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THE BABY JANE DOE LITIGATION AND SECTION 504: AN EXERCISE IN RAW EXECUTIVE POWER

by Michael Vitiello*

Especially over the past several years, federal courts have been under attack as activist, imperialistic, undemocratic and biased by several constituencies.¹ This article focuses on the position of the Reagan administration and its political allies among the right-to-life movement. As an example of their opposition to federal courts' activism, both unsuccessfully backed the Human Life Bill,² which would have denied lower federal courts jurisdiction over cases involving abortion.³ The attempt to remove abortion cases from lower federal courts was motivated by the perception that these courts had "demonstrated a consistent and unexplainable accommodation of the pro-abortion position."⁴

Discussions "seldom address the basic question of what constitutes

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1. See, e.g., Glazer, *Toward an Imperial Judiciary*, 41 PUB. INT. 104 (1975); Uddo, *A Wink from the Bench: The Federal Courts and Abortion*, 53 TUL. L. REV. 398 (1979). The same criticism has been implied by Justice Rehnquist. See, e.g., *Richmond Newspapers, Inc. v. Virginia*, 448 U.S. 555, 604-06 (1980) (Rehnquist, J., dissenting). See also R. BERGER, *GOVERNMENT BY JUDICIARY: THE TRANSFORMATION OF THE FOURTEENTH AMENDMENT* (1977). But cf. *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, 97th Cong., 1st Sess. vol. 1, at 160 (1981) (prepared statement by Senator Daniel Patrick Moynihan).

In 1981, there were more than twenty bills pending in Congress to remove jurisdiction from federal courts in several controversial areas, including school prayer and busing as well as abortion. *An Introduction to This Issue*, 65 JUDICATURE 177 (1981).

2. S. 158, 97th Cong., 1st Sess. reprinted in *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, supra note 1, at 1117 (1981); H.R. 900, 97th Cong., 1st Sess. (1981).

3. See, e.g., *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, supra note 1. President Reagan gave his full endorsement to these efforts in an article appearing in *Human Life Review*. Reagan, *Abortion and the Conscience of the Nation*, 9 HUM. LIFE REV. 7, 12-13 (1983).

4. Uddo, supra note 1, at 460.

judicial activism," which is "often equated with political liberalism," while restraint is aligned with conservatism.⁵ Although much of the recent attack on federal courts suffers a similar lack of defined and principled objections,⁶ two themes emerge from a review of the literature and testimony in support of the Human Life Bill. First, the Supreme Court's decision in *Roe v. Wade*⁷ is activist because "the right of reproductive privacy was discovered by the Supreme Court itself in 1965, somehow in the penumbras formed by the emanations from the Bill of Rights, whatever that means. This is a judicial creation out of the whole cloth."⁸ That is, one aspect of activism is an "extravagant interpretation"⁹ of the law, not grounded in the language or intent of the law. Second, federal courts have intruded upon an area of the law rightfully entrusted to the states. Federal courts should defer to the states because: (1) questions touching on the family are an integral part of state police and *parens patriae* powers;¹⁰ (2) state statutes are often involved, and state courts should give definitive interpretation to state statutes; and (3) federalizing the abortion question has denied the people and the states the right to form a consensus on the abortion question.¹¹

Insofar as the Reagan administration's and right-to-life groups' attack on federal courts is based on principles and is not merely political,

5. Canon, *Defining the Dimensions of Judicial Activism*, 66 JUDICATURE 237, 237 (1983).

6. During the course of hearings on the Human Life Bill, Professor Archibald Cox suggested that the bill was "radical and dangerously unprincipled." *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1, at 328. That comment produced an angry response from Senator John East. *Id.* at 423-25.

7. 410 U.S. 113 (1973).

8. *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1, at 627 (comments of Professor Charles Rice).

9. *Id.* at 622. ("One of the difficulties here arises from the Supreme Court's extravagant interpretation of the 14th amendment. . . . The Supreme Court has reached out to take jurisdiction for itself and responsibilities for itself that have proven not to be wise.")

10. "*Parens patriae* jurisdiction is a right of sovereignty and imposes a duty on the sovereignty to protect the public interest and . . . such persons with disabilities who have no rightful protector [I]t extends to the personal liberty of persons who are under a disability whether by reason of infancy, incompetency, habitual drunkenness, imbecility, etc. . . ." Johnson v. State, 18 N.J. 422, 430, 114 A.2d 1, 5 (1955); *see also* Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 736-45, 370 N.E.2d 417, 424-30 (1977) (discussing state's right to decide for an incompetent whether to forgo medical treatment for a terminal illness). More generally, the police power has been defined as "the power inherent in the state to prescribe . . . reasonable regulations necessary to preserve the public order, health, safety or morals." Tighe v. Osborn, 149 Md. 349, 356, 131 A. 801, 803 (1925).

11. *See infra* text accompanying notes 325-34.

recent efforts by those groups in *Baby Jane Doe*¹² and *United States v. University Hospital*¹³ reflect an abandonment of such principles. In *Baby Jane Doe*, a right-to-life advocate sued to compel the hospital to treat a seriously ill newborn over the objections of her parents. In *University Hospital*, the government attempted to secure medical records of a seriously ill newborn, obviously with a long-range view toward compelling surgery for the infant. The government's objective was to override both parental refusal to consent to surgery and acquiescence in the parental decision by health care professionals.¹⁴

This article examines these cases and the government's effort to use section 504 of the Rehabilitation Act of 1973¹⁵ to bring similar cases into federal court. Essentially, the government's position is that section 504 prohibits discrimination against seriously ill newborns by denial of medical treatment, regardless of the infant's potential for a meaningful life. This article argues that the government's attack violates the very principles advanced in the abortion context. The government was inviting the federal district court to interpret section 504 in an "extravagant" manner, without the support of the section's language or legislative history, in a way that would dramatically alter the state-federal balance in favor of federal court jurisdiction.¹⁶ In addition to creating jurisdiction over traditional state law cases, the government's proposed interpretation of section 504 "discrimination" would replace the state substantive law, in which the "best interest" standard is the norm.¹⁷ The government's section 504 strategy is without foundation in the law and is an open invitation to federal courts to override state law

12. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *aff'g* 95 A.D.2d 587, 467 N.Y.S.2d 685, *cert. denied*, 104 S. Ct. 560 (1983).

13. 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

14. Before the Second Circuit, the government argued that its suit in the district court was intended only to determine whether a violation of section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (Supp. 1983), was taking place. Brief for the United States at 12, *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984). But the Department of Health and Human Services made clear that it contemplated using the full panoply of remedies available from a federal court. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

15. 29 U.S.C. § 794 (Supp. 1983).

Section 504 provides in relevant part: "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 subject to discrimination under any program or activity receiving Federal financial assistance. . . ." *Id.*

16. See *infra* text accompanying notes 122-45.

17. See *infra* notes 205-90 and accompanying text.

and adopt a uniform national standard.

Apart from *Baby Jane Doe* and *University Hospital*,¹⁸ Congress has now legislated, in part, the government's reading of section 504 with the passage of H.R. 1904.¹⁹ Therefore, this article considers the soundness of the government's interpretation of discrimination and concludes that Congress erred in adopting H.R. 1904 which, despite ethical and legal arguments militating against treatment,²⁰ requires treatment in some cases without regard for the infant's best interest and federalizes treatment decisions in an area traditionally left to the states.

BABY JANE DOE AND THE GOVERNMENT'S SECTION 504 STRATEGY

In a 1983 report, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research reviewed current practices governing decisionmaking for seriously ill newborns.²¹ While it did not endorse in toto current practices, it found that "[d]espite reports of occasional cases in which seriously erroneous decisions about the treatment of newborns were carried out, such events appear to be very rare."²²

One such instance is the now infamous Indiana case of *Infant Doe*²³ "in which parents elected to forgo treatment of their newborn

18. Further litigation concerning Baby Jane Doe became moot because the parents consented to surgery to implant a shunt to relieve pressure on the brain. See *Baby Jane Doe Has Surgery to Remove Water from the Brain*, N.Y. Times, Apr. 7, 1984, § 1, at 28, col. 3. The federal government apparently has dropped its efforts to obtain Baby Jane Doe's medical records, but plans to pursue the issue of access in litigation instituted by the American Medical Association and five other groups. See *U.S. Drops 'Baby Jane Doe' Effort*, The Hartford Courant, Aug. 18, 1984, at A2, col. 4.

19. The House of Representatives passed H.R. 1904, 98th Cong., 1st Sess., reprinted in *Hearings Before the Subcomm. on Select Education of the Comm. on Education and Labor*, 98th Cong., 1st Sess. 2-14 (1983), by a vote of 396 to 4. The bill passed in the Senate by a vote of 89 to 0 as amended by S. 1003, 98th Cong., 1st Sess. (1984). The House of Representatives agreed to a conference on August 2, 1984. After conference, the House and Senate agreed on final amendments. See H.R. Rep. No. 1038, 98th Cong., 2d Sess. (1984) [hereinafter cited as Conference Report]. On October 9, 1984, the legislation was signed by President Reagan, as the Child Abuse Act, Pub. L. No. 98-457 (Oct. 9, 1984). See *Baby Doe at Age 1: A Joy and Burden*, N.Y. Times, Oct. 14, 1984, at A56, col. 4.

20. See *infra* text accompanying notes 147-290.

21. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 197-229 (1983) [hereinafter cited as Commission Report].

22. *Id.* at 208-09.

23. *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), writ of mandamus dismissed sub nom. *State ex rel. Infant Doe v. Baker*, No. 482 S 140 (Ind. Sup. Ct.

child who had Down's syndrome, tracheoesophageal atresia, and possibly additional anomalies."²⁴ Instead, the parents and treating physicians agreed on a course of nontreatment. Judicial proceedings were commenced by the hospital,²⁵ and the trial court upheld the parents' decision. Nontreatment presumably caused the child's death,²⁶ thereby making moot an appeal to the Indiana Supreme Court.²⁷

Upon hearing about the case, President Reagan circulated a memorandum to the Attorney General and the Secretary of Health and Human Services. The President's memorandum suggested that any hospital that received federal funds and denied treatment based on an infant's handicap, as in the *Infant Doe* case, was engaging in discriminatory practices prohibited by section 504.²⁸ The memorandum led first

May 27, 1982). According to one commentator, "the case appears to elevate inappropriately the parents' interest in having the child die immediately (rather than be adopted or raised in an institution) over the child's interest in life." J. ROBERTSON, *THE RIGHTS OF THE CRITICALLY ILL* 88 (1983). But see *infra* discussion at note 26.

24. Commission Report, *supra* note 21, at 224 n.92.

25. The action was commenced by the child welfare authorities "on the complaint of some party other than either the physicians or the parents of the child." See *id.*

26. The facts of the case are not entirely clear because, following an unusual procedure, the court ordered the record sealed. *Id.* The case has been subjected to considerable criticism. See, e.g., J. ROBERTSON, *supra* note 23, at 88; Commission Report, *supra* note 21, at 224; Reagan, *supra* note 3, at 9-10. The Americans United for Life Legal Defense Fund calls it "the most blatant . . . infanticide episode." AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, SUMMARY ANALYSIS OF FINAL "BABY DOE" RULES WITH RECOMMENDATIONS FOR ACTION 10 (Jan. 20, 1984).

There is some indication that the parents' decision to forgo treatment was defensible. As reported in Smith, *Life and Death Decisions in the Nursery: Standards and Procedures for Withholding Lifesaving Treatment from Infants*, 27 N.Y.L. SCH. L. REV. 1125, 1136 n.41:

[T]he infant had multiple serious heart defects, . . . a guardian ad litem [*sic*] had been appointed who declined to join in an effort to overturn the decision to withhold treatment, and . . . a six person task force reviewed the decision not to treat and concurred with it. . . .

Because so little is known about the details of the Baby Doe case, it is virtually impossible to know what standards were applied in the case. If, for example, the child had serious heart defects in addition to the esophageal defect the surgery required may have been contraindicated. The fact that a guardian ad litem [*sic*] was appointed and that a six-person committee considered and approved the decision to withhold treatment suggests that a significant review process was employed by the physicians, hospital or courts.

27. There is some confusion about the role of the Indiana Supreme Court in the *Infant Doe* case. It has been reported that the appeal was refused because it was moot. Commission Report, *supra* note 21, at 224 n.92; Smith, *supra* note 26, at 1136 n.41. Other commentators have suggested that the court decided the case on the merits, but affirmed without an opinion. J. ROBERTSON, *supra* note 23, at 88; Reagan, *supra* note 3, at 10 ("The [trial] judge let Baby Doe starve and die, and the Indiana Supreme Court sanctioned his decision.").

28. *Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to*

to a May 8, 1982, notice to health care providers "to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973."²⁹ Then, apparently after viewing a sensationalized television series on the treatment of seriously ill newborns, President Reagan instructed HHS to issue a more forceful regulation.³⁰ Within days of its promulgation, the American Academy of Pediatrics, among others, sued for equitable relief to prevent its implementation.³¹ In finding for the plaintiffs, the district court summarized the regulation:

Under the regulation a possible violation reported anonymously or otherwise via the "hotline" may be referred by the agency in turn to state child protective authorities or to the Department of Justice for civil rights enforcement. The regulation also authorizes immediate intervention by an HHS Office of Civil Rights investigation squad to protect the life or health of a handicapped infant. Institutions receiving federal financial assistance are required to give 24-hour access to hospital records and facilities during the investigation, and physicians, families and hospital staff are subject to immediate on-the-scene questioning while in the midst of providing newborn care and treatment.³²

The district court ruled the regulation invalid on procedural grounds, finding it arbitrary and capricious because it was made hastily

Health Care for Handicapped Infants, 49 Fed. Reg. 1622, 1622-23 (1984) (to be codified at 45 C.F.R. pt. 84) (final rules, Jan. 12, 1984).

On April 30, 1982, President Reagan instructed the Department of Health and Human Services (HHS) "to notify health care providers of the applicability of section 504 of the Rehabilitation Act of 1973 to the treatment of handicapped patients . . . Regulations under this law specifically prohibit hospitals and other providers of health services receiving federal assistance from discriminating against the handicapped." *Id.* at 1622.

29. *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, 47 Fed. Reg. 26,027 (1982), quoted in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 397 (D.D.C. 1983). See also Annas, *Disconnecting the Baby Jane Doe Hotline*, HASTINGS CENTER REP., June 1983, at 14; Strong, *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, LAW, MED. & HEALTH CARE, Sept. 1983, at 168, 169.

Although the notice immediately followed the President's memorandum, the government stated that its notice was to "remind" health care providers of the applicability of the statute. This is certainly inaccurate because this was the first time in the almost ten years since passage of the Act that HHS or its predecessor, HEW, took this position on the coverage of the Act. See *United States v. University Hosp.*, 729 F.2d at 152-53.

30. Annas, *supra* note 29, at 14.

31. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 395.

32. *Id.* at 398.

without adequate consideration of numerous factors.³³ Alternatively, the rule was declared invalid because the Secretary failed to follow procedural requirements and issued it without public notice or time for public comment.³⁴

Undeterred, HHS issued revised regulations less than three months later.³⁵ In substance, the revised rules reinstated the 24-hour hotline and, more important, required medically indicated treatment without consideration of the newborn's handicap.³⁶

In a July 5, 1983, supplementary information, HHS attempted to clarify instances in which nontreatment was appropriate:

Section 504 simply preserves the decision-making process customarily undertaken by physicians in any treatment decision: will the treatment be medically beneficial to the patient and are those benefits outweighed by any medical risk associated with the treatment? *It is only when non-medical considerations, such as subjective judgments that an unrelated handicap makes a person's life not worth living, are interjected in the decision-making process that the Section 504 concerns arise.*³⁷

As discussed below,³⁸ HHS's invocation of an objective medical standard, eschewing quality of life as a relevant factor, is beguilingly simple, but is violated by HHS's own explanation of its position. That position, however, remains unchanged in HHS's final rule, which was issued on January 12, 1984.³⁹

33. *Id.* at 399. The court found arbitrary and capricious the Secretary's failure to consider several factors that the court apparently found relevant to a rule governing treatment decisions on behalf of seriously ill newborns. Among these factors were the disruptive effects of the "hotline" on treatment for the newborn; the impact on the newborn if the parents were to remove the infant from the hospital, which was originally contemplated as an alternative to the hospital's assisting the parents to discriminate against the handicapped newborn; the impact on the hospital as a whole if financial assistance were terminated; possible malpractice and ethical problems created for physicians; the effect on the allocation of scarce medical resources between seriously ill newborns and other newborns and patients; and the effect of substituting HHS in place of parents in the long-term interests of the newborn. *Id.* at 399-400.

34. *Id.* at 400-01.

35. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14. See also Annas, *Baby Jane Doe Redux: Doctors as Child Abusers*, HASTINGS CENTER REP., Oct. 1983, at 26.

36. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14.

37. *Id.* at 30,847 (emphasis added).

38. See *infra* text accompanying notes 240-90. See also *infra* note 98.

39. *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to*

Apart from the analytic inconsistency of the government's position, Surgeon General C. Everett Koop and HHS have made it reasonably clear that the government contemplates treatment for infants suffering from mongolism, but not for those afflicted with anencephaly or lack of an intestine.⁴⁰ Less clear was HHS's original position on spina bifida and hydrocephaly. While the July 5, 1983, supplementary information contains repeated references to mongolism, it refers only once to spina bifida. Further, it cites with approval *Application of Cicero*,⁴¹ a New York case in which a trial court ordered treatment for a child born with spina bifida.⁴² But the child in that case had a good prognosis: the lesion was low on her spine and it was likely that she would be ambulatory and of normal intelligence.⁴³ It is unclear from the Secretary's reference to *Cicero* whether consideration of more serious physical and mental impairment might ever be relevant to a treatment decision.⁴⁴ Whatever the Secretary's intention on July 5, 1983, subsequent action by the government indicates that the government reads *Cicero* broadly; that is, consideration of even very serious impairment is a violation of section 504.

Baby Jane Doe was born in Port Jefferson, New York, on October 11, 1983. She was diagnosed as suffering from multiple congenital defects: myelomeningocele,⁴⁵ hydrocephaly,⁴⁶ microcephaly,⁴⁷ bilateral

Health Care for Handicapped Infants, *supra* note 28, at 1622. See generally Singer & Kuhse, *The Future of Baby Jane Doe*, N.Y. REV. OF BOOKS, Mar. 1, 1984, at 17 (discussion of the final rule). The final rule does modify the notice requirement and its investigatory procedures if the hospital has an Infant Care Review Committee. *United States v. University Hosp.*, 729 F.2d at 154.

40. The Surgeon General articulated his views at the hearing before Judge Gesell in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). See Singer & Kuhse, *supra* note 39, at 18-19. He took a similar position on CBS's *Face the Nation* on Nov. 6, 1983. HHS's view is most clearly expressed in its July 5, 1983, proposed rules. See *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14.

41. 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979).

42. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,848.

43. 101 Misc. 2d at 701, 421 N.Y.S.2d at 967. See also J. ROBERTSON, *supra* note 23, at 88.

44. See *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,848. But see *id.* at 30,852:

The Secretary deems the following to be examples . . . of . . . a violation of section 504.

. . . .

(3) Denial of treatment for medically correctable physical anomalies in children born with Spina Bifida, when such denial is based on anticipated mental impairment, paralysis, or incontinence of such child, rather than on reasonable medical judgments that treatment would be futile or too unlikely of success given complications in the particular case.

45. Myelomeningocele involves a saccular enlargement that includes the spinal cord or nerves

upper extremity spasticity, a prolapsed rectum, a malformed brain stem, and additional problems indicating severe malformation of her nervous system.⁴⁸ Her parents initially consented to a transfer of the infant for corrective surgery to the Stony Brook University Hospital, a state institution and recipient of federal funds.⁴⁹ After consultation with doctors, nurses, religious counselors, and a social worker,⁵⁰ the parents chose to adopt a course of "conservative" treatment as an alternative to surgery.⁵¹ Unlike the *Infant Doe* case,⁵² medical care and

in the sac formation and protrudes through the vertebral column.

For a description of myelomeningocele, see Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 214 n.7 (1975) (citing J. WARKANY, CONGENITAL MALFORMATIONS 272 (1971)).

46. "Hydrocephaly is characterized by an increase of free fluid in the cranial cavity which results in a marked enlargement of the head. . . ." *Id.* at 213 n.4 (citing J. WARKANY, *supra* note 45, at 217). For a detailed list of the symptoms, see *id.* (citing J. WARKANY, *supra* note 45, at 226-27). But see Brief for the State of New York at 4, *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984):

This condition, in combination with the microcephalic condition, indicates an "extremely high risk for profound and severe retardation . . . to the point that (Baby Jane Doe) would not be expected to even obtain interaction with her environment or with other people". . . . This condition was apparently present substantially prior to her birth, most likely occurring during the fourth or fifth week of gestation. . . . [citations omitted].

47. "Microcephaly is characterized by an unusually small head and brain at birth. . . . The condition is a result of a failure of the brain to properly form . . . and is indicative of brain malfunction. . . . As a result, Baby Jane Doe is severely retarded. . . ." Brief for the State of New York at 4, *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984) (citations omitted).

48. *Id.* at 3-4. See also *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.

49. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.

50. Interestingly, in its final rule HHS allowed hospitals to refer care-withholding decisions to a hospital review committee made up of similar individuals. *Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to Health Care for Handicapped Infants*, *supra* note 28, at 1651-53. The President's Commission Report also favors improved communication with parents as an alternative to judicial proceedings. Commission Report, *supra* note 21, at 224-27. The University Hospital apparently had in place the kind of review procedure favored in the final rules and the Commission Report. Interestingly, also, there is less than universal enthusiasm for review committees. In its *Summary Analysis*, the Americans United for Life Legal Defense Fund observed:

There is no question but that the prominent role assigned by the final rule, at the option of each hospital, to Infant Care Review Committees is a major defeat. As we have said in the past, studies demonstrate that the bulk of those in the medical profession continue to harbor outdated views about the potential of people with disabilities. Giving internal hospital review committees the basic role in enforcing section 504's equal treatment requirements is like giving the job of enforcing the Voting Rights Act in the early 1960s to local Boards of Elections in the South.

AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, *supra* note 26, at 15.

51. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 588, 467 N.Y.S.2d at 686.

52. See J. ROBERTSON, *supra* note 23, at 88.

nourishment were provided to Baby Jane.⁵³ Unlike Infant Doe and Phillip Becker,⁵⁴ a California child whose parents resisted treatment, Baby Jane was not suffering from mongolism, but was far more debilitated than those children.

Based on anonymous information, HHS filed a complaint with the Child Protection Services, the appropriate state agency with jurisdiction over child abuse cases, alleging that the course of treatment constituted neglect. After its investigation, the state agency found the complaint groundless.⁵⁵

Thereafter, A. Lawrence Washburn, Jr., a Vermont resident with "no disclosed connection with Baby Jane Doe or her family," filed an action in the New York Supreme Court to compel surgery.⁵⁶ Washburn was replaced by William E. Weber, a court-appointed guardian ad litem. In turn, Weber petitioned the court for authorization to consent to surgery on behalf of the infant.⁵⁷ The trial court found that she was "in need of immediate surgical procedures to preserve her life."⁵⁸ Four days later, on October 20, 1983, the appellate division entered a stay of the trial court's order. On the following day, the court unanimously reversed the trial court's order on narrow grounds:

It is manifest . . . that this is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. . . . These concededly concerned and loving parents have made an informed, intelligent, and reasonable determination based upon and supported by medical authority. On this record, and in light of all the surrounding circumstances, we find the parents' determination to be in the best interest of the infant.⁵⁹

53. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 589, 467 N.Y.S.2d at 687.

54. *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert denied*, 445 U.S. 949 (1980). Interestingly, a trial court subsequently took guardianship for Phillip from his parents, creating the opportunity for the couple who had been caring for Phillip to consent to surgery. See *Guardianship of Phillip Becker*, Superior Court, Santa Clara County, Cal. No. 10198 (Aug. 1981), discussed in Annas, *A Wonderful Case and an Irrational Tragedy: The Phillip Becker Case Continues*, HASTINGS CENTER REP., Feb. 1982, at 25.

55. *United States v. University Hosp.*, 729 F.2d at 147.

56. *Id.* at 146. See also *Weber v. Stony Brook Hosp.*, 60 N.Y.2d at 209, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64 ("Rather than pursuing the procedures prescribed in the Family Court Act, he applied directly to a Justice of the [New York] Supreme Court.").

57. *United States v. University Hosp.*, 575 F. Supp. at 610.

58. *Id.*

59. *Weber v. Stony Brook Hosp.*, 95 A.D.2d at 589, 467 N.Y.S.2d at 687.

The court of appeals affirmed,⁶⁰ but rejected the approach of the appellate division. Instead, it alluded to the "unusual, and sometimes offensive, activities" by those attempting to substitute their judgment for that of the parents.⁶¹ The court concluded that the legislature had provided for a course of intervention into family matters that was limited by due process requirements. Specifically, New York provides that neglect proceedings are to be commenced only by a child protection agency or "a person on the court's direction,"⁶² a provision intended to protect the family from proceedings "casually initiated."⁶³ The court found that the supreme court erred when it allowed a stranger to commence proceedings, and thereby, to "catapult [himself] into the very heart of a family circle, there to challenge the most private and most precious responsibility vested in the parents for the care and nurture of their children—and at the very least to force the parents to incur the not inconsiderable expenses of extended litigation."⁶⁴

The court's decision is only partially procedural. In effect, the court found that the original plaintiff lacked standing because he did not come within the relevant statute providing for specific parties who might initiate proceedings.⁶⁵ But the opinion indicates that due process privacy interests may be violated by allowing strangers to call into court the family of a seriously ill newborn.⁶⁶

Despite dissimilarities between Baby Jane Doe's and Infant Doe's handicaps and treatment, the government⁶⁷ and at least one right-to-

60. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *aff'd* 95 A.D.2d 587, 467 N.Y.S.2d 685, *cert. denied*, 104 S. Ct. 560 (1983).

61. *Id.* at 209, 456 N.E.2d at 1187, 469 N.Y.S. at 64.

62. *Id.* (citing the Family Court Act, N.Y. DOM. REL. LAW § 1032 (McKinney 1983)).

63. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d at 209, 456 N.E.2d at 1187, N.Y.S.2d at 64.

64. *Id.* at 210, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.

65. *Id.*

66. *Id.* at 209, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64. ("[Section 10 of the Family Court Act] is designed to provide a due process of law for determining when the state, through its family court, may intervene against the wishes of a parent on behalf of a child so that his needs are properly met.") The tension between the parental right to privacy and the state *parens patriae* role of protecting children has been noted elsewhere. *See, e.g.*, Commission Report, *supra* note 21, at 213-16. Some advocates of aggressive treatment for seriously ill newborns give virtually no weight to the parental right. *See, e.g.*, Robertson, *supra* note 45, at 216.

67. *United States v. University Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984). That Baby Jane Doe's case was viewed by the government as a test case for its section 504 strategy was revealed by Surgeon General Koop: "According to a report in the London *Sunday Times*, Dr. Koop has said that he is not so much interested in Baby Jane Doe as in 'the idea of her' as a way of 'fighting for the principle of this country that every life is individually and uniquely sacred.'" Singer & Kuhse, *supra* note 39, at 21.

life advocate⁶⁸ chose to make *Baby Jane Doe* a test case for the section 504 strategy suggested in HHS's July 5, 1983, Interim Final Rule and supplementary information. On the day after the New York Supreme Court Appellate Division decision, HHS requested Baby Jane Doe's medical records from University Hospital.⁶⁹ After access was refused, HHS filed a complaint on November 2, 1983, naming University Hospital as a defendant in the United States District Court for the Eastern District of New York and requesting an order to compel production of Baby Jane Doe's medical records.⁷⁰ Jurisdiction was alleged under section 504.⁷¹ After various motions were filed on an expedited basis, the district court granted summary judgment for the defendants.⁷² On November 18, 1983, the government filed a notice of appeal to the Second Circuit Court of Appeals.⁷³ On February 23, 1984, the Second Circuit affirmed.⁷⁴ The government has abandoned efforts to secure the infant's medical records because she was able to leave the hospital and to go home with her parents.⁷⁵

The *University Hospital* litigation illustrates what this article has labelled the government's section 504 strategy. First, the action and HHS's original notice to health care providers evidence the govern-

68. The following account of Washburn's "interest" in the case is provided in the newsletter of Concern for Dying, CONCERN FOR DYING NEWSLETTER, Winter 1984, at 3:

Lawyer A. Lawrence Washburn, unrelated to the infant but actively involved in "right-to-life" advocacy, applied directly to a justice of the New York Supreme Court, the lower court, to intervene.

. . . .

. . . [After the decision by the New York Court of Appeals,] [t]he matter, unfortunately, was not so easily laid to rest. Washburn . . . requested that the Federal District Court in Albany appoint another legal guardian for the infant, but Judge Roger Miner ruled that there was no need for such an appointment and, in fact, fined Washburn \$500 for attempting "to harass or to cause unnecessary delay or needlessly increase the cost of litigation."

For the views of Americans United for Life Legal Defense Fund, see generally, AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, *supra* note 26, at 9-16 (approving of similar aggressive tactics).

69. Brief for the State of New York at 9-10, *United States v. University Hosp.*, 729 F.2d 144. See also 729 F.2d at 147-48.

70. Brief for the State of New York at 10, *United States v. University Hosp.*, 729 F.2d 144. See also 729 F.2d at 148.

71. 29 U.S.C. § 794 (Supp. 1983).

72. *United States v. University Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

73. Brief for the State of New York at 3, *United States v. University Hosp.*, 729 F.2d 144.

74. *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984), *aff'g* 575 F. Supp. 607 (E.D.N.Y. 1983).

75. See *U.S. Drops 'Baby Jane Doe' Effort*, *supra* note 18.

ment's definition of discrimination; i.e., it is unlawful for a federally assisted institution to withhold nutrition or treatment to correct a life-threatening condition because an infant is handicapped if sustenance or treatment are not contraindicated by the handicap.⁷⁶

The government asserts that section 504 establishes a substantive standard of decision in treatment cases. In effect, because the consideration of the handicap is forbidden, whenever treatment would be provided for an otherwise healthy child, it must also be provided for the handicapped infant.⁷⁷

Second, the government's stance is that federal courts are appropriate fora in which to litigate treatment cases. In *University Hospital*, the government sought discovery of medical records only.⁷⁸ But HHS's July 5, 1983, supplementary information plotted the government's strategic alternatives and makes clear that termination of federal assistance was not the only sanction to be sought under section 504 and that the cooperation of state and local government was to be enlisted.⁷⁹ The

76. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,851.

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.

Id.

77. The cases that require treatment under the government's theory differ depending on the spokesperson. President Reagan argues that all lives are of equal value and, therefore, require treatment without regard to handicap. Reagan, *supra* note 3, at 11-12. Surgeon General Koop took a more moderate approach while arguing before Judge Gesell in *American Academy of Pediatrics*. Koop stated that some handicaps, even where biological life can be sustained for a substantial period of time, are relevant to a decision to deny treatment. Singer & Kuhse, *supra* note 39, at 18-19. In *University Hospital*, the infant was not suffering from one of the anomalies that Koop thought permitted nontreatment; despite that, the government conceded that it had not found any discrimination against Baby Jane Doe in the chosen course of treatment. *United States v. University Hosp.*, 729 F.2d at 148. See also *infra* note 98.

78. Brief for the United States at 12-15, *United States v. University Hosp.*, 729 F.2d 144.

79.

The Secretary intends to rely heavily on the voluntary cooperation of State and local agencies, which are closest to the scene of violations, and which have traditionally played the key role in the investigation of complaints of child abuse and neglect. This will not exclude, of course, a vigorous federal role in enforcing the federal civil rights that are at issue.

Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9630 (1983) (to be codified at 45 C.F.R. pt. 84) (interim final rule Mar. 7, 1983). For a critique of HHS's threat that federal assistance might be terminated if HHS found a violation of section 504, see Commission Report, *supra* note 21, at 224-27.

Secretary apparently expects state agencies to intervene to require treatment in most cases; but HHS is fully prepared, in effect, to make a federal case out of treatment decisions if state agency action is considered insufficient.⁸⁰

The first issue raised by these cases is whether Congress intended to bring into federal court cases like Baby Jane Doe's when it enacted section 504. The hospital argued in the federal case that it was not a recipient of federal financial assistance within the meaning of the Act. The district court gave that argument short shrift⁸¹ but agreed with the hospital that the papers before it clearly demonstrated that the hospital was not discriminating against a handicapped person. The court observed that the hospital was willing to treat the infant if the parents would consent to surgery but that it lacked the legal right to do so absent consent. Therefore, the hospital failed to perform the surgery, not because of the infant's handicap, but because her parents refused to consent.⁸² The court found further that the conservative course of treatment was "a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child."⁸³ In effect, the district court assumed that Congress intended to create jurisdiction under section 504 over cases involving medical treatment, but held that the hospital's failure to act could not be construed as a breach of duty. Section 504, on that view, failed to create a duty to act affirmatively.

This argument is only superficially appealing. As the government argued to the Second Circuit, the hospital is in a position to sue in state court to compel the parents to consent to treatment that is medically

80.

For those cases where district federal action appears helpful, the Secretary will have at his disposal the usual means of federal civil rights enforcement. The interim final rule makes it possible for the Secretary . . . to make immediate referrals to the Department of Justice for such legal action as may be necessary to save the life of a handicapped child who is subjected to discrimination by a recipient.

Nondiscrimination on the Basis of Handicap, *supra* note 79, at 9631, *reprinted in* Commission Report, *supra* note 21, at 469.

81. *United States v. University Hosp.*, 575 F. Supp. at 612-13. The Second Circuit found that question to be a far more difficult one than did the district court. *See United States v. University Hosp.*, 729 F.2d at 151. The Second Circuit also noted the fact that the government had not presented evidence that Medicare or Medicaid funds were provided specifically for the infant care program in the hospital, as opposed to the hospital generally. *Id.* It suggested that the government's position appeared inconsistent with the position it had recently taken before the Supreme Court in *Grove City College v. Bell*, 104 S. Ct. 1211 (1984). *See* 729 F.2d at 151.

82. *United States v. University Hosp.*, 575 F. Supp. at 614.

83. *Id.* at 615.

appropriate. The government contended that the failure of the hospital to do so because of the infant's handicap was violative of section 504.⁸⁴ The hospital relied on the Supreme Court as authority for its assertion that section 504 does not require affirmative action to alter existing programs significantly.⁸⁵ That authority would seem inapposite where, as in *University Hospital*, there is little question that the hospital would have sought judicial intervention in other instances.⁸⁶ The government refuted the contention that acquiescence in a parental decision can never be discriminatory by hypothesizing that a court would be quick to find discrimination if the hospital sought judicial intervention to compel parental consent in cases involving white infants but not black infants. The government argued by analogy that the hospital would be guilty of discrimination if it sought judicial intervention only for children with the capacity for normal development, not for those likely to be retarded or otherwise handicapped.⁸⁷

While the district court's reasoning is suspect, there are more fundamental reasons for rejecting the government's attempted use of section 504 to compel medical treatment. The Second Circuit gave a far more detailed analysis of congressional intent in enacting section 504 than did the district court. For the Second Circuit, the issue was: "Did Congress intend section 504 to reach the conduct HHS seeks to investigate,"⁸⁸ that is, treatment decisions for seriously ill newborns. The district court did not hold that section 504 was inapplicable to such decisions, but instead held that the hospital's conduct could not be

84. Brief for the United States at 17-19, 27-30, *United States v. University Hosp.*, 729 F.2d 144.

85. Brief for the State of New York at 34, *United States v. University Hosp.*, 729 F.2d 144 (citing *Southeastern Community College v. Davis*, 442 U.S. 397 (1979) (woman rightly denied admission to a nursing program because her serious hearing deficiency meant she was not "otherwise qualified" for the program; section 504 does not compel a recipient of federal financial assistance to undertake affirmative action)).

86. The Second Circuit also relied on the *Davis* holding that section 504 does not compel recipients of federal financial assistance to undertake affirmative action:

[T]he Supreme Court emphasized that "[t]he language and structure of the Rehabilitation Act of 1973 reflect the recognition by Congress of the distinction between the even-handed treatment of qualified handicapped persons and affirmative efforts to overcome the disabilities caused by handicaps." . . . The Court concluded that "neither the language, purpose, nor history of § 504 reveals an intent to impose an affirmative-action obligation on all recipients of federal funds". . . .

United States v. University Hosp., 729 F.2d at 160 (citations omitted).

But the affirmative action required in *Davis* is distinguishable from that involved in the instant case, at least as a matter of degree.

87. Brief for the United States at 27-30, *United States v. University Hosp.*, 729 F.2d 144.

88. *United States v. University Hosp.*, 729 F.2d at 150.

construed as section 504 discrimination.⁸⁹

The Second Circuit amassed considerable support for its view that section 504 was not intended to encompass treatment decisions for seriously ill newborns. First, it cited the curious reversals within the federal agency's interpretation of the statutory provision.⁹⁰ For example, in 1976, HHS's predecessor agency, HEW, announced that section 504 did not empower it to promulgate rules regulating the rights of institutionalized patients.⁹¹ Further, HEW's original regulations were limited to making services available, e.g., by modifying facilities to give physical access to handicapped patients.⁹² The appellate court did not feel that subsequent clarification of the federal regulations supported the government's position.⁹³

HHS first contended that section 504 contemplated treatment of seriously ill newborns after President Reagan's 1982 memorandum to HHS in response to reports about the *Infant Doe* case. But even after its May 18, 1982, notice to health care providers,⁹⁴ HHS shifted its interpretation of section 504. Initially, after recognizing that a hospital may not have full control over a parental refusal to consent, HHS warned that section 504 may be violated if the health care provider counseled parents to make a discriminatory decision or allowed an infant being discriminatorily denied treatment to remain in the hospital.⁹⁵ In its March, 1983, interim final rule, HHS contended that section 504 required recipients of federal financial assistance to display a poster in nurseries and maternal wards warning that failure to feed and care for handicapped infants violates federal law; that the regulation authorized a 24-hour handicapped hotline; and that it permitted vigorous federal investigation including access to medical records at times

89. *United States v. University Hosp.*, 575 F. Supp. at 614-15.

90. 729 F.2d at 152-53. By contrast, a court should be guided by the administering agency's long-standing, consistent interpretation of a statute. *See, e.g., Frank Diehl Farms v. Secretary of Labor*, 696 F.2d 1325, 1330 (11th Cir. 1983) ("We are more reluctant to defer to an agency's more recent interpretation as authoritative when it conflicts with earlier pronouncements of the agency.").

91. *United States v. University Hosp.*, 729 F.2d at 152 (citing 41 Fed. Reg. 29,548, 29,559 (1976)).

92. *Nondiscrimination on the Basis of Handicap*, 41 Fed. Reg. 19,548, 19,567 (1976) (to be codified at 45 C.F.R. § 84.52) (proposed rules July 18, 1976).

93. *United States v. University Hosp.*, 729 F.2d at 154.

94. *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, 47 Fed. Reg. 26,027 (1982).

95. *United States v. University Hosp.*, 729 F.2d at 152 (citing *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, *supra* note 94, at 26,027).

beyond normal business hours.⁹⁶ Following the successful challenge to the regulation by the American Academy of Pediatrics,⁹⁷ HHS made minor revisions in its proposed rule, including a list of specific instances in which the agency believed that nontreatment would constitute discrimination.⁹⁸ Finally, in its most recent rule, HHS again modified its interpretation of section 504 and its notice requirement.⁹⁹ Given the several agency interpretations of section 504, the court concluded, quite moderately, that there was no long-standing and consistent interpretation by an administering agency to which it might otherwise have looked for guidance.¹⁰⁰

96. *United States v. University Hosp.*, 729 F.2d at 153 (citing amendments to 45 C.F.R. § 84.61, contained in *Nondiscrimination on the Basis of Handicap*, *supra* note 79, at 9630-31).

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

98. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846-47. At this time, HHS specifically mentioned only anencephaly or intracranial bleeding as instances where denial of treatment was permissible. By contrast, during testimony before Judge Gesell, the American Academy of Pediatrics identified three instances in which nontreatment was appropriate: the anencephalic infant; the infant with intracranial bleeding; and the infant born without an intestine. *See Singer & Kuhse*, *supra* note 39, at 18-19. During his testimony before the House of Representatives, Surgeon General Koop mentioned two instances where nontreatment was appropriate:

Medicine may *never* have all the solutions to all the problems that occur at birth. I personally foresee no medical solution to a cephalodymus or an anencephalic child. The first is a one-headed twin; the second, the child with virtually no functioning brain at all. In these cases the prognosis is an early and merciful death by natural causes. . . . For such infants, neither medicine nor law can be of any help. And neither medicine nor law should prolong these infants' process of dying.

Commission Report, *supra* note 21, at 219 n.81.

During oral argument before the district court the government conceded that, despite considerable discovery of Baby Jane Doe's medical records (the records had been produced during the state court proceedings), it had found no discrimination based on her handicap. *United States v. University Hosp.*, 729 F.2d at 148. There are two possible reasons for the government's findings: (1) the limited "conservative" treatment being provided was adequate treatment in any spina bifida case; or (2) aggressive treatment might be unnecessary in some cases, like Baby Jane Doe's, where other anomalies gave the newborns a very poor prognosis. The first position is inconsistent with the government's initial efforts to have the Child Protection Services declare Baby Jane Doe a neglected child. *United States v. University Hosp.*, 729 F.2d at 147. The second position would mean that, despite the equal value of all lives, not all children suffering from spina bifida need to be treated equally. *See infra* text accompanying notes 241-60.

99.

For example, HHS adopted the recommendation of several commentators that the federal government encourage, but not require, hospitals to establish Infant Care Review Committees "to assist the health care provider in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases."

United States v. University Hosp., 729 F.2d at 154 (quoting 45 C.F.R. § 84.55(a), 49 Fed. Reg. at 1651 (1984)).

100. 729 F.2d at 154. The Americans United for Life Legal Defense Fund found objectiona-

The Second Circuit also found the express statutory language inconclusive.¹⁰¹ Despite some ambiguity, it held that Baby Jane Doe was a "handicapped individual" within the statutory definition.¹⁰² But the court had more difficulty with the intertwined issues of whether she was an "otherwise qualified" handicapped individual and whether she was "subjected to discrimination."¹⁰³ As observed by the court, it is not entirely clear what "otherwise qualified" means in the context of a medical treatment decision. However, the court notes that the handicap gives rise to the need for treatment, and, as the defendants argued, "it would be pointless to inquire whether a patient who was affected by a medical treatment decision was, 'solely by reason of his handicap, . . . subjected to discrimination.'" ¹⁰⁴ The court's reasoning thus was that the statutory language does not seem to encompass a case like *Baby Jane Doe*. In effect, the statute sets up three criteria: (1) existence of a

ble the final rule because HHS abandoned its earlier position that section 504 creates "a universal duty to provide nutrition." AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, *supra* note 26, at 8. The author agrees that HHS has taken various positions on the content of section 504, each with no reference to statutory language or history. The mere fact that HHS felt free to negotiate on the "content" of section 504 suggests how far HHS was from the intent of Congress and that it was drafting on a clean slate a medical code for the treatment of newborns. Further, the standard created by HHS that all treatment must be provided unless "medically contraindicated" has been described by one commentator as "unintelligible." *Fost, Putting Hospitals on Notice*, HASTINGS CENTER REP., Aug. 1982, at 5, 6.

101. *United States v. University Hosp.*, 729 F.2d at 156-57.

102. *Id.* at 155-56. 29 U.S.C. § 706(7)(B) (Supp. 1983), provides: "[T]he term 'handicapped individual' means . . . 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. . . ."

103. *United States v. University Hosp.*, 729 F.2d at 156. Although the term "otherwise qualified" defies precise definition, it can be explained by illustration. For example, a handicapped candidate for a graduate program with an undergraduate record equivalent to the records of students who were admitted to the program would be "otherwise qualified" and could not be denied admission if admission decisions were based on undergraduate record. *See, e.g., Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Doe v. New York University*, 666 F.2d 761 (2d Cir. 1981); *Pushkin v. Regents of University of Colorado*, 658 F.2d 1372 (10th Cir. 1981). *See also Dopico v. Goldschmidt*, 687 F.2d 644 (2d Cir. 1982); *Simon v. St. Louis County*, 497 F. Supp. 141 (E.D. Mo. 1980), *aff'd in part, rev'd in part*, 656 F.2d 316 (8th Cir. 1981), *cert. denied*, 455 U.S. 976 (1982).

This does not mean, however, that a handicap is irrelevant in all cases:

[A]n institution is not required to disregard the disabilities of a handicapped applicant, provided the handicap is relevant to reasonable qualifications for acceptance, or to make substantial modifications in its reasonable standards or program to accommodate handicapped individuals but may take an applicant's handicap into consideration, along with all other relevant factors, in determining whether she is qualified for admission.

United States v. University Hosp., 729 F.2d at 156 (quoting *Doe v. New York University*, 666 F.2d at 775).

104. *United States v. University Hosp.*, 729 F.2d at 156.

handicap; (2) an otherwise qualified patient; and (3) discrimination based on the handicap. But a seriously ill newborn is only otherwise qualified for treatment because of the existence of the handicap. For there to be "discrimination," there must be at least two classes of patients. Here there was only one, those suffering from the handicap; that is, the only patients qualified for closure of the spine are those suffering from spina bifida. The government argued to the Second Circuit that in effect there were two classes of patients: those suffering from spina bifida with a reasonable prognosis for intellectual development and those like Baby Jane Doe who suffered additional anomalies that made severe retardation probable.¹⁰⁵

The Second Circuit rejected the government's position for two reasons. First, the court stated that the plain meaning of "otherwise qualified" was "geared toward relatively static programs or activities such as education . . . employment . . . and transportation systems," not "the comparatively fluid context of medical treatment decisions."¹⁰⁶ Second, the court viewed the government's interpretation of "subject to discrimination" as an oversimplification that would require lengthy litigation and conflicting expert opinions before a determination of discrimination could be made in individual cases.¹⁰⁷

Finally, the court addressed the statutory history, which proved overwhelmingly that Congress "never contemplated that section 504 would apply to treatment decisions of this nature."¹⁰⁸ As pointed out by the state, section 504 is codified in Title 29 of the United States Code, generally governing labor law, and the purpose of the Rehabilitation Act was "to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living."¹⁰⁹ Thus, the Act specifically contemplated a goal of equal

105. *Id.*

106. *Id.*

107.

[Such determinations] would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment," however that phrase might be defined. Before ruling that Congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.

Id. at 157.

108. *Id.*

109. Brief for the State of New York at 30, *United States v. University Hosp.*, 729 F.2d 144 (quoting 29 U.S.C. § 701).

employment opportunities,¹¹⁰ rather than standards of medical treatment.

As the court in *American Academy of Pediatrics v. Heckler* concluded, "[a]s 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."¹¹¹ By contrast, during consideration of 1974 amendments to the Act, the Senate Committee addressed the Act's coverage exclusively in terms of access or admission to federally assisted programs.¹¹² Moreover, the Secretary of Health, Education and Welfare previously had concluded that the agency was not empowered under section 504 to promulgate rules on the rights of institutionalized patients to receive or to refuse medical treatment.¹¹³

The Second Circuit noted that the legislative history of section 504 showed that medical issues were considered only in connection with proposed programs to benefit particular groups of handicapped persons and also noted that the Congress eventually was forced to drop those provisions because they intruded into the medical realm.¹¹⁴ The court further recognized that the legislative record included examples of individuals who may have been denied benefits of federally assisted services because of mental or physical handicaps: the child denied admission to

110. All the provisions of the Act relate to education, training, vocational rehabilitation and employability. There is no evidence that the intention of Congress was for section 504 to be used as a basis for federal intervention in medical decisionmaking concerning any individual, much less the medical treatment decisions of the parents of seriously ill infants based upon consultation with their doctors.

Brief for the State of New York at 30-31, *United States v. University Hosp.*, 729 F.2d 144.

111. 561 F. Supp. at 401.

112. See S. REP. NO. 1297, 93d Cong., 2d Sess. (1974), reprinted in 1974 U.S. CODE CONG. & AD. NEWS 6373, 6388-89. See also *infra* text accompanying note 115.

113. *Programs and Activities Receiving or Benefiting from Federal Financial Assistance, Nondiscrimination on Basis of Handicap*, 41 Fed. Reg. 29,548 (1976). See also *United States v. University Hosp.*, 729 F.2d at 152.

114.

Interestingly, the only consideration of medical issues that occurred in connection with the 1973 legislation did not involve the nondiscrimination provision that would eventually become section 504. In the first two versions of the legislation, congress had created several categorical programs to benefit target populations including those with end-stage renal disease and those with severe spinal cord injuries. In vetoing each of the first two versions of the Rehabilitation Act, President Nixon took issue with what he perceived to be congress's attempts to extend what was essentially a vocational program into the medical realm. . . . Ultimately, congress was forced to back down.

United States v. University Hosp., 729 F.2d at 157.

school; the aged person denied admission to a nursing home; individuals denied access to various federal programs because their handicap made any employment unfeasible; and individuals who have completed vocational training and are nonetheless subject to discrimination. By contrast, the record is devoid of discussion of treatment of seriously ill newborns.¹¹⁵

Furthermore, as observed in the challenge by the American Academy of Pediatrics, no medical association or religious group testified during the hearings, despite the implications that such a rule would have for those groups.¹¹⁶ The Second Circuit also cited post-enactment history that "indicates both that congress was primarily concerned with affording the handicapped access to federally-funded programs and activities, and that congress never envisioned that HEW (or HHS) would attempt to apply section 504 to treatment decisions."¹¹⁷

The failure of Congress to mention a specific application of a statute does not necessarily make the statute inapplicable.¹¹⁸ However, even if the government could have argued that section 504's language applied to medical treatment, other factors weighed against its application to cases like *Baby Jane Doe*. First, Medicare and Medicaid payments were the alleged federal financial assistance that triggered section 504,¹¹⁹ but Medicare provisions state that "[n]othing in this subchapter shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided."¹²⁰ That position has been reiterated elsewhere by Congress.¹²¹ Again, the

115. *Id.* at 158.

116. 561 F. Supp. at 401.

117. *United States v. University Hosp.*, 729 F.2d at 159.

[T]he House Subcommittee on Select Education conducted oversight hearings on the section 504 regulations in September 1977. During these hearings, the subcommittee heard testimony covering a wide range of topics from witnesses representing the federal government, state governments, education agencies, and organizations serving handicapped people. Throughout the hearings, the issue of program accessibility was a recurrent theme.

Id.

118. *Jefferson County Pharmaceutical Ass'n v. Abbott Laboratories*, 460 U.S. 150, 159 n.18 (1983); *United States v. Jones*, 607 F.2d 269 (9th Cir. 1979), *cert. denied*, 444 U.S. 1085 (1980).

119. *United States v. University Hosp.*, 575 F. Supp. at 611; Brief for the United States at 9, *United States v. University Hosp.*, 729 F.2d 144.

120. 42 U.S.C. § 1395 (1976).

121. See S. Rep. No. 1230, 92d Cong., 2d Sess. 256-58 (1972). The government did not specifically address these provisions, but in distinguishing *Youngberg v. Romeo*, 457 U.S. 307, 322 (1982) (in assessing whether person involuntarily committed has received minimally adequate training, court must show deference to the judgment exercised by a qualified professional), the

history surrounding section 504 offers no support that Congress intended to overrule those provisions.

Second, the Second Circuit rejected the government's interpretation of section 504 in part on the reasoning that a federal court should not presume on a silent record that Congress intended to intrude upon a matter traditionally occupied by the states.¹²² The government's reading of section 504 would greatly expand federal court jurisdiction, and it is highly unlikely that Congress meant to do so in light of its silence on that issue.¹²³ Although the government's complaint requested only access to medical records and not an order compelling treatment,¹²⁴ HHS's July 5, 1983, supplementary information made perfectly clear that the government would seek full federal court adjudication of treatment cases, thereby bypassing state courts and remedies in cases that HHS deemed appropriate. Thus, the government implicitly was asking

government argued as follows: "[A] health care decision based on a bona fide, professionally, [*sic*] acceptable medical judgment would not be based on handicap, which is all that Section 504 forbids." Brief for the United States at 18, *United States v. University Hosp.*, 729 F.2d 144. Thus, according to the government, the government's intrusion in a case would not amount to "control over the practice of medicine" because a doctor when discriminating is not practicing medicine. That interpretation, of course, would ignore the statutory phrase "or the manner." Again, the government cites no authority for the questionable distinction. But the hardest problem for the government is that its position is circular. HHS eschews decisions made on subjective quality-of-life judgments. Presumably, one is not practicing medicine if she does so. But to make sense out of the proposed rules necessarily brings one back to those considerations:

Perhaps—and the guesswork required is what makes this aspect of the regulation undesirable—the second clause [allowing denial of treatment if it would be medically contraindicated] was intended to refer to conditions that are so hopeless, or a life so devoid of quality or meaningful existence, that it would be medically contraindicated to expose the child to an uncomfortable or intrusive treatment, even though it would prolong life, or perhaps *because* it would prolong life. If this is what is meant, a second objection arises: namely, this is not a *medical* reason for withholding treatment but an ethical one.

If by "medical contraindication" the regulation means a condition which, in the opinion of a doctor, is not sufficiently correctable to warrant treatment, then we are back at square one: a doctor may permissibly withhold treatment simply by expressing an opinion on the value of the child's life.

Forst, *supra* note 100, at 6-7. Ordinarily, one refers to actual practice within the medical community in establishing norms for the practitioner. See, e.g., *Shilkret v. Annapolis Emergency Hosp. Ass'n*, 276 Md. 187, 349 A.2d 245 (1975); *Brune v. Belinkoff*, 354 Mass. 102, 235 N.E.2d 793 (1968); PROSSER AND KEETON ON THE LAW OF TORTS, § 32 (W.P. Keeton 5th ed. 1984). But that cannot be the meaning of the government's "medically contraindicated" standard; as recognized by Dr. Koop, a majority of doctors admit that they would honor the request of parents of a seriously ill newborn to withhold treatment. Singer & Kuhse, *supra* note 39, at 18-19.

122. *United States v. University Hosp.*, 729 F.2d at 160.

123. See, e.g., *United States v. Bass*, 404 U.S. 336, 349 (1971).

124. *United States v. University Hosp.*, 575 F. Supp. at 609; Brief for the United States at 7, 12, *United States v. University Hosp.*, 729 F.2d 144.

the federal district court for a radical expansion of federal court jurisdiction.¹²⁵

Traditionally, as HHS recognized, cases involving treatment of minors and incompetents have been within the jurisdiction of state courts.¹²⁶ Moreover, courts universally have recognized a right of parents to make medical decisions on behalf of their children.¹²⁷ It is now beyond debate that this parental right is part of a federally guaranteed right to privacy, and, therefore, a state's effort to supersede parental discretion may create federal question jurisdiction.¹²⁸ But almost all of the cases involving state power to override parental refusal to have a child treated have been brought in state court.¹²⁹ Indeed, the Supreme Court has held that it lacked jurisdiction for want of a substantial federal question in a case in which parents objected to compulsory vaccination of their child.¹³⁰ Recourse to state courts in such cases is un-

125. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,849: "For those cases where direct federal action appears helpful, the Department will have at its disposal the usual means of federal civil rights enforcement." *See also* 29 U.S.C. § 794a (Supp. 1983) (setting forth available remedies).

126. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846. *See supra* note 79.

127. *See, e.g.*, *Parham v. J.R.*, 442 U.S. 584 (1979); *Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941); *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980); *In re Hoffbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

128. *See, e.g.*, *H.L. v. Matheson*, 450 U.S. 398 (1981) (rights of parents to know of their immature minor's decision to have an abortion); *Bellotti v. Baird*, 443 U.S. 622 (1979) (same); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (right of parents to determine education of their children); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (same).

129. *See, e.g.*, *Wright v. DeWitt School Dist.*, 238 Ark. 906, 385 S.W.2d 644 (1965); *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980); *In re Benjamin (Minor)*, Sup. Ct. Los Angeles County, Cal., No. J914419, Feb. 15, 1979; *In re Ivey*, 319 So. 2d 53 (Fla. Dist. Ct. App. 1975); *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 Ga. 86, 274 S.E.2d 457 (1981); *People ex rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769 (1952), *cert. denied*, 344 U.S. 824 (1952); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *Maine Medical Center v. Houle*, Sup. Ct. Civil Action No. 74-145 (Cumberland Co., Me. 1974); *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1979); *Brooklyn Hosp. v. Torres*, 45 Misc. 2d 914, 258 N.Y.S.2d 612 (N.Y. Sup. Ct. 1965); *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979); *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970); *In re Clark*, 185 N.E.2d 128 (Ohio 1962); *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942). Parents and doctors have also been prosecuted in state court when the child has been injured or died as a result of the failure to treat. *See, e.g.*, *State v. Clark*, 5 Conn. Cir. Ct. 699, 261 A.2d 294 (1969); *Bradley v. State*, 79 Fla. 651, 84 So. 677 (1920); *Eaglen v. State*, 249 Ind. 144, 231 N.E.2d 147 (1967); *Commonwealth v. Edelin*, 371 Mass. 497, 359 N.E.2d 4 (1976); *State v. Staples*, 126 Minn. 396, 148 N.W. 283 (1914); *Matthews v. State*, 240 Miss. 189, 126 So. 2d 245 (1961); *State v. Stehr*, 92 Neb. 755, 139 N.W. 676 (1913), *aff'd on rehearing*, 94 Neb. 151, 142 N.W. 670 (1913).

130. *Zucht v. King*, 260 U.S. 174 (1922).

doubtedly routine because of state statutes treating those cases as neglect.¹³¹ Such statutes are part of the state role as *parens patriae*, at the core of the state police power.¹³²

Further, the parental right of privacy will usually be raised defensively when the state or guardian seeks treatment for the newborn.¹³³ In that context, the federal question will not appear on the face of the complaint, and, therefore, the district court will lack jurisdiction under the well-pleaded complaint rule.¹³⁴ In addition, in the related areas of domestic relations and child custody, federal courts have abstained from deciding such cases despite the existence of federal jurisdiction.¹³⁵ Further, apart from the federal right of privacy of parents in governing family decisions, intervention is justified when action is necessary to protect the child's interests. Those cases are decided by reference to the best interest standard, which is typically a matter of state law.¹³⁶

Adoption of the government's interpretation of section 504 would create federal jurisdiction over many treatment decisions now left to

131. "The duty [to provide necessary medical assistance to a helpless minor child] . . . is now imposed by statute in every state." Robertson, *supra* note 45, at 218. See also *id.* at 222-24.

132. See *supra* note 10.

133. See, e.g., *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980) (action by juvenile probation department alleging that Phillip Becker was being deprived of the necessities of life); *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 Ga. 86, 274 S.E.2d 457 (1981) (action brought by hospital to allow it to give pregnant woman blood transfusions over her refusal to consent; separate action by county department to have fetus declared a deprived child).

134. See *Skelly Oil Co. v. Phillips Petroleum Co.*, 339 U.S. 667 (1950); *Louisville & N.R.R. v. Mottley*, 211 U.S. 149 (1908).

135.

Traditionally, it has been the policy of federal courts to avoid assumption of jurisdiction in this species of litigation [state domestic relations cases]. "The whole subject of the domestic relations of husband and wife, parent and child, belongs to the laws of the states and not to the laws of the United States." . . . Indeed, this court has explicitly held there is no federal diversity jurisdiction in a domestic relations case involving a child. . . .

"As a matter of policy and comity, [such cases are] local problems [which] should be decided in state courts. Domestic relations is a field peculiarly suited to state regulation and control, and peculiarly unsuited to control by federal courts."

Magaziner v. Montemuro, 468 F.2d 782, 787 (3d Cir. 1972) (citations omitted). See also C. WRIGHT, *HANDBOOK OF THE LAW OF FEDERAL COURTS* § 25 (4th ed. 1983).

136. See, e.g., *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981); cases cited *supra* note 129. See also Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 Mo. L. REV. 337, 361-68 (1981); Smith, *supra* note 26, at 1131-38. Organ transplant cases provide an interesting contrast to the cases controlled by the best interest standard. There courts have incorporated the substituted judgment standard to allow organ donations under carefully circumscribed conditions, even if the donation is not in the incompetent's best interest. See Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 76 COLUM. L. REV. 48 (1976).

state courts. As in *University Hospital*, the government would be able to proceed as a plaintiff, not only to discover medical records or to terminate federal funds, but also to coerce treatment. Whether the government would defer to the state agencies and courts apparently would depend on the extent of compliance of the state with the government's view of the merits in an individual case. But the decision to proceed in federal court, according to HHS, is within its own discretion.¹³⁷

Under the government's reading of section 504, however, the government is not the only potential federal plaintiff. Federal courts have been virtually unanimous in holding that section 504 creates a private right of action on behalf of a handicapped individual, and that a plaintiff may proceed directly in federal courts without exhausting administrative remedies.¹³⁸ Typical is the Tenth Circuit's decision in *Pushkin v. Regents of University of Colorado*,¹³⁹ in which the court affirmed a district court's decree directing that the plaintiff, a physician suffering from multiple sclerosis, be admitted to the next class at the University's psychiatric residency program. The court applied the four-pronged test of *Cort v. Ash*:¹⁴⁰ first, the plaintiff must be "one of the class for whose *especial* benefit the statute was enacted"; second, there must be evidence of the legislative intent to create the private right of action; third, a private right of action must be consistent with the underlying legislative scheme; and fourth, the area must not be "basically the concern of the States, so that it would be inappropriate to infer a cause of action based solely on federal law."¹⁴¹

Given the congressional history, specifically stating that Congress intended to "permit a judicial remedy through a private action,"¹⁴² it is

137. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,849.

138. See, e.g., *Miener v. Missouri*, 673 F.2d 969 (8th Cir. 1982); *Doe v. New York Univ.*, 666 F.2d 761 (2d Cir. 1981); *Pushkin v. Regents of Univ. of Colorado*, 658 F.2d 1372 (10th Cir. 1981); *Helms v. McDaniel*, 657 F.2d 800, *reh'g denied*, 664 F.2d 291 (5th Cir. 1981), *cert. denied*, 455 U.S. 945 (1982); *Kling v. County of Los Angeles*, 633 F.2d 876 (9th Cir. 1980); *Camenisch v. University of Texas*, 616 F.2d 127 (5th Cir. 1980), *vacated on other grounds*, 451 U.S. 390 (1981); *Davis v. Southeastern Community College*, 574 F.2d 1158 (4th Cir. 1978), *rev'd on other grounds*, 442 U.S. 397 (1979); *United Handicapped Fed'n v. Andre*, 558 F.2d 413 (8th Cir. 1977); *Lloyd v. Regional Transp. Auth.*, 548 F.2d 1277 (7th Cir. 1977). The only disputed question is whether a plaintiff may secure damages in addition to injunctive relief. See *Pushkin v. Regents of Univ. of Colorado*, 658 F.2d 1372, 1377 n.2. See also 29 U.S.C. § 794a (Supp. 1983).

139. 658 F.2d 1372 (10th Cir. 1981).

140. 422 U.S. 66 (1975).

141. 658 F.2d at 1378 (quoting *Cort v. Ash*, 422 U.S. at 78).

142. 658 F.2d at 1378 (quoting S. REP. NO. 1297, 93d Cong., 2d Sess. 39-40, *reprinted in* 1974 U.S. CODE CONG. & AD. NEWS 6373, 6391 (1974)).

not surprising that the courts of appeals have been virtually unanimous in finding a private right of action. Thus, according to the government's interpretation of section 504, as long as the defendant-hospital was a recipient of federal financial assistance—and almost all hospitals would qualify because, along with University Hospital, they receive reimbursement under the Medicare and Medicaid programs—and an infant's treatment was arguably affected by the hospital's action or inaction, the infant's representative could proceed in federal court.¹⁴³

If adopted, the government's position not only would have allowed treatment decisions to be litigated in federal court, but also would have created by logical extension a limited federal medical malpractice action. The most obvious private cause of action would be to compel treatment for an infant or incompetent, like Baby Jane Doe, who arguably was denied surgery because of her handicap. But HHS's original May 18, 1982, notice also required that health care providers who counsel parents "should not discriminate by encouraging patients to make decisions, which, if made by the health care provider, would be discriminatory under section 504,"¹⁴⁴ presumably including placing the infant in foster care or allowing his adoption. Assume that hospital personnel failed to inform parents of a seriously ill newborn of the existence of such alternatives, that the parents refused to consent to surgery in a case like *Baby Jane Doe's*, and that failure to perform surgery resulted in the infant's death. According to HHS, a duty exists under section 504 to inform parents of alternatives to nontreatment. As long as the parents could establish that the breach of the hospital's duty to inform caused them to refuse treatment and that their refusal led to the infant's death, the parents could have a federal cause of action pursuant to section 504.¹⁴⁵

The foregoing analysis suggests that Congress never contemplated the use to which the government seeks to put section 504. The government's position requires an extravagant distortion of the law, the creation of federal jurisdiction out of whole cloth. That is not to suggest,

143. As discussed by the Second Circuit in *United States v. University Hosp.*, whether the hospital was a recipient of federal financial assistance was not entirely clear on the record. Interestingly, the government's position on the meaning of those terms was inconsistent with the position it had taken recently in *Grove City College v. Bell*, 104 S. Ct. 1211 (1984). See 729 F.2d at 151.

144. *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, *supra* note 94.

145. Cf. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972), *cert. denied*, 409 U.S. 1064 (1972); *Wilkinson v. Vesey*, 110 R.I. 606, 295 A.2d 676 (1972).

however, that Congress could not create jurisdiction over bona fide cases of discrimination. In fact, Congress has enacted legislation that, in effect, enacts the government's interpretation of section 504.¹⁴⁶ This legislation and HHS's interpretation of section 504 raise a second important issue. The government's position, although not without ambiguity, would establish a national treatment standard not necessarily consistent with the approach taken by state courts.

THE RIGHT TO REFUSE MEDICAL TREATMENT

Cases involving the right to refuse medical treatment are of recent origin, almost all having been decided in the past ten years.¹⁴⁷ Some

146. Child Abuse Act, Pub. L. No. 98-457 (Oct. 9, 1984).

147. See, e.g., *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983) (whether removal of intravenous feeding tube from persistently comatose patient was homicide); *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. 1980) (whether comatose wife may be removed from respirator by husband as her guardian); *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980) (whether hospital must honor a competent terminally ill patient's request to be withdrawn from respirator); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982) (whether persistently vegetative newborn could be withdrawn from respirator under restrictive Louisiana statute, LA. REV. STAT. ANN. § 40:1299.36.1(A), (C) (West Supp. 1984)); *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982) (whether prior judicial authorization is required to withdraw treatment from a seriously ill newborn); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980) (whether senile patient may be withdrawn from dialysis consistent with family's expression of patient's judgment); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (whether chemotherapy was required for a severely retarded 67-year-old ward of the state who was suffering from leukemia); *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978) (whether prior judicial authorization is necessary before entering a "no-code" (order not to resuscitate) in a comatose patient's medical record); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976) (whether persistently vegetative patient may be removed from a respirator consistent with guardian ad litem's perception of the patient's wishes); *In re Conroy*, 190 N.J. Super. 453, 464 A.2d 303 (whether guardian for persistently vegetative patient may insist on removal of nasogastric tube from patient), *cert. granted*, 470 A.2d 418 (1983); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978) (whether hospital must honor elderly patient's refusal to consent to surgical removal of gangrenous extremity, despite fact that death would result from nontreatment); *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, (whether blood transfusions must be provided for a severely retarded cancer patient; also, whether a persistently vegetative patient may be withdrawn from a respirator consistent with his recent statements on that subject), *cert. denied*, 454 U.S. 858 (1981); *In re Yetter*, 62 Pa. D. & C.2d 619 (C.P. Northampton County 1973) (whether patient competent to decide course of medical treatment may be forced to undergo a mastectomy); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983) (whether persistently vegetative patient may be removed from respirator). Most of the earlier cases involved a hospital seeking a court order to give a blood transfusion to a Jehovah's Witness over the patient's or patient's guardian's refusal. See, e.g., *In re President of Georgetown College*, 331 F.2d 1000 (D.C. Cir.), *reh'g denied*, 331 F.2d 1010 (D.C. Cir.), *cert. denied*, 377 U.S. 978 (1964); *United States v. George*, 239 F. Supp. 752 (D. Conn. 1965); *In re Osborne*, 294 A.2d 372 (D.C. 1972); *In re Brooks' Estate*, 32 Ill. 361, 205 N.E.2d 435 (1965); *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670

writers argue that the right to refuse medical treatment has ancient origins.¹⁴⁸ Early cases centered on other issues, such as whether a physician committed an assault or battery when treating a patient without securing an informed consent¹⁴⁹ or whether a court could order a litigant to undergo a medical examination.¹⁵⁰ But those cases often contained strong dicta suggesting a right to refuse treatment.¹⁵¹ Given the great risk of infection that existed before sterilization and the use of antibiotics became standard practice, and given the intrusiveness of even minor surgery without benefit of anesthesia, common law courts probably would have found such a right had the issue been squarely presented. Newer technologies may make the refusal of treatment irrational in some cases.¹⁵² Nonetheless, the technology explosion of recent years has resulted in the development of extremely intrusive therapies and the ability to delay at least briefly the death of a patient suffering from almost any disease.¹⁵³ Medical advances, especially in the wide area where overall benefits are questionable, have met resistance from various sources, including right-to-die groups,¹⁵⁴ patients,¹⁵⁵ surrogates

(1971). Earlier cases also involve the refusal of parents to allow a transfusion for their child. *See, e.g., Jehovah's Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968); *People ex rel. Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769 (1952), *cert. denied*, 344 U.S. 874 (1952). Finally, there are cases concerning parents who refused to consent to other medical treatment for their children. *See cases cited supra* note 129.

148. CONCERN FOR DYING, A LEGAL GUIDE TO THE LIVING WILL 4 (1979): "Federal and state courts generally have viewed the right to self-determination as encompassing [sic] the right of a competent patient to refuse treatment in most cases, even when such refusal appears foolhardy, reckless, or irrational."

149. *See, e.g., Pratt v. David*, 118 Ill. App. 161 (1905), *aff'd*, 224 Ill. 300, 79 N.E. 562 (1906); *Mohr v. Williams*, 95 Minn. 516, 104 N.W. 12 (1905); *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914).

150. *See, e.g., Union Pac. Ry. v. Botsford*, 141 U.S. 250 (1891).

151. *See, e.g., id.* at 251 ("No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.").

152. *See, e.g., In re Yetter*, 62 Pa. D. & C.2d 619 (C.P. Northampton County 1973).

153. Commission Report, *supra* note 21, at 1.

154. One such group has distributed millions of living wills. CONCERN FOR DYING, QUESTIONS & ANSWERS ABOUT THE LIVING WILL (1984) (pamphlet distributed by Concern For Dying, New York, N.Y.).

155. *See, e.g., the Bouvia case*, in which a 26-year-old cerebral palsy victim attempted to get a court to order the hospital to cease feeding her by force, while providing her with painkilling drugs and hygienic care. Reported at CONCERN FOR DYING NEWSLETTER, Winter, 1984, at 3. *See also Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978); *In re Lydia E. Hall Hosp.*, 116 Misc. 2d 477, 455 N.Y.S.2d 706 (Sup. Ct. 1982).

for incompetents,¹⁵⁶ and legislators.¹⁵⁷ There is an enormous body of literature on the subject, most of it recent, and much of it in praise of the right to die.¹⁵⁸

Although cases on point are relatively few,¹⁵⁹ some principles have emerged. The courts have almost universally recognized the right of a competent patient to refuse medical treatment.¹⁶⁰ Ironically, the semi-

156. See, e.g., *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. 1980); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).

157. As of 1983, thirteen states and the District of Columbia had enacted natural death acts. See Commission Report, *supra* note 21, at Appendix D, 318-87. Since that time, eight states have passed natural death acts: Florida, 1984 Fla. Laws 84:58; Georgia, GA. CODE ANN., §§ 31-32-1 to -12 (1984); Louisiana, 1984 La. Acts 382 (to be codified at LA. REV. STAT. ANN. § 40:1299.58.1-.58.10); Mississippi, 1984 Miss. Laws 365; Virginia, VA. CODE § 54-325.8.1 to 8.13 (1984); West Virginia, W. VA. CODE §§ 16-30-1 to -10 (1984); Wisconsin, WIS. STAT. ANN. § 154.01 to .15 (West Supp. 1984); Wyoming, WYO. STAT. § 33-26-144 to -151 (1984).

A natural death act provides for recognition of a patient's right to refuse certain medical treatment and for procedures to be followed in such cases. See generally Comment, *The Right to Die a Natural Death and the Living Will*, 13 TEX. TECH. L. REV. 99 (1982).

158. See, e.g., Commission Report, *supra* note 21; T. BEAUCHAMP & J. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS (2d ed. 1983); J. CHILDRESS, WHO SHOULD DECIDE? (1982); P. RAMSEY, ETHICS AT THE EDGES OF LIFE (1978); J. ROBERTSON, *supra* note 23; R. STINSON & P. STINSON, THE LONG DYING OF BABY ANDREW (1983); R. VEATCH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION (1976); LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS (A. Doudera & J. Peters eds. 1982); Annas, *supra* note 54, at 25; Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, 4 AM. J. L. & MED. 367 (1979); Annas, *Nonfeeding: Lawful Killing in CA*, Homicide in NJ, HASTINGS CENTER REP., Dec. 1983, at 19; Baron, *Medicine and Human Rights: Emerging Substantive Standards and Procedural Protections for Medical Decision Making Within the American Family*, 17 FAM. L.Q. 1 (1983); Battin, *The Least Worst Death*, HASTINGS CENTER REP., Apr. 1983, at 13; Brant, *supra* note 136; Cantor, *Quinlan, Privacy, and the Handling of Incompetent Dying Patients*, 30 RUTGERS L. REV. 243 (1977); Delgado, *Euthanasia Reconsidered—The Choice of Death as an Aspect of the Right of Privacy*, 17 ARIZ. L. REV. 474 (1975); Fost, *supra* note 100, at 5; Lynn & Childress, *Must Patients Always Be Given Food and Water?* HASTINGS CENTER REP., Oct. 1983, at 17; Paris, *Compulsory Medical Treatment and Religious Freedom: Whose Law Shall Prevail?*, 10 U.S.F. L. REV. 1 (1975); Robertson, *supra* note 45; Robertson, *supra* note 136; Singer & Kuhse, *supra* note 39; Smith, *supra* note 26; Strong, *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, 11 LAW, MED. & HEALTH CARE 168 (1983); Y. Kamisar, *A Life Not (Or No Longer) Worth Living: Are We Deciding the Issue Without Facing It?* (Nov. 10, 1977) (Mitchell Lecture delivered at the State University of New York at Buffalo).

159. See *supra* cases cited in note 147.

160. See, e.g., *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. 1980); *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978); *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, cert. denied, 454 U.S. 858 (1981); *In re Lydia E. Hall Hosp.*, 116 Misc. 2d 477, 455 N.Y.S.2d 706 (Sup. Ct. 1982); *In re Yetter*, 62 Pa. D. & C.

nal case involved the right of an incompetent patient to be withdrawn from a respirator. In *In re Quinlan*,¹⁶¹ the New Jersey Supreme Court found that the right of a competent patient to refuse treatment is a part of a constitutional right of privacy. The court then held that principles of equality dictated that the comatose patient retained her right to be withdrawn from treatment.¹⁶² Since *Quinlan*, courts explicitly have found a constitutional right of a competent patient to refuse treatment.¹⁶³ As with other privacy rights, including the right to an abortion, the state may override the exercise of this right upon a showing of a compelling state interest.¹⁶⁴ Such instances, however, have been infrequent.¹⁶⁵

Courts have frequently followed *Quinlan*'s lead in extending the right to refuse treatment to incompetents without regard to the source of incompetence.¹⁶⁶ Commonly, the patient, like Karen Ann Quinlan, was once competent, but is now in a persistently vegetative state.¹⁶⁷ Others may be incompetent because of retardation,¹⁶⁸ senility,¹⁶⁹ or mental illness.¹⁷⁰ *Quinlan* created some controversy, largely for its

619 (C.P. Northampton County 1973); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983). *But see* *Commissioner of Corrections v. Myers*, 379 Mass. 255, 399 N.E.2d 452 (1979).

161. 70 N.J. 10, at 38-41, 355 A.2d 647, at 661-64.

162. *Id.* at 41, 355 A.2d at 664.

163. *See, e.g.*, *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980); *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978).

164. *See, e.g.*, *Roe v. Wade*, 410 U.S. 113 (1973) (state's interest in protecting the potentiality of human life allows regulation and prohibition of abortion in third trimester).

165. *See, e.g.*, *Commissioner of Corrections v. Myers*, 379 Mass. 255, 399 N.E.2d 452 (1979) (interest in prison discipline sufficient to override recalcitrant prisoner's refusal to submit to hemodialysis) (criticized as anomalous in *Brant*, *supra* note 136, at 346). *But see* *Zant v. Prevatte*, 248 Ga. 832, 286 S.E.2d 715 (1982) (court refused to order forced feeding of prisoner on a hunger strike).

166. Only the New York Court of Appeals has not followed *Quinlan*'s constitutional holding; instead, that court found a common law right to refuse medical treatment. *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981).

167. *See, e.g.*, *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983); *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. 1980); *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981); *Leach v. Akron Gen. Medical Center*, 68 Ohio Misc. 1, 426 N.E.2d 809 (C.P. 1980); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).

168. *See, e.g.*, *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

169. *See, e.g.*, *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980).

170. *Department of Human Servs. v. Northern*, 563 S.W.2d 197 (Tenn. Ct. App. 1978) (patient was found incompetent to decide whether to submit to surgery; thus her refusal to consent could be overridden if treatment was in her best interest).

holding that routine judicial proceedings are not required in such cases if the decision to withdraw the incompetent from treatment was approved by a hospital ethics committee.¹⁷¹

A patient obviously is not compelled to exercise her constitutional right to refuse medical treatment. It is fairly clear whether or not a competent patient chooses to exercise that right, subject to some uncertainty as to whether the person really wants treatment to be stopped or is seeking assurances from family members that her life has not become burdensome.¹⁷² The problem is far more difficult with incompetents.

In *Quinlan*, the court recognized the problem that an "affirmation of Karen's independent right of choice . . . would ordinarily be based upon her competency to assert it."¹⁷³ The court reasoned:

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death.¹⁷⁴

Consistent with its analysis that it was the incompetent's choice to exercise her personal right, the court borrowed the substituted judgment test from the law governing gifts from an incompetent's estate and organ donations by incompetents: "The only practical way to prevent destruction of [her] right is to permit the guardian and family of Karen to render their best judgment" as to whether she would choose to cease treatment.¹⁷⁵ This standard assumes that there is a surrogate in a posi-

171. See, e.g., Annas, *Reconciling Quinlan and Saikewicz*, *supra* note 158, at 378-82; Baron, *supra* note 158, at 14-15; Relman, *The Saikewicz Decision: Judges as Physicians*, 298 NEW ENG. J. MED. 508 (1978).

172. See Commission Report, *supra* note 21, at 47:

Helping to shape the deliberations of a patient who must decide about the course and duration of his or her life is a complex and weighty obligation. For example, letting a patient know that his or her death is now seen by others to be appropriate—or at least not unexpected—may be "giving permission to die" to a patient who no longer wishes to struggle against overwhelming odds. On the other hand, it may encourage overly rapid acceptance of death by a patient who feels rejected and unimportant.

173. 70 N.J. at 41, 355 A.2d at 664.

174. *Id.* at 39, 355 A.2d at 663.

175. *Id.* at 42, 355 A.2d at 664.

tion to substitute his judgment for the patient's in a meaningful way.¹⁷⁰

In some cases, it has been quite clear that the patient would have chosen to exercise her right to refuse treatment. For example, Brother Fox, the comatose patient in *In re Storar*,¹⁷⁷ had discussions about the *Quinlan* case with members of his religious order shortly prior to his own surgery and had expressed views that were consistent with the Catholic position on terminating treatment.¹⁷⁸ Similarly, in *Severns v. Wilmington Medical Center*,¹⁷⁹ the patient was a member of the Delaware euthanasia society and had communicated her views on life-support systems to her family. It has become increasingly common for people to evidence their desires as to extraordinary medical treatment by executing a living will.¹⁸⁰ Surprisingly, living wills have been virtually untested in the courts.¹⁸¹ They may be ambiguous and require interpretation, but certainly in recurring situations, such as the use of a respirator on a comatose patient, a living will is good evidence of the patient's wishes.

At least where the incompetent patient's views can be ascertained, it is not surprising that courts have adopted the substituted judgment test. Commentators on biomedical ethics have concluded that morality dictates that society honor a patient's refusal to accept treatment.¹⁸² For medical personnel or a court to violate a person's autonomy may be

176. See *infra* text accompanying notes 186-201.

177. 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, cert. denied, 454 U.S. 858 (1981).

178. For a statement of the Catholic position, see SACRED CONGREGATION FOR THE DOCTRINE OF THE FAITH, DECLARATION ON EUTHANASIA (May 5, 1980), reprinted in Commission Report, *supra* note 21, at 300-07. At least since the 1950's, the Church has maintained that it is "not mortally sinful to use 'extraordinary' treatment for a terminal patient. However, neither is it required since such a patient need be given only 'ordinary' treatment." See *Eichner v. Dillon*, 73 A.D.2d 431, 439 n.3, 426 N.Y.S.2d 517, 526 n.3 (1980) (discussing Pope Pius XII's November 24, 1957, *allocutio* to a group of anesthesiologists).

179. 421 A.2d 1334 (Del. 1980).

180. See CONCERN FOR DYING, *supra* note 154. In addition, undoubtedly many people have executed such documents now that almost half of the states have legislatively recognized them. See *supra* note 157. See also *The 'Living Will' Gains Acceptance*, N.Y. Times, Sept. 20, 1984, at C9, col. 3.

181. See J. ROBERTSON, *supra* note 23, at 99-100. Cf. *John F. Kennedy Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984).

182. For example, in his influential article *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, Professor Robertson, while arguing in favor of vigorous treatment for seriously ill newborns, recognizes that

[t]he notion that a person is an autonomous being with inherent dignity and value and whose life and actions are—to the greatest extent compatible with the rights of others—to be controlled by his own choices, has been a dominant theme in the philosophy and politics of Western civilization since the Enlightenment.

Robertson, *supra* note 136, at 48 n.2.

to treat the person as a means, which is condemned almost universally as immoral.¹⁸³ Limited intervention against a person's will may be justified, as in suicide prevention.¹⁸⁴ Such instances are limited, however, and most commentators distinguish between suicide and the refusal of medical treatment.¹⁸⁵

Where the incompetent patient's wishes are not known, courts may strain to apply the substituted judgment test. In a 1977 lecture, Professor Kamisar took the New Jersey Supreme Court to task for its application of the substituted judgment test in the *Quinlan* case.¹⁸⁶ At trial, friends and relatives testified concerning statements made by Karen evidencing her views on the use of life-support systems. Both the trial court and the supreme court found those statements "so informal, impersonal, abstract and equivocal as to lack the requisite probative value."¹⁸⁷ The supreme court remanded the case and ordered that Karen's father be allowed to have the respirator withdrawn if that decision was found to be consistent with Karen's views. According to Kamisar, the court thus narrowed the gap between voluntary and involuntary euthanasia.¹⁸⁸

Absent evidence of Karen's views, the court relied on a presumption that the decision of the guardian and family to withdraw a comatose patient from the respirator "should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them."¹⁸⁹ Kamisar argues that the court lacked factual support for its conclusions, and that even if supported by data,

183. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 158. "To violate a person's autonomy is to treat that person merely as a means, because he or she is treated in accordance with rules not of his or her choosing." *Id.* at 62. "Diverse figures in philosophy, ranging from Kant, Mill, Nietzsche, and Sartre to Robert Paul Wolff, have held that morality requires autonomous persons." *Id.* at 59.

184. J. CHILDRESS, *supra* note 158, at 164.

185. See *id.* at 157-81. See also Commission Report, *supra* note 21, at 37-39.

186. Y. Kamisar, *supra* note 158.

187. *Id.* at 5.

188.

Presumably the guardian and family of Karen had presented to the court *everything they knew* bearing on Karen's supposed choice. But the court concluded that what evidence was submitted was insufficient, that her previous conversations with friends were "without sufficient probative weight." How, then, can the guardian and the family discern Karen's choice on the basis of the *the same remote and impersonal* previous conversations both *Quinlan* courts found inconclusive?

Id. at 6-7.

189. *In re Quinlan*, 70 N.J. at 41-42, 355 A.2d at 664.

the desire of a majority of people should not control the treatment of an individual patient.¹⁹⁰

Professor Kamisar is an effective critic of those seeking to make death too easy.¹⁹¹ But there may be a kinder understanding of the *Quinlan* case. Kamisar's assertion that the guardian and family "had presented to the court *everything they knew* bearing on Karen's supposed choice" is misleading. They no doubt presented all statements that she had made concerning life support systems, but that is quite different from whether Karen's parents knew her values and goals. One can imagine, for example, a husband, who has never discussed the use of a respirator with his wife but who may nonetheless be aware of her values and be able to infer from them whether she would choose to be sustained indefinitely on a respirator. She may have shunned medical treatment, disliked hospitals, had an aversion to unnecessary financial expenditures, been unsentimental about death, expressed hope that her husband not grieve unduly if she predeceased him, or provided for her organs to be donated upon her death. A surrogate decisionmaker might consider all of those stances in substituting his judgment for that of the comatose patient because they do bear on the patient's actual preference. Consideration of such factors is more than what rules of evidence might term reliance on presumptions or surmises.

Apart from whether *Quinlan* can withstand critical analysis, Kamisar's criticism points to a weakness in the substituted judgment test. In some cases, there simply will be no basis of any kind on which to conclude how the patient would decide for herself. A simple hypothetical underscores the point: a patient is brought to a hospital emergency room; he is comatose, has no identification and no family or friends come forward to identify him.¹⁹² How might a surrogate substi-

190.

Even if only a very few patients in Karen's set of circumstances were determined to struggle on, that they are in the distinct minority is no justification for denying them their *personal* right to struggle on. After all, comatose patients are not fungibles. Even if we accept the unexamined and undocumented assumption of the New Jersey Supreme Court that a majority of those in Karen's situation would choose to die, this silent majority cannot speak for *all* those in such situations.

Y. Kamisar, *supra* note 158, at 13.

191. See also Kamisar, *Some Non-Religious Views Against Proposed "Mercy-Killing" Legislation*, 42 MINN. L. REV. 969 (1958).

192. Patients for whom there is no adequate surrogate are apparently quite numerous: [T]he undeniable tragic fact of the matter is that many, many people, into the thousands, do not have a brother or sister, a mother, a parent, a daughter, or son who can be appointed guardian. There isn't anybody. A lot of them are in institutions, and with the

tute her judgment for that of the comatose patient?

Harder still is the use of the substituted judgment test in cases like *Superintendent of Belchertown State School v. Saikewicz*.¹⁹³ There the patient was "sixty-seven years old, with an I.Q. of ten and a mental age of approximately two years and eight months. He was profoundly mentally retarded."¹⁹⁴ Saikewicz was suffering from leukemia, and the court was faced with a decision whether to order chemotherapy for him. The Massachusetts Supreme Judicial Court found that principles of equality dictated that the right to refuse medical treatment be extended to incompetent patients, as exercised by a surrogate.¹⁹⁵ Although its decision is not without ambiguity, the court held that the surrogate should employ the substituted judgment standard even in a case like Saikewicz's.¹⁹⁶

Substituted judgment is difficult to understand in such a case. The standard "requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose."¹⁹⁷ It is more flexible than the competing best interest standard because substituted judgment allows the decisionmaker to consider the idiosyncrasies of the incompetent patient¹⁹⁸ and is, therefore, more obviously consonant with the concept that refusal of medical treatment is the exercise of a personal constitutional right.¹⁹⁹ But it is illogical to

deinstitutionalization process, a lot are now in the community. And there isn't a person to appoint. And we have run out of volunteers.

Testimony of Paul Rogers to the President's Commission, *quoted in* Commission Report, *supra* note 21, at 130.

193. 373 Mass. 728, 370 N.E.2d 417 (1977).

194. *Id.* at 731, 370 N.E.2d at 420.

195. "The recognition of that right must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both." *Id.* at 745, 370 N.E.2d at 427.

196. Elsewhere, the Massachusetts Supreme Judicial Court has acknowledged that the substituted judgment test amounts to the best interest test in such cases: "In a case . . . involving a child who is incompetent by reason of his tender years, we think that the substituted judgment doctrine is consistent with the 'best interest of the child' test." *Custody of a Minor*, 385 Mass. 697, 710 n.10, 434 N.E.2d 601, 608 n.10 (1982). *See also* Guthrie & Appelbaum, *Substituted Judgment: Best Interests in Disguise*, HASTINGS CENTER REP., June 1983, at 8.

197. Commission Report, *supra* note 21, at 132.

198. *Id.* at 132-33. *See also* Robertson, *supra* note 136, at 62-63 (The substituted judgment test is grounded on the doctrine of respect for persons, which holds that "people are free to make choices according to their own conception of their interests. This freedom generally prevails even if we disagree with the person's choice of ends or means. . . .").

199. *See, e.g., In re Quinlan*, 70 N.J. at 41, 355 A.2d at 664 ("Our affirmation of Karen's independent right of choice, however, would ordinarily be based upon her competency to assert it. . . . [W]e have concluded that Karen's right of privacy may be asserted on her behalf by her guardian under the peculiar circumstances here present."). Arguably, a court would have to con-

talk about whether Joseph Saikewicz would choose chemotherapy if he were able to do so, unless the court is simply assuming that he would choose whatever treatment was in his best interest. A surrogate substituting her judgment for the incompetent must do so by reference to goals and values that a severely retarded patient cannot form in any meaningful sense. In concluding that Saikewicz need not receive chemotherapy, the court never satisfactorily responded to this point. It relied on the patient's disorientation, a continuing state of pain, adverse side effects, and an inability to cooperate with treatment as evidence of how Saikewicz would exercise his judgment.²⁰⁰ But even if all of those factors were present, it is inconceivable that the court would have ruled the same way if the treatment clearly had been in his best interest.²⁰¹

The substituted judgment test is even harder to apply in a treatment decision on behalf of a seriously ill newborn. Nonetheless, the Massachusetts Supreme Judicial Court has insisted that surrogates apply the substituted judgment test in such cases. The court is surprisingly frank, however, that application of the test in such cases is a fiction:

In a case . . . involving a child who is incompetent by reason of his tender years . . . the substituted judgment doctrine is consistent with the best interests of the child test. It is true that, when applying the best interest test, the inquiry is essentially objective in nature, and the decisions are made not by, but on behalf of, the child. . . . Nevertheless, the best interests analysis, like that of the substituted judgment doctrine, requires a court to focus on the various factors unique to the situation of the individual for whom it must act. . . . As a practical matter, the criteria to be examined and the basic applicable reasoning are the same.²⁰²

The court's insistence that the best interest test be clothed in substituted judgment language can best be understood as a way to make

front the difficult question of whether it was sanctioning involuntary euthanasia if it did not have recourse to the substituted judgment test. *See* Kamisar, *supra* note 158.

200. *Superintendent of Belchertown School v. Saikewicz*, 373 Mass. at 753-54, 370 N.E.2d at 432.

201. For example, the Pasteur treatment for rabies may cause similar pain and disorientation to a severely retarded patient. It is inconceivable that a court would allow the patient, bitten by a rabid animal, to die without ordering treatment. Elsewhere the court explicitly stated that the substituted judgment test may amount to the best interest test for incompetents. *Custody of a Minor*, 385 Mass. 697, 710 n.10, 434 N.E.2d 601, 608 n.10 (1982).

202. *Id.* (citing *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978)).

surrogate decisions for infants consistent with the constitutional underpinnings of the right to refuse treatment. As indicated above, the right is a personal one that a patient may choose not to exercise.²⁰³ It makes sense that the appropriate standard attempts to ensure that the patient's choice is honored. Relying on the substituted judgment test circumvents a need to decide whether, even if acting in the infant's best interest, withdrawal from treatment is in reality a form of involuntary euthanasia.²⁰⁴

It is important to consider how a state court might decide a case like *Baby Jane Doe*, consistent with the emerging principles governing denial of treatment. Several arguments are advanced by proponents of vigorous treatment for seriously ill newborns that failure to treat an infant like Baby Jane Doe constitutes, at a minimum, neglect, and quite probably, homicide, if her death results from the parents' and physician's omission.²⁰⁵ They also argue that, apart from the law, treatment ought to be provided for such infants.²⁰⁶

Initially conceding that not all seriously ill newborns must be treated, Professor Robertson recognizes the principle that permits withdrawal of treatment only if, on balance, treatment provides no reasonable hope of benefit to the newborn. To the proponents of vigorous treatment, this principle does not justify denial of treatment in a case like Infant Doe's or Baby Jane Doe's:

When the procedure entails great expense or inconvenience to the family, or pain to the infant, there is lack of reasonable hope of benefit only if life itself is not deemed a benefit to the child.

The case of lifesaving treatment for the defective infant is thus distinguished from the cases of terminal illness where resuscitation, surgery, or medication, although possibly prolonging life, are considered extraordinary procedures. . . . Thus, *treatment merely prolongs dying*. The defective infant, on the other hand, if treated, can normally live for significant periods. Unless the quality of life affects its value, a judgment *for which there is no legal precedent*, the likelihood that treat-

203. See *supra* text accompanying note 199.

204. See Kamisar, *supra* note 158.

205. See, e.g., Robertson, *supra* note 45, at 217-35; Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, in *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, *supra* note 158; Smith, *supra* note 26.

206. See Reagan, *supra* note 3, at 10, 11; Robertson, *supra* note 45, at 216, 251-62.

ment means life should justify the procedure.²⁰⁷

Thus, an omission is culpable only if there is a duty to act,²⁰⁸ and the line between that duty and its absence is determined by the net benefit to the infant. Robertson and others argue, however, that the law is well-settled that quality of life may not be considered in measuring the relative benefits and burdens. Instead, one must ask whether treatment merely prolongs dying, in which case no duty would exist, or whether treatment will sustain life for a significant period of time, in which case a duty would exist.

A balancing test is almost necessarily imprecise. The weight to be given to various factors will allow varied results. For example, Professor Robertson recognizes that "life is not in a patient's interests when it is so full of suffering or so devoid of meaning that the burdens of the medical care necessary to keep him or her alive do not seem worth it."²⁰⁹ He rejects, however, the notion that children inflicted with spina bifida fall into that category.²¹⁰

207. Robertson, *supra* note 45, at 236-37 (emphasis added). See also Smith, *supra* note 26, at 1143 ("To suggest that the state interest in preserving life is somehow reduced by a defect would be to alter seriously the traditional legal view of the value of human life."). In support of his statement that there is no legal precedent for quality of life decisions, Professor Robertson cites *Gleitman v. Cosgrove*, 49 N.J. 22, 227 A.2d 689 (1967) (actions for wrongful life and wrongful birth disallowed). Since that time, serious inroads have been made. Subsequently, the New Jersey Supreme Court overruled *Gleitman* insofar as the case disallowed the parents' action for wrongful birth. *Berman v. Allan*, 80 N.J. 421, 404 A.2d 8 (1979). That cause of action has been adopted by numerous courts. See G. CHRISTIE, CASES AND MATERIALS ON THE LAW OF TORTS 773 n.4 (1983). See also Comment, 'Wrongful Life': *The Right Not to be Born*, 54 TUL. L. REV. 480 (1980). An infant's action for wrongful life was allowed in *Curlender v. Bio-Science Laboratories*, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980). See also *Turpin v. Sortini*, 31 Cal. 3d 220, 182 Cal. Rptr. 337, 643 P.2d 954 (1982) (allowing a limited right of recovery); *Speck v. Finegold*, 497 Pa. 77, 439 A.2d 110 (1981) (denial of child's right of action affirmed by equally divided court).

208. W. LAFAVE & A. SCOTT, HANDBOOK ON CRIMINAL LAW § 26 (1972); PROSSER AND KEETON ON THE LAW OF TORTS, *supra* note 121, at § 56.

209. Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, *supra* note 205, at 222.

210.

These infants may suffer from repeated medical interventions, and may not have access to the full range of opportunities available to nondisabled persons. But the perspective of the healthy, normal individual is the wrong perspective to take. The view of ordinary people who know ordinary capacities for experience and interaction, and who may view the infant's existence as a fate worse than death, does not tell us how the infant who has no other life experience views it. For that child life in a severely disabled form would seem better than no life at all, even if it is lived in the custodial wards of a state institution.

Id. at 223-24. Elsewhere Professor Robertson explicates his reasons for believing that life in almost any form is better than no life at all:

One who has never known the pleasures of mental operation, ambulation, and social in-

Robertson also rejects as irrelevant the devastating impact that such a seriously ill newborn may have on a family, health care professionals, or society at large.²¹¹

Most advocates of aggressive treatment for seriously ill newborns concede that there are some cases in which treatment hardly seems worthwhile. For Robertson, those cases are few indeed. His response to the infant in unbearable pain is that pain can be made bearable with analgesics.²¹² Even where the prognosis is grim, he argues that the margin of error at birth is too great to allow parents to deny treatment to the infant.²¹³ Finally, in those limited cases where denial of treatment is morally justified, allowing the parents to refuse consent, in ef-

teraction surely does not suffer from their loss as much as one who has. While one who has known these capacities may prefer death to life without them, we have no assurance that the handicapped person, with no point of comparison, would agree. Life, and life alone, whatever its limitations, might be of sufficient worth to him.

Robertson, *supra* note 45, at 254.

211. Robertson, *supra* note 45, at 255-61. This article considers the extent to which the quality of life is relevant to deciding the best interest of an infant without reference to the benefit of others. Interestingly, though, in the context of organ donations, incompetents have been allowed to donate organs to benefit family members when the operation and donation in fact create medical risks for the incompetents. See, e.g., *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969). One justification is that respect for a person's autonomy requires that he be permitted to act altruistically. Robertson, *supra* note 136, at 49, 73. Professor Robertson rejects application of that principle in cases involving seriously ill newborns: "[The substituted judgment] doctrine is unlikely to support decisions in favor of passive euthanasia of defective newborns. . . ." *Id.* at 77. It is not clear why in a case of an infant with a severely limited cognitive existence a decisionmaker must deem entirely irrelevant suffering imposed on third parties. It is certainly not immoral for conscious patients to consider the impact of their illness and continued treatment on third parties. See, e.g., SACRED CONGREGATION FOR THE DOCTRINE OF THE FAITH, DECLARATION OF EUTHANASIA (May 5, 1980), reprinted in Commission Report, *supra* note 21, at 300, 306, which states:

It is also permitted, with the patient's consent, to interrupt these means, where the results fall short of expectations. But for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, and also of the advice of the doctors who are specially competent in the matter. The latter may in particular judge that the investment in instruments and personnel is disproportionate the [sic] the results foreseen. . . .

That third party concerns should not be controlling does not render them irrelevant.

212. Robertson, *supra* note 45, at 253. Recourse to painkilling drugs is not necessarily the panacea that Professor Robertson suggests. Some conditions may be painful despite the use of painkilling drugs that leave the marginally conscious patient even less aware of her environment. See Battin, *supra* note 158, at 14. Further, effective pain management may require increasing drug dosages, which in turn increases the risk of the patient's death. See Commission Report, *supra* note 21, at 77-82.

213. Robertson, *supra* note 45, at 255. If the dispute is about the degree of accuracy of medical prognosis, the dispute is factual, not moral, and the solution might be improved prognostic techniques. Cf. Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BRIT. MED. J. 201 (1973). The current debate suggests, however, that the dispute is primarily a moral one. See, e.g., Reagan, *supra* note 3.

fect, places society on the slippery slope of judging the quality of life.²¹⁴

As indicated above, advocates of aggressive treatment contend that precedent clearly establishes a duty to treat an infant faced with a life-threatening illness. There is, for example, a long line of cases involving parents who denied children medical treatment based on the parents' religious convictions.²¹⁵ Courts typically have ordered blood transfusions for children of Jehovah's Witnesses, even if the court would allow the parents to refuse similar treatment for themselves.²¹⁶ Parents have been found criminally liable even when they interposed a defense of ignorance and poverty.²¹⁷ At the same time, courts have recognized that parental discretion in family matters is part of a federally guaranteed right to privacy.²¹⁸ As a result, courts have honored parental refusal to consent to treatment in some cases. Despite the frequent assertions that the law clearly requires treatment in cases like *Baby Jane Doe's*,²¹⁹ that is far from true. The absence of criminal prosecutions of parents and doctors for denying treatment to seriously ill newborns is evidence that the law is not as well settled as advocates for aggressive treatment allege.²²⁰ The black letter principle may be clear that parents and physicians owe a duty to provide beneficial or ordinary treatment to an infant, but there is still an active debate on what constitutes ordinary treatment.²²¹

214. This appears to be another formulation of the "slippery slope" argument, rebutted elsewhere. See *infra* note 282 and accompanying text.

215. See cases cited *supra* note 147.

216. See cases cited *supra* note 147. See also Paris, *supra* note 158.

217. See, e.g., *Stehr v. State*, 92 Neb. 755, 139 N.W. 676 (1913), *aff'd on rehearing*, 94 Neb. 151, 142 N.W. 670 (1913).

218. See cases cited *supra* note 128.

219. See, e.g., J. ROBERTSON, *supra* note 23, at 90; Robertson, *supra* note 45, at 243; Smith, *supra* note 26, at 1143.

220. Professor Robertson contends that a clear basis for prosecution exists. He considers several explanations for why no parents have been prosecuted for withholding care for seriously ill newborns. Robertson, *supra* note 45, at 243-44. One obvious explanation would seem to be the low visibility of the practice. But given the current interest by strangers in the *Baby Jane Doe* case, either there will be more prosecutions in such cases or we must look for other explanations. One explanation rejected by Professor Robertson is that the law simply is not settled. State appellate courts have not defined the duty owed to seriously ill newborns. See discussion *infra* notes 222-40 and accompanying text.

One interesting aside—Professor Robertson gave an accurate prognostication in his 1975 article: "Although the right-to-life groups have focused on abortion and not yet entered this area, they may rechannel their efforts in the future, particularly as they suffer defeat on the abortion issue." Robertson, *supra* note 45, at 244. The *Baby Jane Doe* and *University Hospital* cases prove this point. See also AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, *supra* note 26.

221. See, e.g., Commission Report, *supra* note 21, at 82-89.

Furthermore, the line between parental privacy rights and the duty to provide treatment wavers,²²² and courts have drawn the line between corrective and lifesaving treatment.²²³ Elsewhere, parental refusal has been upheld where the benefits of the surgery might arguably be outweighed by the risks.²²⁴

Professor Robertson has argued that the law is settled in cases involving infants at risk with spina bifida. His premises are that treatment is required in life-threatening situations and that, untreated, myelomeningocele, a form of spina bifida, will become life-threatening; therefore, surgery must be provided.²²⁵ In virtually every case cited by Robertson, corrective surgery and treatment held the possibility of a cure for the underlying malady, and the child had the chance to live a normal existence.²²⁶ Those decisions do not compel surgery in an extreme case like *Baby Jane Doe* because neither condition is met.

Until recently, treatment was not available in cases like *Baby Jane Doe*. Neonatal intensive care units did not exist until the 1960's,²²⁷ and surgical procedures to correct many pediatric anomalies are also recent developments.²²⁸ It would be irrational to suggest that technological growth be stymied; it is similarly unreasonable, however, to accept uncritically the law developed in cases that predate these developments.

One also must examine the precedential value of those cases that, advocates of aggressive treatment argue, mandate treatment for seriously ill newborns with severe anomalies.²²⁹ The citations are merely

222. Compare *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (court refused to order corrective surgery over the objections of a 14-year-old boy with a cleft palate and a harelip), with *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972) (court remanded case to determine whether 16-year-old consented to blood transfusions necessary to perform surgery to correct a severe curvature of his spine). See also *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942) (court may not order surgery over parent's objections if parent has legal custody).

223. See *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955).

224. See *In re Tuttendario*, 21 Pa. D. 561 (1911).

225. See J. ROBERTSON, *supra* note 23, at 85-88.

226. The obvious cases are those involving blood transfusions. See cases cited *supra* note 147. See also *In re Sampson*, 65 Misc. 2d 658, 660, 317 N.Y.S.2d 641, 644 (Fam. Ct. 1970) (court ordered surgery to repair enormous facial deformity which, untreated, "must inevitably exert a most negative effect upon his personality development, his opportunity for education and later employment and upon every phase of his relationship with peers and others"), *aff'd*, 37 A.D.2d 668, 323 N.Y.S.2d 253 (1971), *aff'd*, 29 N.Y.2d 900, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972); *In re Green*, 448 Pa. 338, 292 A.2d 387 (1972) (court remanded to determine whether 16-year-old boy consented to blood transfusions during surgery that would correct his physical impairment).

227. See Commission Report, *supra* note 21, at 203.

228. *Id.* at 197.

229. J. ROBERTSON, *supra* note 23, at 86-88; Smith *supra* note 26.

trial court decisions.²³⁰ Although at least one appellate court decision has clearly entrusted the treatment decision to the parents,²³¹ the pro-treatment camp has dismissed this out of hand.²³² Further, even the frequently cited *Application of Cicero* does not necessarily support a broad requirement of treatment in cases like *Baby Jane Doe*. In *Cicero*, the infant's prognosis indicated normal intellectual development and ambulation with braces.²³³ An assertion that such precedent mandates aggressive treatment in all spina bifida cases ignores the *Baby Jane Doe* decision by the appellate division and the court of appeals. The appellate division did, after all, uphold a parental decision to refuse fully aggressive treatment, at least where a claim was made that some alternative therapy was provided;²³⁴ the court of appeal decision balanced family privacy interests and those of the seriously ill newborn and allowed parental discretion to control absent clear benefit to the newborn.²³⁵

In the absence of settled precedent, the issue is whether a court should compel treatment in a case like *Baby Jane Doe*. Advocates of aggressive treatment frequently assert that courts do not and should not consider quality of life in deciding whether treatment should be provided.²³⁶ While courts have stated that quality of life is irrelevant to whether treatment should be compelled, closer scrutiny reveals that courts and commentators clearly do consider quality of life to be relevant.

The *Quinlan* case is illustrative. It was assumed at trial that Karen was being kept alive by a respirator and would continue to be

230. *Maine Medical Center v. Houle*, Sup. Ct. Civ. Action No. 74-145 (Cumberland County, Me. 1974); *In re Kerri Ann McNulty*, No. 1960 (P. Ct. Essex County, Mass. Feb. 15, 1978); *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979).

231. *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980).

232. "The *Becker* decision is poorly reasoned, and is unlikely to be followed by other courts that consider the issue. (Indeed, it has binding effect only within the fourth appellate district of California—the San Jose Area.)" J. ROBERTSON, *supra* note 23, at 89. *Becker* may in fact be indefensible. *But see Annas, supra* note 54. The latter criticism, however, that *Becker* lacks precedential value, is even truer of the trial court decisions relied on to assert that treatment is required in cases like *Baby Jane Doe*.

233. 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979).

234. *Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 467 N.Y.S.2d 685, *aff'd*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *cert. denied*, 104 S. Ct. 560 (1983).

235. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *cert. denied*, 104 S. Ct. 560 (1983). See also Commission Report, *supra* note 21, at 217-23, which advocates that in ambiguous cases, the parents' decision be honored.

236. Robertson, *supra* note 45, at 237; Smith, *supra* note 26, at 1161-65.

kept alive almost indefinitely.²³⁷ The New Jersey Supreme Court believed that most would agree that such a life was not worth living and that Karen's guardian could reasonably conclude that she would feel similarly.²³⁸ Every court and virtually every commentator considering that issue has agreed.²³⁹

By direct analogy, infants suffering from painful and life-threatening anomalies can be kept alive by extraordinary treatment. Even Surgeon General Koop agrees that some infants—those suffering from either anencephaly or intracranial bleeding, and those born without an intestine—may be denied treatment. Koop contends that treatment for those infants is not compelled under section 504 despite the possibility of prolonged existence with treatment.²⁴⁰

Advocates of aggressive treatment concede that those cases are exceptions to the rule of treatment. But they also contend that the quality of life is not involved in drawing the line.²⁴¹ One commentator suggests that the persistently vegetative patient, such as an anencephalic, does not have a low quality of life, but instead has no life at all.²⁴² At best, that is a semantic distinction. It was conceded that Karen Ann Quinlan was alive at the time of trial,²⁴³ and she remains alive even without the assistance of a respirator.²⁴⁴ No legislature or court has held that a

237. *In re Quinlan*, 70 N.J. at 19, 25, 355 A.2d at 652, 655.

238. *Id.* at 41-42, 355 A.2d at 664.

239. See, e.g., cases cited *supra* note 147; J. CHILDRESS, *supra* note 158, at 172-75; Cantor, *supra* note 158. But see Y. Kamisar, *supra* note 158. While Professor Kamisar is critical of the court's reasoning, he suggests that the same result might have been reached by a different rationale. *Id.* at 32.

240. Singer & Kuhse, *supra* note 39, at 18-19, quoting Surgeon General Koop's testimony before Judge Gesell in *American Academy of Pediatrics*. For example, despite being able to maintain an infant born without an intestine for up to eighteen months, Koop contended that treatment would not be required in such a case. As observed by Singer & Kuhse, "[w]hy does Dr. Koop not think such infants should be kept alive as long as possible? Would he not think an eighteen-month extension of life worthwhile for a normal child? Would he not think it worthwhile for a normal adult? If he would, the obvious explanation for his different view in the first case is that he does not regard the life of an artificially nourished infant as being of the same worth as that of a normal infant or a normal adult." *Id.* at 18. One commentator, ordinarily an advocate of treating seriously ill newborns, cf. Robertson & Fost, *Passive Euthanasia of Defective Newborn Infants: Legal Considerations*, 88 J. PEDIATRICS 883 (1976), has criticized HHS's regulation as unintelligible because of such inconsistencies. Fost, *supra* note 158.

241. Singer & Kuhse, *supra* note 39, at 19-20. See also *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14.

242. Smith, *supra* note 26, at 1162-63.

243. *In re Quinlan*, 70 N.J. at 20, 25, 355 A.2d at 652, 654.

244. Karen Ann Quinlan is still alive despite having been weaned from the respirator. *The 'Living Will' Gains Acceptance*, *supra* note 180, at col. 4. That such a patient is alive is clear from her bodily functions:

persistently comatose patient is dead, even when adopting a brain death standard.²⁴⁵

Others have relied on different semantic distinctions. HHS, for example, has insisted that treatment decisions are discriminatory if influenced by subjective quality of life judgments, but that nontreatment is permissible if "medically indicated." In turn, HHS considers treatment futile or medically contraindicated if it will "merely temporarily prolong the process of dying,"²⁴⁶ as opposed to curing the underlying malady. Professor Robertson advances the same distinction.²⁴⁷

There are at least two analytical problems with those distinctions. First, it is hard to understand why a duty to treat should turn on the length of time that treatment prolongs life, unless factors like cost of treatment or quality of life are in fact being considered. Second, reliance on "terminal illness" does not explain the examples advanced by advocates of aggressive treatment in which they deem nontreatment acceptable. Closer scrutiny suggests that quality of life has influenced their judgment.

If one has recourse only to black-letter principles, any shortening of life constitutes homicide.²⁴⁸ One commits homicide whether one shoots a person in the prime of life, a dying cancer patient, a passenger as he boards the Titanic or a skier about to be crushed in an ava-

Application of noxious stimuli to the nerve endings of an unconscious patient leads to simple, unregulated reflex responses at both the spinal and the brain stem levels. Reflexes may allow some eye movement, grimacing, swallowing, and pupillary adjustment to light. If the reticular activating system in the brain stem is intact, the eyes can open and close in regular daily cycles.

Commission Report, *supra* note 21, at 175.

245. See Commission Report, *supra* note 21, at 9-10 (citing PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DEFINING DEATH: A REPORT ON THE MEDICAL, LEGAL AND ETHICAL ISSUES ON THE DETERMINATION OF DEATH (1981)) concerning the problem of defining when death occurs.

246. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846-47. H.R. 1904 requires that patients be provided with "medically indicated" treatment and seemingly would be subject to the same criticisms as the standard adopted by HHS.

247.

The terminally ill patient will soon die, with or without the procedure. Thus, treatment merely prolongs dying. The defective infant, on the other hand, if treated, can normally live for significant periods. Unless the quality of his life affects its value, a judgment for which there is no legal precedent, the likelihood that treatment means life should justify the procedure. But, where the medical procedure has no reasonable prospect, given the state of the art, of substantially prolonging the child's life, the procedure may be extraordinary and thus not required.

Robertson, *supra* note 45, at 237.

248. W. LAFAVE & A. SCOTT, *supra* note 208, at §35.

lanche.²⁴⁹ Cases dealing with the rights of seriously ill or persistently vegetative patients force courts to draw finer distinctions. Some courts have relied on the patient's putative choice;²⁵⁰ others have advanced the argument that denial or refusal of treatment is appropriate if death is imminent.²⁵¹

It is important to ask why life can be abandoned if the prospects are for a short life; rephrased, one might ask why prolongation for a short period of time is not worthwhile. One might argue that the financial cost of prolonging life for such a short time is not worth the benefit, but the counterargument has been made that cost is an inappropriate basis for deciding to deny treatment to the seriously ill newborn.²⁵² If cost is relevant at all to medical treatment cases, it is unclear why it would not be relevant to the treatment of an infant who may require expensive treatment during her entire lifetime. Another explanation might be that it is unfair to prolong third-party suffering when the benefits to the patient are so limited. Again, third-party suffering has been rejected as entirely irrelevant to the treatment decision on behalf of a seriously ill newborn.²⁵³

What then justifies allowing a patient or her surrogate to choose death if treatment will merely prolong life for a relatively short period of time? In the case of sapient patients, we now know that a patient prepares psychologically to die and it may be unconscionable to interfere with that natural process.²⁵⁴ It is doubtful that the newborn shares that experience. Furthermore, even an insubstantial period of existence constitutes life, and if all lives are equal, as asserted by President Reagan and HHS,²⁵⁵ shortness of life span would not seem to be a justification for allowing an infant to die.²⁵⁶ There is a hidden premise in the argument that denial or refusal of treatment is appropriate if death is imminent. Underlying the distinction is a quality of life judgment: an

249. *Id.* Cf. PROSSER AND KEETON ON THE LAW OF TORTS, *supra* note 121, at § 52. See generally D. MAGUIRE, DEATH BY CHOICE 22-50 (1974).

250. See, e.g., *In re Quinlan*, 70 N.J. at 41-42, 355 A.2d at 664.

251. See, e.g., *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980).

252. Robertson, *supra* note 45, at 252, 258-61.

253. *Id.*

254. See E. KUBLER-ROSS, DEATH AND DYING (1969).

255. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846; Reagan, *supra* note 3, at 11-12.

256. This is especially true when one realizes that the administration views eighteen months as an insubstantial period of time. Singer & Kuhse, *supra* note 39, at 18-19 (citing Surgeon General Koop's testimony in *American Academy of Pediatrics*).

insubstantial life span makes impossible a sapient existence; lacking that opportunity the life is not worth living.

The second distinction is between merely prolonging life when treatment is not mandatory, and curing the infant of a life-threatening illness.²⁵⁷ Again advocates of that distinction contend that it avoids subjective quality of life judgments and is an objective medical evaluation.²⁵⁸ However, it is not immediately clear what "merely prolonging life" means. One might argue that the distinction requires treatment if it will cure a life-threatening situation, but not otherwise. Some treatments, however, may never cure an underlying condition, but could be considered mandatory if they provide time for other curative therapies to be applied.²⁵⁹

Some hopelessly debilitated patients are capable of being sustained for substantial periods of time.²⁶⁰ If the decision to withdraw them from treatment is medically indicated, it is only because doctors sometimes do make quality of life decisions. Those patients may be withdrawn from life support systems because society believes that a life without cognitive brain function is not worth living. Advocates of treatment may attempt to distinguish among particular cases, but not without recourse to some consideration of the quality of life. Line drawing may be easier if difficult quality-of-life decisions can be avoided, but efforts to do so cannot explain the results that advocates of aggressive treatment argue for in actual cases.

Cases involving comatose patients are not the only instances in which courts and commentators have in fact considered quality of life relevant to whether treatment is appropriate. In *Superintendent of Belchertown School v. Saikewicz*,²⁶¹ the Massachusetts Supreme Judicial Court, like HHS, asserted that the quality of a severely retarded patient's life was irrelevant to whether he should be given chemotherapy.²⁶²

257. See, e.g., *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846-47.

258. *Id.* at 30,847.

259. Use of a respirator might be required where available to keep a patient breathing after having suffered, for example, an allergic reaction to a bee or wasp sting, where full recovery might be expected.

260. See, e.g., Field & Romanus, *A Decerebrate Patient: Eighteen Years of Care*, 45 CONN. MED. 717 (1981).

261. 373 Mass. 728, 370 N.E.2d 417 (1977).

262.

The sixth factor identified by the [trial] judge as weighing against chemotherapy was the quality of life possible for him even if the treatment does bring about remission. To the

The court insisted that it was applying the substituted judgment test, but, as argued above, given Saikewicz's inability to form goals and values, it was in fact applying a best interest test.²⁶³ Even under the less flexible best interest standard, Saikewicz's severe retardation should have been considered, and in fact was considered, relevant to treatment. The court in *Saikewicz* found that a majority of competent patients would choose to undergo chemotherapy if faced with Saikewicz's diagnosis.²⁶⁴ His retardation limited his ability to cooperate in or to understand the need for treatment. Also relevant were the extent of his pain and his ability to understand that pain. The quality of life Saikewicz faced with treatment, affected as it had to be by his severe retardation, was highly relevant to whether a court should force him to submit to treatment.²⁶⁵

Biological life is not the only value; respect for the person requires that he be treated according to his individual needs.²⁶⁶ A refusal to consider the fact of his retardation would violate his dignity as a unique person. By direct contrast, under a simplistic analysis that would make consideration of his handicap irrelevant, Saikewicz would have been compelled to submit to chemotherapy contrary to his best interest.

It should not be surprising that quality of life considerations affect treatment decisions. While not everyone has the same threshold of intolerable suffering, competent adults frequently make treatment deci-

extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it. . . . *The judge, as well as all the parties, were keenly aware that the supposed ability of Saikewicz, by virtue of his mental retardation, to appreciate or experience life had no place in the decision before them.*

Id. at 754, 370 N.E.2d at 432 (emphasis added). The emphasized statement is patently untrue. Moreover, there is some confusion in the use of the term "quality of life." "Sometimes it refers to the value that the continuation of life has for the patient, and other times to the value that others find in the continuation of the patient's life, perhaps in terms of their estimates of the patient's actual or potential productivity or social contribution." See Commission Report, *supra* note 21, at 135 n.43. Throughout this article, the term "quality of life" has been used in the first sense only.

263. See *supra* notes 193-204 and accompanying text.

264. 373 Mass. at 733-34, 370 N.E.2d at 421.

265. *Id.* at 754-55, 370 N.E.2d at 432. Custody of a Minor, 375 Mass. 733, 379 N.E.2d 1053 (1978), offers further evidence that quality of life is relevant to treatment decisions. Chad Green, a two-year-old, had a chance of a cure only slightly better than Saikewicz's. Chad could understand the need for treatment only slightly better than could Saikewicz; the treatment presumably would cause him disorientation to about the same degree as it would Saikewicz. Balanced against those factors, however, was the prospect of a fully sapient existence for the young child. That benefit was clearly entitled to a great deal of weight.

266. 373 Mass. at 750-51, 370 N.E.2d at 430-31; see also J. CHILDRESS, *supra* note 158, at 172-75.

sions for themselves based on the potential quality of life available after treatment. Patients faced with surgical removal of gangrenous extremities have resisted treatment because death seemed a better option than life as a cripple.²⁶⁷ Some people are willing to die rather than face the guilt of violating their religious principles.²⁶⁸ Others have pleaded with family members to allow them to starve²⁶⁹ or to kill them²⁷⁰ to avoid continuing a severely incapacitated existence. Millions of people have executed living wills in the hope of being spared a vegetative existence.²⁷¹ Ethicists and religious leaders have found many of those decisions to be morally acceptable.²⁷²

The obvious distinction between a competent adult and a seriously ill newborn is the adult's capacity to choose a course of treatment. Necessarily, the legal basis for making a decision for a seriously ill newborn is different from that governing decisions of competent adults or even once-competent adults.²⁷³ But that does not mean that quality of life is irrelevant to the application of the best interest standard.

There is increasing recognition that treatment decisions for incompetents should be governed by reference to the proportional benefits and burdens of the proposed treatment.²⁷⁴ As indicated above, most advocates of aggressive treatment concede that there are some extreme cases where denial of treatment is appropriate. But they resist that op-

267. See, e.g., *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978); *In re Quackebush*, 156 N.J. Super. 282, 383 A.2d 785 (Morris County Ct., P. Div. 1978).

268. See, e.g., cases cited *supra* note 147, involving Jehovah's Witnesses. See also *Paris*, *supra* note 158.

269. See, e.g., the *Bouvia* case discussed in CONCERN FOR DYING NEWSLETTER, *supra* note 155, at 3.

270. See, e.g., D. MAGUIRE, *supra* note 249, at 23-25.

271. See CONCERN FOR DYING, *supra* note 154, cited in Commission Report, *supra* note 21, at 139.

272. See D. MAGUIRE, *supra* note 249.

273. See Commission Report, *supra* note 21, at 132-36.

274. As summarized by the President's Commission:

If the ordinary/extraordinary distinction is understood in terms of the usefulness and burdensomeness of a particular therapy, however, the distinction does have moral significance. When a treatment is deemed extraordinary because it is too burdensome for a particular patient, the individual (or a surrogate) may appropriately decide not to undertake it. The reasonableness of this is evident—a patient should not have to undergo life-prolonging treatment without consideration of the burdens that the treatment would impose. Of course, whether a treatment is warranted depends on its usefulness or benefits as well.

. . . [S]o long as mere biological existence is not considered the *only* value, patients may want to take the nature of that additional life into account as well.

Id. at 88.

tion regarding spina bifida.²⁷⁵ Moreover, Professor Robertson contends that we cannot know whether a severely debilitated infant's life is worse than death.²⁷⁶ He does not mean that we cannot know whether we suffer in death. Instead, he argues that we cannot know what the severely retarded and crippled infant experiences. In some sense, the same problem exists even with competent patients.²⁷⁷ The law frequently must decipher someone's state of mind and make critical decisions based on that finding.²⁷⁸ The Supreme Court has recently imposed stringent limits on the use of presumptions, but the law is settled that state of mind may be inferred from surrounding circumstances.²⁷⁹ Consequently, the fact that many of the people who are responsible for treating seriously ill newborns, who are aware of an infant's prognosis and of the facts of institutionalized life, favor nontreatment is highly relevant to the issue of whether we can infer that a seriously retarded

275. See *supra* text accompanying notes 210 & 225. See also Robertson, *supra* note 136, at 77 n.135, discussing the substituted judgment doctrine: "[e]xcept for the situation in which the newborn is in incessant pain or will survive only a few days, it will be hard to conclude that from its perspective no life is better than this life it now has."

276. Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, *supra* note 205, at 224. This is not necessarily true:

I offer the following description of a child whose life was apparently "saved" by aggressive treatment as a foil against arguments in favor of treatment:

I used to annually take a class of senior students in abnormal psychology to visit the hospital ward in a training school for medical defectives. There was a little boy about 4 years old the first time we visited in the hospital. He was a hydrocephalic with a head so immensely large that he had never been able to raise it off the pillow and he never would. He had a tiny little body with his huge head and it was difficult to keep him from developing sores. The students asked, "Why do we keep a child like that alive?"

The next year we went back with another class. This year the child's hands had been padded to keep him from hitting his head. Again the students asked, "Why do we do this?" The third year we went back and visited the same child. Now the nurses explained that he had been hitting his head so hard that in spite of the padding he was injuring it severely and they had tied his arms down to the sides of his crib.

D. MAGUIRE, *supra* note 249, at 173 (quoting R. BAKER, *DILEMMAS OF EUTHANASIA* at 35 (pamphlet from Fourth Euthanasia Conference, New York, N.Y., Dec. 4, 1971, published by Euthanasia Educational Council, Inc., New York, N.Y.)).

277. See, e.g., Commission Report, *supra* note 21, at 174 ("No one can ever have more than inferential evidence of consciousness in another person.").

278. The most typical example is a criminal case in which a prosecutor must prove a defendant's state of mind despite the fact that he will not testify on his own behalf and a court or jury may have to make a life or death decision based on the prosecutor's evidence.

279. See, e.g., *Sandstrom v. Montana*, 442 U.S. 510 (1979) (holding that conclusive presumption that a person intends the ordinary consequences of his voluntary acts is violative of due process); *Ulster County Court v. Allen*, 442 U.S. 140 (1979) (holding that permissive presumptions are to be judged by rational connection between proven fact and fact to be presumed).

and crippled infant "values" its life.²⁸⁰

Advocates of aggressive treatment in spina bifida cases also contend that even if we could identify those infants who will be seriously retarded and suffer greatly despite treatment, the risks of denying treatment are too great.²⁸¹ In effect, their position is that it may well be moral to deny treatment to one child because its suffering cannot be alleviated. However, because that might lead to the denial of treatment of another infant where treatment would be beneficial, society should require that the hopeless case be treated as well. This is a variation of the slippery slope argument, which has been effectively rebutted elsewhere.²⁸² One additional word about that argument is necessary here. If one concedes that treatment is not in the best interest of an infant who will suffer greatly anyway, and I believe that most commentators would so concede, at least in an extreme case, the only justification for insisting on treatment is that it may benefit another infant. A sapient individual is capable of making an autonomous choice to act benevolently, even if the act is against her best interest. In some limited instances, decisions arguably against an incompetent's best interest have been made for her based on the substituted judgment test.²⁸³ But in the context of seriously ill newborns, it has been argued that the substituted judgment test is inappropriate and that any benefit to third parties is irrelevant in treatment decisions.²⁸⁴ Those arguments would militate against requiring treatment if the justification is that benefit will inure only to another. In effect, the argument would allow one child to

280. See, e.g., Goldstein, *Medical Care for the Child at Risk: On State Supervision of Parental Autonomy*, in *WHO SPEAKS FOR THE CHILD?* 153 (W. Gaylin & R. Macklin eds. 1982), cited in Commission Report, *supra* note 21, at 228-29 ("As long as the state offers institutions that provide little more than storage space and 'hay, oats, and water' for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity."). One response might be that we need to spend more on care for the handicapped. That response may be appropriate, but probably is unrealistic given the current administration's general views on social services. Further, absent infusion of funds, decisionmakers must consider treatment in light of currently available facilities. As observed by Professor Maguire, "morality is based on reality," D. MAGUIRE, *supra* note 249, at 78. The mere possibility of improved conditions does not justify compelling suffering today.

281. See Robertson, *supra* note 45, at 255; Smith, *supra* note 26, at 1164-65.

282. See, e.g., Commission Report, *supra* note 21, at 28-30. "The cost of accepting such an argument is the continued prohibition of some conduct that is actually acceptable." *Id.* at 29-30. See also T. BEAUCHAMP & J. CHILDRESS, *supra* note 158, at 115-26; D. MAGUIRE, *supra* note 249, at 131-40.

283. See, e.g., *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969).

284. Robertson, *supra* note 45, at 255-61; Robertson, *supra* note 136, at 76-77.

be used only as a means to an end, and to do so is immoral.²⁸⁵

The arguments advanced by advocates of aggressive treatment for seriously ill newborns can be and have been rebutted. Historical cases in which treatment has been required over parental refusal to consent are factually distinguishable from cases like *Baby Jane Doe*, leaving courts free to rethink the correct result.²⁸⁶ Appellate courts are only now confronted with cases like *Baby Jane Doe*, and their decisions will be influenced by the growing moral debate on the issue. There is virtually unanimous agreement that treatment ought to be compelled where the benefits outweigh the burdens of treatment,²⁸⁷ but there is considerable disagreement on what factors may be placed in that balance. It is simply irrational to suggest that quality of life is or should be irrelevant to whether treatment is appropriate.²⁸⁸ Advocates of aggressive treatment are unwilling to acknowledge that they in fact do consider quality of life. As demonstrated in *Saikewicz*, the degree of retardation or suffering is a fact that must be considered in making a decision that honors a patient as a unique individual.²⁸⁹ Once one concedes that a seriously ill newborn's best interest is not served by treatment, there can be no justification for continued treatment by reference to the results that might ensue if treatment is denied.²⁹⁰

SECTION 504 AND THE IMPERIAL JUDICIARY

Despite the uncertainty of state law on this question, the government contended that section 504 created federal jurisdiction over treatment cases and established a definitive substantive standard by which such cases are to be decided.

285. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 158, at 59, 62. Forcing treatment on a seriously ill newborn may put us on the reverse side of the slippery slope, e.g., a side that is disturbingly reminiscent of Nazi experimentation. See *supra* text accompanying note 282. At times doctors have justified keeping patients alive because of what they might learn in order to help other patients. See, e.g., Karnofski, *Why Prolong the Life of a Patient with Advanced Cancer?*, 10 CA at 10 (1960) ("[t]here are a number of practical reasons for treating patients with advanced cancer. The physicians, both in training or in practice, can learn a great deal from the study of these patients. . . ."). See also Stinson & Stinson, *On the Death of a Baby*, ATL. MONTHLY, July 1979, at 64 (discussing the attitude of the treating physicians). Keeping someone alive contrary to his best interests may produce useful information for treatment of others, but the patient has, in effect, become the subject of an experiment if that is the principal justification for continued existence.

286. See *supra* notes 215-35 and accompanying text.

287. See, e.g., Commission Report, *supra* note 21, at 88.

288. See *supra* notes 241-73 and accompanying text.

289. See *supra* notes 261-66 and accompanying text.

290. See *supra* notes 282-83 and accompanying text.

President Reagan's original memorandum contended that treatment of seriously ill newborns was guaranteed by equal protection of the law.²⁹¹ Consistent with the President's understanding of the law, HHS sent notice to hospitals that it was unlawful to withhold food or treatment from a handicapped infant 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."²⁹² As indicated above, HHS's standard is at best confusing.²⁹³ It attempts to make treatment decisions objective, based on medical considerations, free from subjective "quality of life" considerations. Testimony by the Surgeon General and HHS's July 5, 1983, supplementary information reveal, however, that the government does not consistently adhere to its own rule.²⁹⁴

Additionally, the *University Hospital* case and HHS's July 5, 1983, supplementary information make it clear that, by the government's view, consideration of spina bifida and attendant retardation does violate section 504.²⁹⁵ It is important to emphasize that the government believes that treatment is required because of the equal worth of all human life and that consideration of handicaps, or at least certain handicaps, is a violation of federal law.

The government's position is startling. First, Dr. Koop and other administration officials were free to choose those handicaps that they believed fell within the nondiscrimination protection of section 504.²⁹⁶ The officials were not constrained by the language or history of section 504 in developing their list of handicaps. That they felt themselves free to fashion a medical code unhampered by statutory authority reinforces the argument that Congress never intended section 504 to encompass cases like *Baby Jane Doe*. Second, and more significantly, states have adopted best interest standards as the principle guiding treatment decisions on behalf of incompetents.²⁹⁷ In developing a federal standard,

291. See Reagan, *supra* note 3.

292. *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, *supra* note 94, reprinted in Commission Report *supra* note 21, at 467-68.

293. See Foster, *supra* note 100.

294. See *supra* note 98; see also Singer & Kuhse, *supra* note 39, at 18.

295. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,848-52.

296. Compare Surgeon General Koop's testimony before Judge Gesell, reported at Singer & Kuhse, *supra* note 39, at 18, with *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, and with Reagan, *supra* note 3.

297. See *supra* note 136.

HHS and President Reagan did not consider the extent to which coercing treatment in a "nondiscriminatory" manner might conflict with state law.²⁹⁸ As argued above, a plausible case can be made that Baby Jane Doe's best interest might be violated by compelling treatment.²⁹⁹

To illustrate the last point, one might consider how a case like *Saikewicz* would be decided under the government's substantive standard. The court in *Saikewicz* applied the substituted judgment test, consistent with the best interest standard, and concluded that chemotherapy was not required.³⁰⁰ Had *Saikewicz's* guardian sued in federal court and stated a private right of action under section 504,³⁰¹ the court would have asked whether treatment was medically indicated, apart from subjective quality-of-life considerations.³⁰² The court would have had to assure itself that treatment was not being withheld because of *Saikewicz's* handicap. What better evidence would have shown that nontreatment was based on the patient's retardation than the fact that a majority of competent patients would opt for therapy, given the prospects of prolonged life? Treatment would be required under the government's section 504 approach despite the patient's inability to cooperate with treatment and the pain and disorientation that it would cause him. Again, there is not a scintilla of evidence in the congressional history that Congress intended to supplant state law with such a federal standard.³⁰³

Ethicists and courts have argued that nontreatment was appropriate in *Saikewicz*.³⁰⁴ As indicated above, individual characteristics are relevant to a treatment decision.³⁰⁵ The emerging principle governing treatment decisions is a balancing test that compares benefits and burdens of treatment. Under this test, the degree of intrusion of therapy and the patient's ability to experience life are factors highly relevant to whether treatment is appropriate.³⁰⁶ The government's simplistic defini-

298. Reagan, *supra* note 3. See also *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14; *supra* note 28.

299. See *supra* text accompanying notes 236-75.

300. 373 Mass. at 744-45, 370 N.E.2d at 427.

301. See *supra* text accompanying notes 138-43.

302. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,846-47.

303. See American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 401 (D.D.C. 1983).

304. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 158, at 132-34; *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980).

305. See *supra* notes 261-74 and accompanying text.

306. See, e.g., Commission Report, *supra* note 21, at 88. On the relevance of the degree of intrusion of a particular therapy, see, e.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*,

tion of discrimination would prevent courts from considering factors recognized as morally relevant.

The administration's section 504 position is particularly ironic given the administration's full concurrence in the efforts by right-to-life groups to remove abortion cases from federal courts.³⁰⁷ This section of this article develops some of the arguments used by those who criticize the federal courts as activist and imperialistic and illustrates that adoption of the government's interpretation of section 504 would violate the very principles advanced by these critics.

The federal courts have been labelled as activist and imperialistic for numerous decisions including the abortion cases.³⁰⁸ Over the past several years, groups disgruntled with federal court decisions have made concerted efforts to curtail federal courts' jurisdiction over particular classes of cases.³⁰⁹ After extensive congressional hearings,³¹⁰ these efforts have proved unsuccessful.³¹¹ The arguments in favor of withdrawing particular areas of law from federal jurisdiction demonstrate the allegedly principled basis for objecting to federal court action.

For example, during 1981 the Senate Subcommittee on Separation of Powers conducted extensive hearings on S. 158, the Human Life Bill.³¹² In substance, the Human Life Bill would have defined the beginning of life as the moment of conception.³¹³ Despite some disagree-

429 U.S. 922 (1976); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978).

307. Cf. Reagan, *supra* note 3.

308. See *supra* note 1. The term activist has not always been used consistently; as one scholar has observed, "commentators have numerous and disparate concepts of activism. . . . Overall, we receive little more than a babel of loosely connected discussion. . . ." Canon, *supra* note 5, at 239.

309. Kay, *The Unforeseen Impact on Court and Congress*, 65 JUDICATURE 185 (1981).

310. See *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1. See also *Hearings Before the Subcomm. on the Constitution of the Senate Comm. on the Judiciary*, 97th Cong., 1st Sess. (1981).

311. See Tolchin, *Amendment Drive on School Prayer Loses Senate Vote*, N.Y. Times, Mar. 21, 1984, at A1, col. 1; *Around the Nation: Civil Liberties Leader Assails Administration*, N.Y. Times, June 20, 1983, at A10, col. 6.

312. *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1.

313. The first section of the Human Life Bill, S. 158, 97th Cong., 1st Sess. 160 (1981); H.R. 900, 97th Cong., 1st Sess. 1-2 (1981), provided:

The Congress finds that present day scientific evidence indicates a significant likelihood that actual human life exists from conception.

The Congress further finds that the fourteenth amendment to the Constitution of the United States was intended to protect all human beings.

Upon the basis of these findings, and in the exercise of the powers of the Congress, including its power under section 5 of the fourteenth amendment to the Constitution of the United States, the Congress hereby declares that for the purpose of enforcing the

ment as to the legal effect of such a rule,³¹⁴ it was fairly obvious that its proponents hoped that it would have the effect of overruling *Roe v. Wade*.³¹⁵

There is a perceived bias of federal courts in favor of abortion,³¹⁶ and therefore S. 158 also contained a provision to limit federal court jurisdiction over abortion cases.³¹⁷ Senate Bill 158 envisioned that challenges to state statutes regulating abortion would be made in state courts with ultimate review by the Supreme Court.³¹⁸ Thus, S. 158 could have had two possible effects. The first would be to overrule the specific holding of *Roe*, or, short of that, to invite far greater diversity of opinion over the legality of abortion legislation. This second effect would be the result of more courts, i.e., state courts, ruling on the constitutionality of particular statutes subject to limited appeal and certiorari routes to the Supreme Court. Proponents of S. 158 offered interesting justifications for this significant reshaping of federal court jurisdiction.³¹⁹

To the supporters of the Human Life Bill, the abortion decisions

obligation of the States under the fourteenth amendment not to deprive persons of life without due process of law, human life shall be deemed to exist from conception, without regard to race, sex, age, health, defect, or condition of dependency; and for this purpose 'person' shall include all human life as defined herein.

314. See Vitiello, *Congressional Withdrawal of Jurisdiction From Federal Courts: A Reply to Professor Uddo*, 28 LOY. L. REV. 61, 62 n.11 (1982).

315. For evidence that the bill was intended to overrule *Roe*, 410 U.S. 113 (1973), see Vitiello, *supra* note 314.

316. See, e.g., Uddo, *supra* note 1.

317. The Human Life Bill, S. 158, § 2, provided:

Notwithstanding any other provision of law, no inferior Federal court ordained and established by Congress under article III of the Constitution of the United States shall have jurisdiction to issue any restraining order, temporary or permanent injunction, or declaratory judgment in any case involving or arising from any State law or municipal ordinance that (1) protects the rights of human persons between conception and birth, or (2) prohibits, limits, or regulates (a) the performance of abortions or (b) the provision at public expense of funds, facilities, personnel, or other assistance for the performance of abortions.

In the version of the bill reported out by the subcommittee, this became § 4. SUBCOMM. ON SEPARATION OF POWERS, THE HUMAN LIFE BILL—S. 158, REPORT TOGETHER WITH ADDITIONAL AND MINORITY VIEWS TO THE COMM. ON THE JUDICIARY, UNITED STATES SENATE, 97th Cong., 1st Sess. 32 (1981).

318. See Galebach, *The Constitutionality of Withdrawal of Lower Federal Court Jurisdiction in the Human Life Bill* (written statement to Senate Subcomm. on Separation of Powers), in *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1, at 235, 237.

319. See, e.g., *id.*; Rice, *Limiting Federal Court Jurisdiction: The Constitutional Basis for the Proposals in Congress Today*, 65 JUDICATURE 190 (1981); Uddo, *supra* note 1.

reflect judicial activism in two respects: (1) reproductive privacy rights are without foundation in the Constitution or statutes;³²⁰ and (2) the federal courts have intruded on an area traditionally reserved to the states.³²¹ According to a number of commentators, the abortion cases should be remitted to state courts because those courts reflect the people's will more than do federal courts with life-appointed judges.³²²

Section 1 of the Human Life Bill was justified because "[o]ne of the difficulties here arises from the Supreme Court's extravagant interpretation of the 14th amendment (in *Roe*) . . . the Supreme Court has reached out to take jurisdiction for itself and responsibilities for itself that have proven not to be wise."³²³ The Supreme Court's *Roe* decision was seen as an instance of judicial activism because the Court did not ground its decision on an express provision of the Constitution, but arguably made up the law without a basis in the Constitution or a statute.³²⁴

The second feature of judicial activism under attack in S. 158 was that *Roe* was undemocratic, altering the traditional state-federal balance. Proponents of the bill were consistent in explaining the purpose of section 2,³²⁵ and that the bill was intended to return abortion decisions to state courts.³²⁶ This states' rights issue was raised repeatedly during

320. See *infra* note 324 and accompanying text.

321. See Galebach, *supra* note 318; *infra* notes 326-27 and accompanying text.

322. See *infra* notes 330-34 and accompanying text.

323. *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158*, *supra* note 1, at 622 (comments of Professor Charles Rice).

More specifically, the bill was described as "a response which is based on the fact that not only is *Roe v. Wade* an exercise in bootstrap jurisprudence through the application of this right of reproductive privacy, which is of the Supreme Court's own invention, but beyond that, *Roe v. Wade* is an intrusion on the prerogatives of the State. It is entirely prudent to correct it in that respect.

Id. at 626 (comments of Professor Charles Rice). The bill also was characterized as follows: "[S. 158] simply provides the underpinning for the States to take such action as they choose to take based on the establishment of personhood within the status of being preborn. . . ." *Id.* at 920 (comments of Representative Henry Hyde).

324. *Id.* at 622 (comments of Professor Charles Rice). See also *id.* at 626 (comments of Professor Charles Rice: "*Roe v. Wade* [was] an exercise in bootstrap jurisprudence through the application of this right of reproductive privacy, which is of the Supreme Court's own invention. . . .").

A similar attack on the Court's activism was raised by Justice Rehnquist, a critic of the undemocratic composition of federal courts. In his dissent in *United Steelworkers v. Weber*, he labelled as Houdini-like efforts by Justice Brennan to justify affirmative action hiring absent support in the relevant statute. *United Steelworkers v. Weber*, 443 U.S. 193, 222 (1979) (Rehnquist, J., dissenting).

325. See, e.g., REPORT OF THE SUBCOMM. ON SEPARATION OF POWERS, *supra* note 317, at 29.

326. See, e.g., Galebach, *supra* note 318.

hearings on S. 158. Senator John East, chairman of the Senate subcommittee, criticized *Roe* for establishing "a universal national standard" without a deliberative process and consensus.³²⁷

Also included in the hearing record was a written statement by Stephen H. Galebach.³²⁸ His theoretical justifications for reallocation of abortion decisions from federal to state courts summarize the views of supporters of S. 158. In brief, the proponents' position was that *Roe* preempted an important area of state court jurisdiction and that federal courts ought not to be interpreting state abortion statutes because of the traditional view that only state courts can definitively interpret state law.³²⁹ The argument also stressed the fact that the Supreme Court fashioned the abstention doctrine, which requires federal courts to refuse jurisdiction in many cases, to avoid unnecessary federal-state conflict.³³⁰ The policy underlying the abstention cases is particularly appropriate in the abortion context because laws concerning protection of human life and family law traditionally are left to the states.³³¹

327. Senator East testified, in part, as follows:

[T]he bill itself . . . would return the abortion question to the State level and allow for a great diversity of approach to the issue.

. . . I might relate it to the effort to restore a little more balance in the American federal system. I have greater confidence in State and local government than you do [referring to Senator Robert Packwood].

My whole quarrel with *Roe v. Wade* is we never even had a public debate on this issue. We were not ever able to do this. The Court precipitated the crisis when they destroyed all State legislation in this area and threw this thing into the public arena.

. . . .

The trouble has been that in *Roe v. Wade*, we had a decision imposed upon us in which the American people were not a part of the dialog. . . . I might be more inclined to accept [*Roe*] if it had been a decision arrived at in the legislative body over a period of time through public discussion, but the deliberative process of the legislative chamber was circumvented by *Roe v. Wade*.

Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158, supra note 1, at 184-85.

328. Galebach, *supra* note 318, at 235.

329. *Id.*

330. *Id.* at 236 (citing *Younger v. Harris*, 401 U.S. 37 (1971); *Railroad Comm'n v. Pullman Co.*, 312 U.S. 496 (1941)).

331.

The lower federal courts have no monopoly of the wisdom required to interpret the Constitution. This is particularly so when the controversy concerns criminal laws protecting human life and family laws concerning the relationship between a woman, her unborn child, and perhaps the father or guardian of the unborn child. Matters of this kind have traditionally been resolved by the states, not by the federal government. Reserving such matters to state courts in the first instance will not jeopardize constitutional rights. . . . The Supreme Court . . . will retain its power of appellate review over questions of consti-

Other proponents of S. 158 testified as to the educative function served by democratically chosen state courts and posited the view that state courts are better situated to decide sensitive right-to-life questions.³³² The effort to remove federal court jurisdiction over abortion cases has been called a "healthful corrective," allowing state courts to have their say on life and death issues raised by the abortion question, and would serve an educative function in that "the Court might learn a salutary lesson . . . [and] avoid future excursions beyond its proper bounds."³³³

Remitting abortion cases to state courts may mean that various state courts and legislatures will arrive at disparate results on the same legal question. The possibility of that result was readily accepted by advocates of the Human Life Bill.³³⁴

The government's view of section 504 is curious in light of the administration's support of the Human Life Bill and its assertions that the states ought to have jurisdiction over abortion cases.³³⁵ The government's strategy seems to invite the federal courts to act in the very manner that earned them the enmity of their critics in the abortion context.

tutional interpretation. Its deliberations may well benefit from the opportunity to consider the views of state courts on matters traditionally resolved under state law.

Galebach, *supra* note 318, at 236-37. *See also id.* at 240-41.

332. The comments of Professor Charles Rice are representative:

I think of course there is a possibility of diverse interpretations, but that is part of the Federal system, too.

. . . .

As I was saying before, I think we have suffered greatly in this country in recent years from the autocratic actions of Federal judges who are unelected and appointed for life. If I were in Congress, I would vote for section 2 on the theory that it is about time for us to repose responsibility in the State courts and it is about time for us to realize that there is no inherent superiority of Federal judges over State court judges.

Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158, supra note 1, at 625.

333. Rice, *supra* note 319, at 197.

334. Senator East commented,

[I]t very well may be [the states] could weigh it one way or weigh it the other.

I am not personally troubled with the idea, or deeply anguished over it in terms of American federalism, that the State might look at this issue and might weigh it, and it might come down one way or the other, and that would not be inconsistent with what S. 158 purports to do, nor would it be inconsistent with the normal utilization of the due process clause. . . .

Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158, supra note 1, at 791. *See also id.* at 188-89 (discussion between Representative Dougherty and Senator Baucus); *id.* at 431 (comments of Professors Uddo and Nagel).

335. *Cf.* Reagan, *supra* note 3.

Apart from constitutional authority or statute, there are prudential reasons to entrust primary responsibility to the states.³³⁶ *Baby Jane Doe* involved a matter traditionally resolved by state courts under the best interest and substituted judgment doctrines,³³⁷ while federal court decisions on point are infrequent. There is no evidence that state courts are unable to resolve such life and death questions.³³⁸ As medical technology develops, the courts may be presented with more cases in which treatment may result in a prolonged but seriously impaired existence. Different states may disagree on what constitutes an infant's best interest in such cases. That states may reach different results on life and death issues presumably is not, however, a basis for federalizing the answer to such problems.³³⁹

The government's deference to state legal process seems to have vanished in the *Baby Jane Doe* case. The New York Court of Appeals has taken a cautious approach to medical withdrawal decisions.³⁴⁰ The accusation that Baby Jane Doe was neglected was investigated by the appropriate state agency,³⁴¹ and the matter was litigated through a three-tiered court system.³⁴² Despite these facts, the government attempted to relitigate the case in federal court under its own substantive standard. Fortunately, the Second Circuit rejected the government's invitation to act in such an imperialistic manner.³⁴³

336. For example, state courts are best suited to interpret state statutes, and entrusting responsibility to the states avoids unnecessary federal-state conflict. Galebach, *supra* note 318, at 236.

337. See *supra* notes 173-204 and accompanying text.

338. Proponents of returning abortion cases to the states recognize that states may reach differing results, some perhaps condoning abortion. See, e.g., *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158, supra* note 1, at 189.

Thus, if principled, the argument that such life and death questions should be left to the states cannot turn on the fact that the states' rights proponents disagree with a particular state's decision in some cases. Further, as discussed *supra* note 26 and *infra* note 393, there is little evidence that state courts were in fact deciding treatment decisions contrary to the best interest of seriously ill newborns.

339. *Hearings Before the Subcomm. on Separation of Powers of the Senate Comm. on the Judiciary on S. 158, supra* note 1, at 189. See also H.A. BEDAU, *THE DEATH PENALTY IN AMERICA* 32-38 (3d ed. 1982) (despite some "federalization" of the death penalty, states still have latitude in determining life and death issues).

340. See, e.g., *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981).

341. *United States v. University Hosp.*, 575 F. Supp. 607, 611 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

342. See *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 211, 456 N.E.2d 1186, 1187, 469 N.Y.S.2d 63, 65, *cert. denied*, 104 S. Ct. 560 (1983).

343. *United States v. University Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

A CONSTITUTIONAL CHALLENGE TO IMPROPER TREATMENT OF NEWBORNS

Contemporaneously with the executive branch's efforts to expand section 504 by regulation and litigation, members of Congress sought passage of a bill which, in effect, would have enacted the government's interpretation of section 504.³⁴⁴ House Bill 1904 was recently signed into law,³⁴⁵ but not until its most sweeping provisions were amended.³⁴⁶ This section of this article considers the provisions of H.R. 1904 and suggests a constitutional challenge to efforts to compel unwanted treatment for seriously ill newborns.

As argued above, the government's section 504 stance would have required treatment contrary to an infant's best interest in some cases.³⁴⁷ As introduced, H.R. 1904 required states to establish "a procedure for any interested person to report" instances of denial of "medically indicated treatment . . . to infants at risk with life-threatening impairments."³⁴⁸ In effect, H.R. 1904 proposed the same ambiguous test as did the HHS regulation.

As a result of political compromise, Congress adopted a more explicit standard.³⁴⁹ While retaining the "medically indicated" language, the act defines that term.³⁵⁰ Treatment is required for a seriously ill newborn if "in the treating physician's or physicians' reasonable medical judgment, [it] will be most likely to be effective in ameliorating or correcting all [life-threatening] conditions."³⁵¹ The act includes important exceptions. Treatment is unnecessary (1) if the infant is persist-

344. H.R. 1904, 98th Cong., 1st Sess. (1983).

345. See *supra* note 19.

346. See *infra* notes 350-57 and accompanying text.

347. See *supra* notes 147-290 and accompanying text.

348. H.R. 1904 amends the Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5101-5107 (Supp. 1982). As introduced, it would have added the following provision to section 4(b)(2)(B):

. . . including (within one year after the date of the enactment of the Child Abuse Amendments of 1983) the establishment of a procedure for any interested person to report to appropriate authorities any known or suspected instance of the denial of nutrition (including fluid maintenance), medically indicated treatment, general care, or appropriate social services to infants at risk with life-threatening congenital impairments.

Hearings Before the Subcomm. on Select Education of the Comm. on Education and Labor, supra note 19, at 5. For a criticism of treatment that is "medically contraindicated" as unintelligible, see Foster, *supra* note 100.

349. See Conference Report, *supra* note 19, at 4.

350. See H.R. 1904, § 121, reprinted in Conference Report, *supra* note 19, at 4.

351. *Id.* § 121(3).

ently comatose;³⁵² (2) if treatment "merely prolong[s] dying";³⁵³ (3) if it cannot ameliorate or correct "all of the infant's life-threatening conditions";³⁵⁴ (4) if treatment is futile;³⁵⁵ or (5) if treatment is "virtually futile" and "the treatment itself under such circumstances would be inhumane."³⁵⁶ In all cases, even if treatment is otherwise unnecessary, "appropriate nutrition, hydration [and] medication" must be provided.³⁵⁷

House Bill 1904 is ambiguous and may require treatment contrary to the infant's best interest in some cases. There can be little debate about exempting from treatment infants whose death is imminent or for whom treatment is futile. In such cases, treatment may increase suffering without offering any benefit to the infant.³⁵⁸ Likewise, compulsory treatment for a persistently comatose patient has been consistently rejected.³⁵⁹ Uncertainty arises when one considers whether such infants must always be given food, water and medicine. For example, state courts³⁶⁰ and moralists³⁶¹ are divided on whether artificial feeding must be provided for a persistently vegetative patient. Without a possibility of gaining consciousness, the patient has no measurable interest in continued existence. While some commentators would require continued artificial feeding, they distinguish food from medical care.³⁶² Indeed, for many, it is morally acceptable to fail to treat with antibiotics a person suffering from an incurable and painful disease who contracts an infection.³⁶³ Death may be in the patient's best interest because it relieves the patient from continued suffering.

Faced with the foregoing examples, medical personnel may be uncertain whether nutrition, hydration and medication are always necessary. Thus the statute provides that "failure to provide treatment

352. *Id.* § 121(3)(A).

353. *Id.* § 121(3)(B)(i).

354. *Id.* § 121(3)(B)(ii).

355. *Id.* § 121(3)(B)(iii).

356. *Id.* § 121(3)(C).

357. *Id.* § 121(3).

358. See Robertson, *supra* note 45, at 236-37.

359. See e.g., *In re Barry*, 445 So. 2d 365 (Fla. App. 1984); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982).

360. See *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983); *In re Conroy*, 190 N.J. Super. 453, 464 A.2d 303, *cert. granted*, 470 A.2d 418 (1983).

361. See Commission Report, *supra* note 21, at 190-91; Annas, *Nonfeeding: Lawful Killing in CA, Homicide in NJ*, *supra* note 158; Lynn & Childress, *supra* note 158.

362. See, e.g., *In re Conroy*, 190 N.J. Super. 453, 464 A.2d 303, *cert. granted*, 470 A.2d 418 (1983).

363. See Commission Report, *supra* note 21, at 84-87.

(other than appropriate nutrition, hydration, or medication)" is not neglect if "the infant is chronically and irreversibly comatose."³⁶⁴ That medication, food and water must be "appropriate" before being required suggests that they are necessary only if in the best interest of the infant.³⁶⁵ But the statute also states that appropriate nutrition, hydration and medication must be given to the comatose infant. That implies that they would always be required for the infant because the statute distinguishes between unnecessary treatment and necessary nutrition, hydration or medication. Once an infant is irreversibly and chronically comatose, it would seem that the need for nutrition, hydration and medication is either appropriate or inappropriate in all such cases. If the statute compels medication, food and water for persistently vegetative infants, it requires treatment in violation of the infant's best interest. As discussed below,³⁶⁶ that may be unconstitutional.³⁶⁷

It was argued above that application of the best interest test to a case like Baby Jane Doe's makes denial of treatment legally acceptable.³⁶⁸ It is unclear how her case would be decided under H.R. 1904. Baby Jane Doe's case would be governed by section 121(3)(C), which allows treatment to be denied or withdrawn if the treatment would be "virtually futile" and "under such circumstances would be inhumane."³⁶⁹

There was conflicting testimony concerning Baby Jane Doe's life expectancy if she were treated.³⁷⁰ Section 121(3)(C) seems to allow denial of treatment if medical testimony establishes that an infant's life expectancy is short. In such a case, treatment would neither "merely prolong dying"³⁷¹ nor be "futile in terms of the survival of the infant."³⁷² But treatment would be "virtually futile,"³⁷³ not because it

364. H.R. 1904, § 121(3)(A), *reprinted in* Conference Report, *supra* note 19, at 4.

365. "Appropriate" is defined as "suitable or fitting for a particular purpose, occasion, person, etc." AMERICAN COLLEGE DICTIONARY 62 (Random House rev. ed. 1975).

366. *See supra* notes 347-61 and accompanying text.

367. A similar problem would arise in a case of an infant for whom treatment "merely prolong[s] dying." H.R. 1904, § 121(3)(B)(i), *reprinted in* Conference Report, *supra* note 19, at 4. If such an infant contracted an infection, failure to treat that illness with medication might be in its best interest. The statute would apparently require treatment.

368. *See supra* text, *The Right to Refuse Medical Treatment*, and accompanying notes 147-290.

369. H.R. 1904, § 121(3).

370. *See* Hentoff, *Big Brother and the Killing of Imperfect Babies*, *The Village Voice*, Dec. 6, 1984, *reprinted in* 10 HUM. LIFE REV. 73, 75-78 (1984).

371. H.R. 1904, § 121(3)(B)(i), *reprinted in* Conference Report, *supra* note 19, at 4.

372. H.R. 1905, § 121(3)(B)(iii).

373. *Id.* § 121(3)(C), *reprinted in* Conference Report *supra* note 19, at 4-5.

failed to correct the underlying anomaly, but because it prolonged life for too short a time. Further, treatment of an infant like Baby Jane Doe might be withdrawn or denied because it is inhumane to subject an infant with little chance of a meaningful existence to repeated surgical procedures.

Both concepts—"virtually futile" and "inhumane" treatment—are subject to interpretation. Read narrowly, section 121(3)(C) may be invoked to compel treatment for an infant relegated to a marginal existence if medical evidence indicates that life expectancy is for more than a year or two. As with the government's section 504 stance, H.R. 1904 allows the treatment decision to be made without reference to the state standard of the child's best interest.

To date, the Supreme Court has denied certiorari in cases in which denial or refusal of treatment was grounded on the constitutional right to privacy.³⁷⁴ Given the Supreme Court's recent development of that right³⁷⁵ and the substantial authority for extending it to medical decisionmaking,³⁷⁶ it is probable that the Supreme Court will find that the right to privacy encompasses the right to refuse medical treatment. If so, H.R. 1904 is subject to constitutional challenge insofar as it may require treatment contrary to an infant's best interest.

A child does not necessarily enjoy the same constitutional rights as an adult. Majority may be a precondition for the exercise of a right,³⁷⁷ or a minor may have a right subject to different conditions.³⁷⁸ State courts have suggested that the constitutional right to be free from unnecessary treatment extends to seriously ill newborns.³⁷⁹ That view, however, has analytical difficulties; ordinarily, a person chooses to exercise her constitutional right, but an incompetent cannot do so. As dis-

374. See *In re Storar*, 52 N.Y.2d 363, 376, 420 N.E.2d 64, 70, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981).

375. See, e.g., *Planned Parenthood Ass'n of Kansas City v. Ashcroft*, 462 U.S. 476 (1983); *City of Akron v. Akron Center for Reproductive Health, Inc.*, 462 U.S. 416 (1983); *H.L. v. Matheson*, 450 U.S. 398 (1981); *Bellotti v. Baird*, 443 U.S. 622 (1979).

376. See cases cited *supra* note 147.

377. See, e.g., *McKeiver v. Pennsylvania*, 403 U.S. 528 (1971) (a child need not be granted the right to a jury trial in juvenile proceedings).

378. *H.L. v. Matheson*, 450 U.S. 398 (1981) (limiting the right of a minor to procure an abortion); *Carey v. Population Servs. Int'l*, 431 U.S. 678 (1977) (recognizing the right of minors to access to information about contraceptives); *In re Gault*, 387 U.S. 1 (1967) (due process applies to juvenile proceedings but does not necessarily apply the same standards relevant in adult proceedings).

379. *In re Barry*, 445 So. 2d 365 (Fla. App. 1984); *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982).

cussed above, some incompetents' surrogates may apply the substituted judgment test, which test has little meaning for a person who has never formed goals and values.³⁸⁰ The Massachusetts Supreme Judicial Court has relied on the thinly veiled fiction that the substituted judgment test applies in such cases; in effect, an infant would choose to have others act in her best interest.³⁸¹ The law does require a court to act in an infant's best interest without considering how an infant might choose to be treated.³⁸²

There is a critical distinction between state law requiring the infant to be treated consistently with her best interest and a constitutional right to privacy that encompasses the right to refuse treatment. Congress might be able to overturn state law, but it cannot impair the constitutional right.³⁸³ If H.R. 1904 were applied to require treatment contrary to an infant's best interest, a litigant might argue that the court should accept the substituted judgment fiction to allow the infant to "choose" to resist treatment. A court might also hold that in the absence of a capacity to make a meaningful judgment, the infant has a constitutional right to be treated consistently with her best interest. That is, instead of denying the infant the constitutional right entirely, a court may fashion a less flexible standard by which an infant would retain part of the right.

There is some precedent for such an approach. For example, the Supreme Court has held that a minor female has a constitutional right to an abortion,³⁸⁴ but that the minor's constitutional right is not coterminous with that of an adult.³⁸⁵ The minor's right to an abortion is subject to reasonable limitations because of "the peculiar vulnerability of children; their inability to make critical decisions in an informed, mature manner; and the importance of the parental role in child rearing."³⁸⁶ As a result, a state may require administrative procedures before a minor can exercise her right, but it cannot deny the right

380. See *supra* notes 186-204 and accompanying text.

381. See *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982); *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

382. See Commission Report, *supra* note 21, at 217-23.

383. See J. NOWAK, R. ROTUNDA & J. YOUNG, *HANDBOOK ON CONSTITUTIONAL LAW* 15-20 (1978).

384. See, e.g., *Bellotti v. Baird*, 443 U.S. 622 (1979); *Planned Parenthood v. Danforth*, 428 U.S. 52 (1976).

385. See, e.g., *H.L. v. Matheson*, 450 U.S. 398 (1981).

386. *Bellotti v. Baird*, 443 U.S. at 634 (Powell, J., plurality opinion). See also *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983).

entirely.³⁸⁷

The Supreme Court also has required, however, that the state allow a mature minor to exercise her own constitutional right,³⁸⁸ indicating that if the minor failed to establish that she was sufficiently mature to make the decision for herself, the state must allow the minor to procure an abortion over parental objection if the abortion would be in her best interest.³⁸⁹ Thus, the Court has established that the right to privacy may be exercised consistently with the best interest standard, at least in the abortion context. If minors incapable of exercising mature judgment have a constitutional right to be treated in a manner that is consistent with their best interest, H.R. 1904 would be unconstitutional insofar as it requires treatment of a seriously ill newborn contrary to her best interest.

CONCLUSION

The *University Hospital* litigation is an instance of an exercise of raw executive power³⁹⁰ and demonstrates the evanescence of principles when they conflict with political ends.³⁹¹ The government developed its section 504 strategy in response to President Reagan's personal insistence after he heard about the *Indiana Infant Doe* case.³⁹² In its subsequent supplementary information, HHS cited only four instances of alleged abuse of newborns suffering from mongolism.³⁹³ In at least one of those cited cases, the child's best interest may have been protected: *Infant Doe* may have been suffering from additional anomalies that could have contraindicated surgery.³⁹⁴ Without hearings on the question, it is hard to understand how the President and HHS concluded that denial of treatment was sufficiently widespread to justify federal intervention.

387. 443 U.S. at 649. *Accord* *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983).

388. 443 U.S. at 649.

389. *Id.*

390. This is a modification of Justice White's phrase, "an exercise of raw judicial power." *Doe v. Bolton*, 410 U.S. 179, 222 (1973) (White, J., dissent, which he also applies to *Roe*).

391. See *supra* notes 307-43 and accompanying text.

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

393. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,847-48. See also *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied sub nom. Bothman v. Warren B.*, 445 U.S. 949 (1980). A considerable amount of controversy arose concerning the appeals court decision, and guardianship was eventually transferred to the couple caring for Phillip, thereby allowing them to consent to surgery. See *supra* note 54.

394. See *supra* note 26.

Apart from the lack of evidence of a need for federal action, the administration chose a course of action for which there was no statutory authority. It is inconceivable that Congress intended to create federal jurisdiction over treatment decisions for seriously ill newborns when it enacted section 504. The statutory language has a plain meaning in other contexts, but must be strained to cover cases like *Baby Jane Doe*. There is no evidence in the record that Congress intended federal officials to coerce parents to consent to treatment for a seriously ill newborn.³⁹⁵ Elsewhere Congress has eschewed that kind of intervention.³⁹⁶ Apart from whether it has the authority to do so, Congress would not silently transform cases within the state police power into federal cases.³⁹⁷ The government's section 504 approach, however, would have precisely that effect. Not only would the government be empowered to sue in federal court, but also a guardian might be so empowered because section 504 creates a private right of action.³⁹⁸ Moreover, although HHS's regulations address only newborns, there would be no reason to limit such actions to this group because there would be no principled basis for distinguishing treatment decisions involving newborns from those made on behalf of incompetent patients.

Although not without uncertainty, it appears that a plaintiff who disagreed with a decision not to treat would be well-advised to sue in federal court rather than in state court. At least at first glance, the government's section 504 interpretation includes a stringent substantive test that forbids subjective quality of life considerations because of the equal value of all lives and that requires the performance of all medically indicated procedures, i.e., those that would be performed on an infant but for its handicap.³⁹⁹ However, the government has shifted its view of that principle on different occasions. When pressed, Surgeon General Koop retreated from the apparent meaning of those words;

395. See *supra* notes 114-45 and accompanying text.

396. See, e.g., 42 U.S.C. § 1395 (1976) (dealing with health insurance for the aged and disabled):

Nothing in this subchapter shall be construed to authorize any Federal officer or employee to exercise any supervision or control over the practice of medicine or the manner in which medical services are provided, or over the selection, tenure, or compensation of any officer or employee of any institution, agency, or person providing health services; or to exercise any supervision or control over the administration or operation of any such institution, agency, or person.

397. See, e.g., *United States v. Bass*, 404 U.S. 336, 349 (1971).

398. See *supra* text accompanying notes 138-45.

399. Reagan, *supra* note 3; *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14.

prolongation of life even for substantial periods of time is not mandated for infants suffering from some severe handicaps.⁴⁰⁰ An even further retreat was made at oral argument to the district court in *University Hospital* when the government conceded that up to that point, despite substantial discovery, it had found no discrimination against Baby Jane Doe.⁴⁰¹ The government's final position, therefore, is unclear. It seems that some infants suffering from spina bifida may be denied aggressive treatment, but not others, despite the likelihood that aggressive treatment will substantially prolong the infant's life. It is difficult to imagine how the government could believe, consistently with the premise of equal value of all lives, that only some children suffering from a particular disorder deserve full treatment. Furthermore, the government, acting as it did, apparently felt free to pick and choose among various congenital abnormalities. In effect, it drafted its own medical code because it was unfettered by any limitations posed by the language or history of the statute. The government's shifting position and arbitrary standards are further evidence that Congress never intended section 504 to affect treatment decisions for seriously ill newborns.

There is a second sense in which *University Hospital* was an exercise in *raw executive power*. Why was *Baby Jane Doe* made the test case? The impetus for the government's section 504 position came from the specter of hospital personnel starving a mongoloid infant to death.⁴⁰² Baby Jane Doe was far more debilitated than Infant Doe, but was provided with food and medical treatment.⁴⁰³ Her case had been extensively litigated through three tiers of the New York court system. Through discovery and judicial opinions, the government was well aware of the basis for the parents' refusal to provide aggressive treatment. The government conceded that it found no discrimination up to October 19, the last date for which it had the medical records.⁴⁰⁴ Nevertheless, it insisted that it needed to continue to monitor the situation. The government's reasoning would make federal intervention a lifetime commitment—an awful specter. It is hard to imagine a similar commitment to continuing discovery of medical records for every seriously

400. Singer & Kuhse, *supra* note 39, at 18-19.

401. United States v. University Hosp., 729 F.2d 144, 148 (2d Cir. 1984), *aff'd* 575 F. Supp. 607 (E.D.N.Y. 1983).

402. See *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, *supra* note 14, at 30,847.

403. United States v. University Hosp., 575 F. Supp. 607, 610 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

404. United States v. University Hosp., 729 F.2d 144, 148 (2d Cir. 1984).

handicapped infant.⁴⁰⁵

Baby Jane Doe simply was in the wrong place at the wrong time. Despite indications in the record that the parents had acted in their child's best interest and despite the government's conceded doubt that failure to authorize surgery was discriminatory, *Baby Jane Doe* was made a test case for the government's section 504 strategy.

Finally, judged by its own principles, the administration engaged in an exercise of *raw executive power*. The administration gave full endorsement to efforts to pass the Human Life Bill.⁴⁰⁶ Anti-abortion advocates have begun to focus attention on decisionmaking for seriously ill newborns and generally see the issues as the same.⁴⁰⁷ Two principles emerged in the hearings on S. 158: first, that *Roe* was an extravagant interpretation of the law, without foundation in the Constitution or statutes; second, that matters like abortion intimately affect family matters and the safety, health and welfare of citizens—areas traditionally left to the states.⁴⁰⁸ Supporters of S. 158 believed that federalizing the abortion decision deprived the people and the states of the opportunity to form a consensus on an important life and death question.

Given those principles and the fact that this administration promised to free individuals from federal intervention, the *University Hospital* litigation is difficult to explain. The extent to which treatment is being denied contrary to the best interest of the child is a matter of speculation, but after its study of the subject, the President's Commission concluded that such instances are rare.⁴⁰⁹ More important, HHS attempted to fabricate a medical code only vaguely related to section 504.⁴¹⁰ But for the refusal of the federal courts to create federal jurisdiction, the federal government would have intruded into intimate family law matters on which the people and states have not had the opportunity to form a consensus.

There now is statutory authority for federal involvement in treatment decisions, and H.R. 1904 incorporates HHS's "medically indi-

405. This administration has shown little interest in other far more serious and widespread forms of discrimination in health care, for example, the inadequate medical treatment that results from poverty.

406. Reagan, *supra* note 3.

407. AMERICANS UNITED FOR LIFE LEGAL DEFENSE FUND, *supra* note 26.

408. See *supra* notes 320-34 and accompanying text.

409. See Commission Report, *supra* note 21, at 208.

410. See *supra* notes 89-145 and accompanying text.

cated" language.⁴¹¹ Passage of H.R. 1904 does not, however, resolve treatment cases without litigation because the terminology is ambiguous. As indicated above, attempting to make such decisions turn on "objective" medical factors, as opposed to "subjective" quality of life considerations, is illusory.⁴¹² Further, there are serious ethical reasons why quality of life considerations ought to affect a treatment decision. State courts are virtually unanimous in holding that treatment should be compelled in life threatening situations, but only if it promises net benefits to the infant.⁴¹³ Although this point is debatable, quality of life should be considered in that balance. Courts, commentators, patients and health care professionals rightly consider quality of life, whether or not they acknowledge it as such. If a patient lacks cognition, corrective procedures offer no benefit.⁴¹⁴ Depending on how courts interpret "medically indicated," H.R. 1904 may compel treatment contrary to an infant's best interest. If so interpreted, H.R. 1904 may be subject to a constitutional challenge.⁴¹⁵

In *University Hospital* the government abandoned its principles, supposedly in the name of higher principles: "My administration is dedicated to the preservation of America as a free land, and there is no cause more important for preserving that freedom than affirming the transcendent right to life of all human beings, the right without which no other rights have any meaning."⁴¹⁶ Apart from the fact that even this administration does not take that statement quite literally, invocation of such a high-sounding goal obscures the facts in *University Hospital*. The government brought to bear all of its political and financial muscle to influence a treatment decision in a case where it concededly doubted that aggressive treatment was appropriate. Baby Jane Doe could not benefit by the government's intervention, but other parents and hospitals cannot miss the lesson of her case: the parental constitutional right to determine appropriate treatment and an infant's right to be free from procedures of questionable value can quickly become exorbitantly expensive.⁴¹⁷ If we are to enact legislation allowing the govern-

411. H.R. 1904, 98th Cong., 1st Sess. (1983).

412. See *supra* notes 236-60 and accompanying text. See also *Fost*, *supra* note 100.

413. See *supra* notes 215-24 and accompanying text.

414. See *supra* text accompanying notes 261-75.

415. See *supra* text accompanying notes 344-89.

416. Reagan, *supra* note 3, at 16.

417. According to the father of Baby Jane Doe, the family had already spent over \$100,000 on legal and medical fees, and they anticipated spending at least that amount again before the matter was finally resolved. CBS television interview, *60 Minutes: Baby Jane Doe's Parents* (Mar.

ment to intervene in treatment decisions, its power should be directed toward more productive results. As observed in a related context, "for the [government] to do other than *either assume* full responsibility for the treatment, care, and nurture of [seriously handicapped] children or *honor* the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life."⁴¹⁸

11, 1984).

418. Goldstein, *supra* note 280, at 153.