have refused consent to the treatment.[96] Without parental consent, a hospital does not have the right to provide treatment to an infant.[97] Under such circumstances, an "infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.' "[98]

From this conclusion, the plurality reasoned that the Final Rules are not necessary to prevent hospitals from denying medical care to handicapped newborns.[99] If parental consent to treatment is withheld, a hospital has no legal right to provide medical treatment to a handicapped infant. Therefore, a hospital could violate section 504 only by refusing to treat a handicapped infant when parental consent to such treatment has been given. According to the plurality, however, the Department offered no evidence of any instance where a hospital refused medical treatment when parental consent had been obtained.[100] The Department also did not at-

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> The courts have exercised their authority to appoint a guardian for a child when the parents are not capable of participating in the decisionmaking or when they have made decisions that evidence substantial lack of concern for the child's interests. Although societal involvement usually occurs under the auspices of governmental instrumentalities—such as child welfare agencies and courts—the American legal system ordinarily relies upon the private initiative of individuals, rather than continuing governmental supervision, to bring the matter to the attention of legal authorities."

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 212-214 (1983) (footnotes omitted)).

[94]*Id.* at 2113.

[95]*Id.*

[96]*Id.* at 2114. Although the Department originally thought that a hospital's duty to provide treatment was unaffected by the absence of parental consent, even the Department conceded, in the preamble to the Final Rules that when "a non-treatment decision, no matter how discriminatory, is made by parents, rather than by the hospital, section 504 does not mandate that the hospital unilaterally overrule the parental decision and provide treatment notwithstanding the lack of consent." 49 Fed. Reg. 1,631 (1984).

[97]*Bowen*, 106 S. Ct. at 2114. According to the plurality, "[i]ndeed, it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent." *Id.*

[98]*Id.*

[99]*Id.* at 2115.

[100]*Id.*

tempt to argue that posted notices, "hotlines," or on-site investigations were needed to prevent hospitals from denying treatment to which parents had consented.[101]

Thus, according to the plurality, the supposed need for federal regulations was not demonstrated by any evidence. In every case that the Department cited to support its argument that hospitals were discriminatorily denying medical treatment, the hospital's refusal was based upon the absence of parental consent.[102] Moreover, in the three cases cited by the Department as "providing the strongest support for federal intervention," not only was parental consent refused, but the effectiveness of existing state mechanisms was demonstrated because surgery was ordered by state authorities after the hospitals sought judicial intervention.[103]

The plurality also considered an argument not advanced by the Department, but which, according to the dissent, was pivotal to the validity of the Final Rules.[104] The dissent maintained that the Final Rules were justified to curtail discriminatory advice by physicians who recommended withholding medical treatment for handicapped newborns because of their handicaps.[105] The plurality, noting that the Department had not even advanced this theory,[106] rejected the dissent's reasoning on a number of grounds. First, the regulations in no way constrained the type of advice physicians may give to their patients.[107] Second, because section 504 does not prohibit parents from refusing consent to medical treatment for handicapped newborns, section 504 may not "prevent the giving of advice to do something which [the statute] does not itself prohibit."[108] Finally, even if attitudinal surveys showed that physicians would acquiesce in, or fail

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[101] *Id.*

[102] The plurality maintained:

> The Secretary's belated recognition of the effect of parental nonconsent is important, because the supposed need for federal monitoring of hospitals' treatment decisions rests *entirely* on instances in which parents have refused their consent. Thus, in the Bloomington, Indiana, case that precipitated the Secretary's enforcement efforts in this area, as well as in the *University Hospital* case that provided the basis for the summary affirmance in the case now before us, the hospital's failure to perform the treatment at issue rested on the lack of parental consent. The Secretary's own summaries of these cases establish beyond doubt that the respective hospitals did not withhold medical care on the basis of handicap and therefore did not violate § 504; as a result, they provide no support for his claim that federal regulation is needed in order to forestall comparable cases in the future.

Id. at 2115 (footnotes omitted).

[103] *Id.* at 2116-17.

[104] *Id.* at 2117, n.22.

[105] *Id.* at 2129 (White, J., dissenting).

[106] *Id.* at 2117, n.22.

[107] *Id.*

[108] *Id.*

to correct, "bad" decisions by parents, there was no evidence that "the parental decisionmaking process is one in which doctors exercise the decisive influence needed to force such results."[109] The plurality thus found no justification for the Final Rules based upon the premise that physicians may violate section 504 by urging parents to decide against treating handicapped newborns.

The plurality also rejected the second justification the Department offered for the Final Rules. The Department maintained that hospitals violated section 504 by failing to report parental decisions to withhold treatment to the appropriate state agencies, and that past failures to report justified federal regulation.[110] The plurality first ruled that section 504 itself imposes no duty upon hospitals to report instances of discriminatory medical treatment.[111] Second, although a hospital could violate section 504 by selectively refusing to report medical neglect, the Department had again proffered no evidence that such conduct had occurred.[112] Third, and perhaps most importantly, the Final Rules did not directly require hospitals to report instances of medical neglect; rather, the Final Rules required state agencies to use their "full authority" to "prevent instances of unlawful medical neglect of handicapped infants."[113]

After finding that the purpose of section 504 was not to impose "an affirmative-action obligation" on recipients of federal financial aid,[114] the plurality found that section 504 did not authorize an affirmative-action command to state agencies with respect to the way they conducted medical neglect investigations.[115] The Court expressly rejected the notion that the

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[109]*Id.* at 2118, n.22.

[110]*Id.* at 2118.

[111]*Id.*

[112]*Id.*

[113]*Id.* at 2119 (citing 45 C.F.R. § 84.55(c)(1) (1985) (footnote omitted). The plurality contended that the Final Rules effectively made handicapped newborns a state investigative priority, with the result that state agencies would necessarily shift scarce resources away from other enforcement activities. Moreover, the Final Rules directly contradicted established state law with respect to mechanisms to investigate the medical neglect of handicapped infants, such as the state law requirement of confidentiality of records. *Id.*

[114]*Id.* According to the plurality, section 504 only "seeks to assure even-handed treatment," and has never been authority to impose an affirmative-action obligation on recipients of federal financial aid. *Id.* (quoting Southeastern Community College v. Davis, 442 U.S. 397, 411 (1979)).

[115]*Id.* at 2120. The plurality concluded:

> State child protective services agencies are not field offices of the HHS bureaucracy, and they may not be conscripted against their will as the foot soldiers in a federal crusade. As we stated in *Alexander v. Choate*, 469 U.S., at ____, 105 S. Ct., at 724, "nothing in the pre- or post-1973 legislative discussion of § 504 suggests that Congress desired to make major inroads on the States' long-standing discretion to choose the proper mix" of services provided by state agencies.

Id. (footnote omitted).

Department, pursuant to section 504, may force state agencies to enforce compliance with section 504 by other recipients of federal funds, such as hospitals.

The plurality, then, ruled that the four mandatory components of the Final Rules were invalid because they were not authorized by section 504.[116] Not only did the plurality rule that there was not an adequate evidentiary foundation for the Final Rules, but it also was concerned by what it perceived to be an unauthorized and unwarranted intrusion of federal power into an otherwise exclusive domain of state authority.[117] Without evidence to the contrary, the plurality was unwilling to authorize "federal intervention into a historically state-administered decisional process that appears . . . to be functioning in full compliance with [section] 504."[118] In short, the plurality ruled that "[s]ection 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children."[119]

The dissent, authored by Justice White, disagreed with the plurality's narrow construction of the proper scope of the Court's review of the lower court decision.[120] According to the dissent, the issue was not whether the Final Rules were invalid, but whether section 504 may ever authorize the Department to regulate medical treatment decisions involving handicapped newborns."[121] This broader scope of review was necessary because

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[116]*Id.* at 2123.

[117]In footnote 33, the plurality reasoned:

> The legislative history of the Rehabilitation Act does not support the notion that Congress intended intervention by federal officials into treatment decisions traditionally left by state law to concerned parents and the attending physicians, or, in exceptional cases, to state agencies charged with protecting the welfare of the infant. As the Court of Appeals noted, there is nothing in the legislative history that even remotely suggests that Congress contemplated the possibility that "section 504 could or would be applied to treatment decisions, involving defective newborn infants." 729 F.2d 144, 159 (1984).
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> "As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were representatives of parents or spokesmen for religious beliefs that would be affected heard." *Id.* at 158 (quoting American Academy of Pediatrics v. Heckler, 561 F. Supp. at 401).

Id. at 2122, n.33.

[118]*Id.* at 2122.

[119]*Id.* at 2123.

[120]Justice White's dissent was in five parts. Justice Brennan joined in the dissent, while Justice O'Connor joined in parts I, II, IV, and V of the dissent.

[121]*Bowen*, 106 S. Ct. at 2123 (White, J., dissenting).

the district court's judgment, summarily affirmed by the Court of Appeals, permanently enjoined the Secretary from " 'continuing or undertaking any other actions to investigate or regulate treatment decisions involving impaired newborn infants taken under authority of section 504, including pending investigations and other enforcement actions.' "[122] Thus, in the dissent's opinion, the Department was completely prohibited from regulating the medical treatment of handicapped newborns via section 504.[123] This conclusion was further compelled by *University Hospital*,[124] the decision which directly controlled the lower courts' decision in this action, in which the court of appeals ruled that section 504 could never apply to medical treatment decisions because handicapped infants are not "otherwise qualified" within the meaning of section 504.[125]

The dissent concluded that there are situations in which section 504 may apply to medical treatment decisions for newborns.[126] The example given by the dissent is where a Down's syndrome infant suffers from an esophageal obstruction. The infant would be "otherwise qualified" for surgery to correct the obstruction because this condition is assumed to be unrelated to the Down's syndrome.[127] Thus, "[i]f an otherwise normal child would be given the identical treatment, so should the handicapped child if discrimination on the basis of handicap is to be avoided."[128] Because there are situations in which handicapped infants are "otherwise qualified" for treatment, section 504 would apply to such medical treatment decisions; the dissent would, therefore, have reversed the court of appeals' judgment.[129]

The dissent, though, went much further than simply arguing that the Department is not absolutely precluded from regulating medical treatment decisions pursuant to section 504. The dissent also maintained that section 504 authorized the mandatory components of the Final Rules.[130] The dissent found an adequate evidentiary basis for the Final Rules because the evidence indicated that discrimination may occur in situations other than where a hospital refuses to treat a handicapped infant when parental consent has been given.[131] Doctors and hospitals substantially influence parental decision-making with respect to the treatment of handicapped

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[122] *Id.* at 2124 (citation omitted).

[123] *Id.*

[124] 729 F.2d 144 (2d Cir. 1984).

[125] *Bowen*, 106 S. Ct. at 2125 (White, J., dissenting).

[126] *Id.* at 2127.

[127] *Id.*

[128] *Id.* (footnote omitted).

[129] *Id.* at 2128.

[130] *Id.* at 2130. The dissent, though, stated it addressed this issue only because the plurality did. *Id.* at 2128.

[131] *Id.* at 2129-30.

newborns. If doctors make discriminatory treatment recommendations to parents, the doctors would violate section 504 whether or not the parents followed their recommendations.[132]

The dissent was convinced that the Department intended to prevent this "elusive" form of discrimination through the Final Rules.[133] The lack of evidence to support the conclusion that such discriminatory practices existed did not invalidate the Final Rules because the dissent agreed with the Department that the Final Rules could properly be prophylactic in nature.[134] Thus, the dissent found a rational connection between the facts found and the regulatory choice made and would not have invalidated the regulations.[135]

V. The Final Rules Were Correctly Invalidated

The only unambiguous result of *Bowen v. American Hospital Association* is that the Final Rules at issue were invalidated. At least three Justices were of the opinion that the Department has authority, pursuant to section 504, to regulate medical treatment decisions involving handicapped newborns.

For this reason, and because the plurality expressly narrowed its opinion to the validity of the Final Rules, the Department will presumably continue to attempt to regulate the area of medical treatment for severely impaired infants. It is difficult, however, to conceptualize any set of regulations that would, or even should, be authorized by section 504 absent express congressional directives.[136]

The Final Rules issued by the Department represented the administration's response to a situation it found deplorable: handicapped infants are allowed to die when the means exist to prolong their lives. The clear purpose of the Final Rules was to prevent, when possible, the practice of passive euthanasia on handicapped infants. To accomplish this goal, the Department chose to utilize section 504.

The fundamental flaw in the Department's attempt to utilize section 504 for this purpose is that it ignored the true cause of the problem: lack of parental consent. Current state common law principles vest parents with the responsibility to make treatment decisions for their children, subject to review by the state acting as *parens patriae* in exceptional cases.[137] The Final Rules did not, nor can any future rules under section 504, prevent parents from exercising their authority to refuse consent to medical

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[132] *Id.* at 2129.

[133] *Id.*

[134] *Id.* at 2130.

[135] *Id.*

[136] *See supra* note 86 and accompanying text.

[137] *See supra* note 117.

treatment for their severely impaired newborns. If parental consent to life-saving medical treatment is refused, and if there is no judicial intervention, a hospital has no authority to perform the medical procedures. Moreover, whenever parental consent is withheld, section 504 can not be used to force hospitals to provide the medical treatment.

The Final Rules, then, were designed to undermine indirectly parental authority to withhold consent to medical treatment, but the rules were necessarily directed to hospitals and state child protective services agencies. The fundamental premise of the Final Rules was that it is unlawful, under section 504, for a hospital to withhold or counsel against medical treatment for handicapped infants, solely because of their handicaps. By requiring posted notices, "hotlines," federal investigative "armies," access to confidential records, and expedited compliance actions, the Final Rules, under the guise of preventing discrimination, were really designed to cause hospitals to fear the loss of federal financial assistance if they, in any manner, counseled parents to withhold medical treatment from handicapped newborns.

The plurality in *Bowen* correctly determined that section 504 did not countenance such federal intrusion. Even if an indirect attempt to undermine parental authority had been a legitimate goal, the very existence of parental authority was fatal to the validity of the Final Rules. If parental consent to treatment is not given, a hospital cannot violate section 504 by withholding treatment. If parental consent to treatment is given, a hospital can violate section 504 by withholding treatment, but it cannot be seriously contended that a hospital would ever withhold such treatment against the wishes of parents.[138]

The justification, then, for the Final Rules can only depend upon alleged discriminatory conduct by doctors or hospitals *before* consent to treatment is given or refused.[139] The dissent in *Bowen* vigorously argued that doctors or hospitals can discriminate within the meaning of section 504 by advising parents to withhold medical treatment from handicapped infants merely because they are handicapped. The dissent agreed, however, that parents have the right to refuse medical treatment solely by reason for the infant's handicapped conditions.[140] The conclusion, then, is that the Department utilized section 504 in an attempt to prohibit doctors or

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[138]The Department proffered no such evidence and, moreover, as the plurality in *Bowen* noted, the parental interest in calling attention to a refusal by a hospital to perform treatment adequately vindicates the interest in enforcing section 504 for that reason. *Bowen*, 106 S. Ct. at 2115. *See supra* note 100 and accompanying text.

[139]The failure of a hospital to report discriminatory treatment can violate section 504, but, again, the Department offered no such evidence and the cases proved otherwise. *See supra* note 112 and accompanying text.

[140]*Bowen*, 106 S. Ct. at 2128, n.10.

hospitals from disclosing to parents that withholding medical treatment from severely impaired newborns is a legitimate medico-legal decision.

Apart from whether the Final Rules were authorized by section 504, the rules represented an ineffective and counter-productive effort to accomplish the true goal—prohibiting the passive euthanasia of severely handicapped infants. If that goal is ever to be accomplished, the true issue that must be resolved is whether parents should continue to have the authority to decide to withhold life-saving or life-sustaining medical treatment from a severely impaired infant based upon a subjective assessment of the potential quality of the infant's expected life.

Our society has, thus far, made a value judgment that parents are the most appropriate decision-makers for their infants, subject to judicial intervention in exceptional cases. As long as this fundamental premise remains viable, a continual effort should be made to ensure that the decision-making process is conducted in the best possible manner with respect to the interests of the infant, its parents, and society. This decision-making process involves complex clinical facts, moral considerations, and difficult, imprecise judgments. Hospitals continually seek to establish meaningful policies and procedures to improve the quality of the decision-making process.[141]

Even if there were an evidentiary foundation for the proposition that doctors or hospitals discriminate in counseling parents of handicapped infants, and even if the purpose of the Final Rules was to improve the quality of care for handicapped infants, the Department's attempts to enforce the rules effectively demonstrated that the rules were counter-productive and actually reduced the quality of care of newborns. The American Hospital Association (AHA), in a letter to the Department on September 2, 1983,[142] in which the AHA commented on the Proposed Rules, described the effects of the federal enforcement mechanisms in several hospitals and concluded,

> The unfortunate consequences of these actions were the disruption of operating procedures designed for the protection of newborns, postponement or interruption of necessary medical treatment of severely-ill infants, and, in at least one case, substantial risk to the health of a child. In sum, these procedures ostensibly designed to enhance the medical care of infants actually

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[141]Many hospitals are implementing institutionally based Bioethical Review Committees. Such committees are made up of clergy, social workers, physicians, nurses and administrators to help parents in the decision-making process.

[142]Letter from American Hospital Association to Director, Office of Civil Rights, Department of Health & Human Services (September 2, 1983) (discussing Proposed Rules stated at 48 Fed. Reg. 30,846 (1983)).

reduced the quality of care that otherwise would have been given pursuant to hospital and medical practice.[143]

Until our society decides to prohibit the withholding of life-saving or life-sustaining medical treatment from handicapped newborns, current efforts to improve the quality of the decision-making process should continue. Federal intervention through the use of section 504, which was never meant to apply to medical treatment decisions,[144] will only impair the operation of existing state mechanisms designed to oversee that process. Whether correct or morally outrageous, the law as it presently exists allows such decisions to be made. Section 504, under the guise of preventing discrimination, is not the proper vehicle for attempting to change existing state procedures.

VI. Conclusion

The plurality in *Bowen v. American Hospital Association* correctly concluded that the Final Rules were not authorized by section 504 of the Rehabilitation Act of 1973. The door remains open, though, for the Department of Health and Human Services to draft new rules to regulate medical treatment of handicapped infants. However, unless the Department can fill an obvious evidentiary void, it is not likely that any new regulations would survive judicial scrutiny. The presence or absence of parental consent will remain the pivotal factor affecting the validity of any new regulations or enforcement proceedings.

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[143] *Id.* at 4.

[144] *See supra* notes 115-18 and accompanying text.