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NOTES

THE CHILD ABUSE AMENDMENTS OF 1984: INADEQUATE PROCEDURAL DUE PROCESS SAFEGUARDS

INTRODUCTION

When we stand before a broken child and ask what we should do or avoid doing, we also stand before ourselves and before the civilization we both reflect and shape.¹

Each year approximately 30,000 severely handicapped infants are born in the United States.² The handicaps with which these children are born range from myelomeningocele (spina bifida)³ and Down's Syndrome⁴ to anencephal.⁵ In significant numbers, handicapped infants have been denied

1. Beck, *On Withholding Treatment: A Working Paper for the Professional Standard and Practice Council of the Canadian Psychiatric Association*, 1978 Canadian Psychiatric Association Position Paper 10a.

2. See *Medical Ethics: The Right to Survival, 1974: Hearings on the Examination of the Moral and Ethical Problems Faced with the Agonizing Decision of Life and Death Before the Subcomm. on Health of the Senate Comm. on Labor and Public Welfare*, 93rd Cong. 2d Sess. 26 (1974).

3. Spina Bifida with myelomeningocele is an open defect in the spine and associated structures, and occurs in up to 4 infants per 1,000 births. W. NELSON, *TEXTBOOK OF PEDIATRICS* 1412-14 (R. McKay & V. Vaughan 10th ed. 1975). The condition causes various degrees of permanent paralysis and deformity. Mental retardation accompanies this condition in fifty percent of the cases, and hydrocephalus (a gross enlargement of the cranium caused by accumulation of fluid in the brain) develops in ninety percent of the cases. *Id.*

4. Down's Syndrome, also known as mongolism or trisomy 21 syndrome, occurs in approximately 1.5 infants per 1,000 births and is accompanied by various degrees of retardation and personality disorders. W. NELSON, *supra* note 3, at 134-37. As a result of recent improvements in the education and training of people with Down's Syndrome, many of those afflicted with the condition are now able to live fairly normal, productive lives. See also, Ellis, *Letting Defective Babies Die, Who Decides?*, 7 AM. J.L. & MED. 393, 396-97 (1982).

5. This condition, which occurs in 1 out of every 1,000 births, is the partial or total absence of brain. So severe is this condition that one medico-legal dictionary terms encephalous "a fetal monster without a brain." B. MALOY, *MEDICAL DICTIONARY FOR LAWYERS* 49 (1960). Medical intervention possibly could sustain life, but the sort of life sustained is difficult to imagine with all or substantial portions of the brain missing. Cognitive function, if at all present, would be minimal. Ellis, *supra* note 4, at 397.

immediate life-saving treatment.⁶

The withholding of immediate medical treatment from handicapped infants has spawned prolonged debate in the legal⁷ and medical⁸ communities. In response, the Child Abuse Amendments of 1984 were signed into law.⁹ The Amendments mandate that infants born with handicaps which endanger their lives are entitled to immediate life-saving treatment.¹⁰ The Amendments, however, allow physicians, exercising competent medical judgment, to withhold treatment from a handicapped infant in three situations: (1) when the infant is chronically comatose; (2) when treatment would prolong dying; (3) when treatment would be inhumane.¹¹ The infants

6. U.S. COMMISSION ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES 35 (1983).

7. Annas, *Refusal of Lifesaving Treatment for Minors*, 23 J. FAM. L. 217 (1984); Clarke, *The Choice to Refuse or Withhold Medical Treatment: The Emerging Technological and Medical Ethical Consensus*, 13 CREIGHTON L. REV. 795 (1980); Ellis, *Letting Defective Babies Die, Who Decides?*, 7 AM. J.L. & MED. 393 (1982); Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice?*, 27 BAYLOR L. REV. 76 (1975); Kelsey, *Which Infants Should Live, Who Should Die?*, 5 HASTINGS CENTER REP. 5 (Apr. 1975); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1974); Shaw, *Genetically Defective Children: Emerging Legal Considerations*, 3 AM. J.L. & MED. 333 (1977); Note, *Baby Doe Decisions: Modern Society's Sins of Omission*, 63 NEB. L. REV. 889 (1984); Note, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEX. TECH. L. REV. 569 (1983).

8. Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele in INFANTICIDE AND THE HANDICAPPED NEWBORN* 69 (M. Delahoyd & D. Horan eds. 1982); Diamond, *The Deformed Child's Right to Life*, in DEATH, DYING AND EUTHANASIA 127 (D. Horan & D. Mall eds. 1977); Koop, *Ethical and Surgical Considerations in the Case of the Newborn with Congenital Abnormalities*, in INFANTICIDE AND THE HANDICAPPED NEWBORN 89 (M. Delahoyd & D. Horan eds. 1982); Black, *Selective Treatment of Infants with Myelomeningocele*, 5 NEUROSURGERY 334 (1979); Campbell & Duff, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (1973); Johnson, *Selective Non-Treatment and Spina Bifida: A Case Study in Ethical Theory and Application*, 3 BIOETHICS Q. 91 (1981); Lorber, *Spina Bifida: To Treat or Not to Treat? Selection—The Best Policy Available*, 147 NURSING MIRROR 14 (1978); McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 339 J.A.M.A. 172 (1974); Shaw, *Dilemma of "Informed Consent" in Children*, 2389 NEW ENG. J. MED. 885 (1973); Silverman, *Mismatched Attitudes About Neonatal Death*, 11 HASTINGS CENTER REP. 12 (Dec. 1981).

9. Child Abuse Amendments of 1984, Pub. L. No. 98-457, tit. 1, secs. 121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C.A. §§ 5101-5103 (Supp. 1986)) [hereinafter Child Abuse Amendments].

10. *Id.* at § 5102(B)(3). Section 5102(B)(3) states in part:

(3) the term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions. . . .

Id.

11. *Id.* Section 5102(B)(3) states in part:

(3) [E]xcept that the term does not include the failure to provide treatment (other

included within each exception are not protected by binding enforcement procedures¹² and consequently will be allowed to die.¹³ As a result of inadequate procedural due process safeguards, the Amendments have proven ineffective in protecting the handicapped infant.¹⁴ The Amendments imperil the life of the newborn. The newborn's life far outweighs the government's interest in curtailing fiscal and administrative costs.¹⁵ As such, more effective procedural safeguards are warranted.

Initially, this note will review the interests involved in the decision to withhold immediate life-saving medical treatment from a handicapped infant. Next, the past regulations and their enforcement procedures will be examined and compared with the Child Abuse Amendments of 1984. Finally, the note will analyze the handicapped infant's constitutional right to procedural due process and will propose suggestions for legislative reform to effectuate this constitutional right.

COMPETING RIGHTS AND INTEREST

In significant numbers, disabled newborns have been denied immediate medical treatment.¹⁶ For example, on April 9, 1982, "Infant Doe" was born in Bloomington, Indiana.¹⁷ The infant needed surgery to correct a blocked esophagus and thereby allow food to reach his stomach.¹⁸ "Infant Doe's" parents refused immediate life-saving treatment.¹⁹ Six days later the infant

than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all the infant's life-threatening conditions, or (iii) otherwise be futile in terms of survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id.

12. 42 U.S.C.A. § 5103 (Supp. 1986). See also Bopp & Balch, *The Child Abuse Amendments of 1984 and their Implementing Regulations: A Summary*, 2 ISSUES IN LAW & MED. 91, 123 (1985).

13. See *infra* notes 77 and 127 and accompanying text.

14. See *infra* note 102 and accompanying text. See also *infra* notes 59-72 and accompanying text.

15. *Lassiter v. Dep't of Social Services*, 452 U.S. 18, 60 (1981) (Stevens, J., dissenting).

16. See *supra* note 6.

17. *In re Treatment and Care of Infant Doe*, No. GU 8204-004A, slip op. at 2 (Monroe County Cir. Ct. Apr. 12, 1983), petition for writ of mandamus and prohibition, *denied*, *sub nom* State of Indiana *ex rel* Infant Doe *v.* Monroe Circuit Court, No. 482 S 140 (Ind. Apr. 14, 1982), *appeal dismissed*, *sub nom. In re Guardianship of Infant Doe*, No. 1-782 A 157 (Ind. Ct. App. Feb. 3, 1983), *petition for transfer denied*, No. 1-782 A 157 (Ind. June 15, 1983), *cert. denied*, 104 S. Ct. 394.

18. *Id.* at 2-3.

19. *Id.*

died.²⁰

The following year, under the "Oklahoma Experiment," twenty-four infants born with spina bifida were denied immediate medical treatment on the basis of a "quality of life" evaluation.²¹ The "quality of life" evaluation was based on arbitrary socio-economic criteria, rather than medical criteria.²² Within thirty-seven days the twenty-four infants died.²³

In most cases, parents have a right to make fundamental decisions with regard to their children's care.²⁴ However, if the parents fail to care for the child, the state will intervene to protect the child.²⁵ In some cases, when parents have refused life-saving medical treatment for their child, the state has intervened²⁶ to ensure the infant's constitutional right to life.²⁷ Moreover, courts have overruled parent's medical decisions even where the situation is not life-threatening.²⁸ As such, the parent's decision-making power is

20. *Baby's Death Brings End to Court Battle*, The Evansville Courier, Apr. 16, 1982, at 1, col. 3.

21. Gross, Cox, Tatyrek, Pollay, & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 PEDIATRICS 450, 455 (1983). An article which describes a five-year experiment conducted by staff of the Department of Orthopaedic Surgery, Pediatrics, Neurosurgery and Urology of the University of Oklahoma Health Sciences Center and staff of the Department of Social Service, Oklahoma Children's Memorial Hospital, Oklahoma City.

22. See *infra* note 31 and accompanying text.

23. See Gross, *supra* note 21 and accompanying text.

24. United States v. Orito, 413 U.S. 139, 142 (1973) (right of privacy extends to certain aspects of family relationship); Wisconsin v. Yoder, 406 U.S. 205 (1972) (right of Amish to educate their children); Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925) (right to choose parochial schools over public schools).

25. *In re Clark*, 21 Ohio Op. 2d 86, 90, 185 N.E.2d 128, 132 (1962). See also Brandt, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337, 362-63 (1981).

26. *Jehovah's Witnesses v. King County Hosp. Unit No. 1*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968) (ordering blood transfusions where parent was a Jehovah's Witness who refused to consent to a transfusion); *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978) (ordering chemotherapy for leukemia-stricken child over parental objections); *John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971) (ordering transfusions for a 22-year old comatose patient over parental objections).

27. See *Roe v. Wade*, 410 U.S. 113 (1973). The Court held that from "the moment of live birth there exists a human being entitled to the fullest protection of the law and the most basic rights enjoyed by every human being." *Id.* See also the fifth, ninth, and fourteenth amendments' guarantee of a person's right to life. The fifth amendment states: "No person shall . . . be deprived of life . . . without due process of law. . . ." U.S. CONST. amend. V. The fourteenth amendment requires the same guarantees to be provided by states. U.S. CONST. amend. XIV, § 1. The right to life might otherwise be guaranteed by the ninth amendment. "The enumeration in the Constitution, of certain rights, shall not be construed to deny, or disparage others retained by the people." U.S. CONST. amend. IX.

28. *Custody of a Minor*, 378 Mass. 732, 393 N.E.2d 836 (1979) (court proscribed treatment in second *Chad Green* case).

tempered by the state's interest in the child's welfare.²⁹

The balancing of these interests is further complicated by the conflicting views held by the medical profession.³⁰ Some physicians argue that before a handicapped infant is treated, several factors must be examined.³¹ These factors include the patient's physical attributes and I.Q., the parent's income and I.Q., and the government's contribution for immediate surgery and life-maintenance.³² Under this scheme, if the patient's resources are too low and the resources required of the government are too high, treatment is denied.³³ As physicians themselves concede, the handicapped infant's future is indeed uncertain under this formulation.³⁴

Other physicians advocate that the decision to withhold treatment should be based on a "sanctity of life" system of ethics and are positive about the infant's future.³⁵ These physicians argue that children born with spina bifida and Down's Syndrome should be given immediate treatment because no valid criteria exists for the selection of infants³⁶ and because there is no way to accurately predict the future health and mental abilities of the child.³⁷ In any event, these physicians feel that the decision to withhold life-saving treatment should not rest with the medical community.³⁸

29. See *supra* notes 25-28.

30. See *infra* notes 31-37 and accompanying text.

31. The recommendation made by the myelomeningocele team in "Oklahoma Experiment" for either vigorous treatment or supportive care (i.e., no active treatment) was primarily made by applying a formula developed by Shaw for assessing the quality of life for an infant. Shaw, *Defining the Quality of Life*, 7 HASTINGS CENTER REP. 11 (1977). The Shaw formula described in Gross, *supra* note 21, at 456, is as follows: "QL = NE x (H + S); QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual; H is the contribution from home and family; and S is the contribution from society." Gross, *supra* note 21, at 456.

32. Gross, *supra* note 21, at 456.

33. See Gross, *supra* note 21, at 455.

34. *Id.* See also Dr. Raymond Duff, Department of Pediatrics, Yale-New Haven Hospital, CBS Morning News, May 18, 1982. "What nature or God has created extremely imperfectly should be left alone and go back to nature." *Id.*

35. McLone, *Letters to the Editor: Care of Infants with Myelomeningocele*, 74 PEDIATRICS 162, 163 (1984).

In our hands prompt treatment of unselected patients with myelomeningocele ensures that 85% survive, and of the surviving children 73% have normal intelligence, 74.5% are community ambulators, and 85% are continent of urine on clean intermediate catheterization.

Id.

36. Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele*, in INFANTICIDE 69, 74 (M. Delahoyd & D. Horan, eds. 1982). See also McLone, *Results of Treatment of Children Born with Myelomeningocele*, 30 CLINICAL NEUROSURGERY 407 (1983).

37. Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele* at 70.

38. Beck, *supra* note 1, at 5a. "The aspiration of our profession has always been to spare no effort in our attempt to prevent illness, to promote healing, to reduce suffering and to

As a result of the conflict between the parents, the state, and the medical community, the handicapped infant's future is not certain. While in some cases courts have upheld the infant's constitutional right to life,³⁹ in others, the parent's right to make decisions with respect to their children's medical treatment has remained paramount.⁴⁰ Some physicians actively treat all disabled newborns,⁴¹ while other physicians only treat infants who meet a socio-economic criteria.⁴² In reaction to this disparity of treatment for the disabled newborn, the "Baby Doe" regulations were passed to prohibit discrimination against handicapped infants.⁴³

PAST REGULATIONS AND THEIR ENFORCEMENT PROCEDURES

Despite the medical community's suggestion that the decision to withhold treatment be left to parents and physicians, the Department of Health and Human Services (HHS) issued the "Baby Doe" regulations.⁴⁴ The "Infant Doe" case prompted the President to direct HHS to take administrative action on behalf of the handicapped infants denied immediate medical treatment.⁴⁵ The first notice HHS issued to health care providers was a flat prohibition against unlawful withholding of nutritional sustenance or re-

save lives. . . . The physician must be on the side of his patient. This is his traditional role, and this is his only role."

Id.

39. See *supra* note 27.

40. See *supra* note 24.

41. See *supra* notes 35-38 and accompanying text.

42. See *supra* notes 21, 31 and 34 and accompanying text.

43. Dep't of Health and Human Services, Off. of the Sec'y., *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 40 C.F.R. § 84.55 (1985) [hereinafter Section 504 Baby Doe Regulations]. These regulations were struck down on June 11, 1984, in a suit brought by the American Hospital Association. *American Hosp. Assoc. v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984). That federal district court ruling was affirmed by the Second Circuit Court of Appeals on December 27, 1984. *American Hosp. Assoc. v. Heckler*, No. 84-6211 (2d Cir. Dec. 27, 1984). Both courts regarded themselves as bound by an earlier Second Circuit ruling which had held that "[c]ongress never contemplated that Section 504 would apply to treatment decisions of this nature." *United States v. University Hosp.*, 729 F.2d 144, 157 (2d Cir. 1984). The United States Supreme Court granted certiorari to review the decision striking down the Section 504 Baby Doe regulations on June 17, 1985. *American Hosp. Assoc. v. Heckler*, 53 U.S.L.W. 3881 (June 17, 1985). The United States Supreme Court held that the district court and the court of appeals correctly held that the investigative actions by the Dep't of Health and Human Services were not authorized by the Rehabilitation Act and that the regulations which purport to authorize a continuation of them are invalid. *Bowen v. American Hosp.*, 106 S. Ct. 2101 (1986).

44. Section 504 Baby Doe Regulations at § 84.55.

45. Presidential memorandum to the Attorney General and the Secretary of Health and Human Services (April 30, 1982) (On the Enforcement of Federal Laws Prohibiting Discrimination Against the Handicapped).

quired medical treatment from disabled infants.⁴⁶ Although the medical profession criticized the notice, HHS reminded hospitals receiving financial aid that Section 504 of the Rehabilitation Act of 1973⁴⁷ applied to disabled infants.

The second version of the regulations decreased the protection for disabled newborns under Section 504.⁴⁸ While Section 504 prohibits discrimination against disabled infants on the basis of handicap, "medical decisions" by parents and physicians to withhold treatment were outside the section's scope.⁴⁹ Rather, Section 504 only applied when "non-medical" quality of life considerations, such as handicap, persuaded parents and doctors to withhold treatment.⁵⁰

The final version of the regulations⁵¹ gave more discretionary power to parents and doctors in the decision-making process⁵² and less protection for the handicapped infant. The new "Baby Doe" regulations required an infant to receive immediate life-saving treatment only when it was in the "reasonable medical judgment" of the physician or the judgment of a hospital review committee.⁵³ The HHS could only outline guidelines for the review committees.⁵⁴ In as much as this medical standard was vague and ar-

46. Office for Civil Rights, Department of Health and Human Services, *Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, 47 Fed. Reg. 26027 (June 16, 1982) (notice issued May 18, 1982, applying 45 C.F.R. § 84 to health services for handicapped children) [hereinafter Notice]. The notice states in part:

[I]t is unlawful . . . to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

Id.

47. 29 U.S.C. § 794 (1976). Section 504 states in 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 subjected to discrimination under any program or activity receiving Federal financial assistance. . . .

Id. at § 504.

48. Office of the Secretary, Department of Health and Human Services, *Nondiscrimination on the Basis of Handicap Relation to Health Care for Handicapped Infants*, 48 Fed. Reg. 30846 (July 5, 1983) (proposed rule modifying 45 C.F.R. § 84.61) [hereinafter Proposed Rule].

49. *Id.* at 30847. The Secretary said, "Section 504 does not compel medical personnel to attempt to perform impossible futile acts of therapies . . . which merely temporarily prolong the process of dying. . . ." *Id.* at 30846.

50. *Id.*

51. Section 504 Baby Doe Regulations, *supra* note 43.

52. 45 C.F.R. §§ 84.55(b)(3), (4) (1985).

53. *Id.*

54. 45 C.F.R. § 84.55(f) (1985). (The Infant Care Review Committees were not governmentally controlled.)

bitrary,⁵⁵ the “Baby Doe” regulations decreased the protection for the disabled newborn.

As a result of the vague “reasonable medical judgment” standard, the “Baby Doe” regulations authorized HHS to activate a special investigative unit.⁵⁶ Also, the “Baby Doe” regulations required the state child abuse agencies to establish procedures⁵⁷ to report instances of discrimination against disabled newborns. Unfortunately, the investigative unit and the reporting procedures did not prove effective in prohibiting the denial of life-saving medical treatment for infants based on their handicap.⁵⁸

HHS not only failed to activate the special enforcement unit,⁵⁹ HHS also failed to respond to reports of cases of treatment denial.⁶⁰ Instead of immediate enforcement action, the new investigative office was changed to a research program to develop information on civil rights.⁶¹ Reported cases of treatment denial continue to be listed by HHS as under investigation.⁶² Therefore, HHS had little effect on the denial of life-saving treatment for disabled infants.⁶³

55. *Id.*

56. 45 C.F.R. § 84, App. C(b) (1985).

57. 45 C.F.R. § 84.55(c) (1985).

58. *See infra* notes 59-77 and accompanying text.

59. *Medical Battle Lines are Drawn*, Sherwood Series in the Wash. Times, July, 1984, at 5, col. 4. “Traditionally the Department of Health and Human Services has been run by and for the medical community, with doctors and hospital administrators in key positions throughout the agency.” *Id.* *See also Infighting Results in Retreat*, Sherwood Series in the Wash. Times, July, 1984, at 13, col. 2:

Records and interviews also demonstrate that, at the same time Mrs. Heckler, Secretary of the Department of Health and Human Services, was promising to rigorously enforce federal regulations, she failed to activate a special ‘Baby Doe’ investigative unit—reversing her own earlier decisions and the recommendations of the U.S. Surgeon General that an ‘autonomous’ investigative office was necessary to enforcement.

Id.

60. *Weakest Protection for Weakest of Weak*, Sherwood Series in the Wash. Times, July, 1984, at 4, col. 1.

In the two years the Department of Health and Human Services has been keeping files on reported nontreatment of handicapped infants, at least 200 cases have been referred to the federal government for action, in many cases by hospital personnel. More than half of those reported incidents—some two years old and involving reports of starvation and injection deaths—continue to be listed by the Department of Health and Human Services as under investigation. So far, no doctor or hospital has been prosecuted by the federal government for depriving a handicapped child medical care.

Id.

61. *Infighting Results in Retreat*, Sherwood Series in the Wash. Times, July, 1984, at 14, col. 4.

62. *See* Sherwood, *supra* note 60 and accompanying text.

63. Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma “Experiment”*, 1 ISSUES IN LAW & MED. 55, 55-57 (1985). The Department of Health and Human Services Office of Civil Rights took ninety-four days for the development of an investigative plan into

Unfortunately, the state child abuse agencies have not proven to be any more effective than HHS in prohibiting discrimination against infants born in need of immediate medical treatment. There are several reasons why state child abuse agencies have been less than effective in pursuing the interests of the handicapped infants.⁶⁴ In some instances, the agency personnel may agree with the "quality of life" judgments underlying non-treatment⁶⁵ and in other cases they do not have the time or expertise to properly contest such practices.⁶⁶ Also, the state child abuse agencies are customarily in a mutually supportive relationship with the medical profession.⁶⁷ The medical profession is responsible for reports of child neglect and abuse.⁶⁸ Therefore, the adversary position fostered by the "Baby Doe" regulations places the agency in a very awkward position.⁶⁹ Consequently, the agencies have not proven effective in protecting the disabled infant from discrimination.

Finally, the hospital review committees, authorized as voluntary advisory groups to protect the disabled newborn from treatment denial, have not been effective in prohibiting discrimination.⁷⁰ In fact, they are often the discriminating party.⁷¹ The review committees frequently base their decision on misinformation.⁷² Also, the review committee's decision may be

the deaths of handicapped infants in the Oklahoma experiment. The order barring federal investigation was not entered until 105 days following receipt of the February 24, 1984, complaint. *See also Complaints to Agencies Rarely Result in Action*, Sherwood Series in the Wash. Times, July, 1984, at 12, col. 1.

Even the original 'Baby Doe' case, the first to be filed with the federal government following the April 1982 death of a Down's Syndrome infant in a Bloomington, Indiana hospital remains officially unresolved. The Department of Health and Human Services records state, 'Final administrative action has not yet been taken.'

Id. at 12, col. 1.

64. *Statement of the Role of Child Protective Services Agencies in Cases Involving Denial of Health Care of Handicapped Infants*, Resolution of the National Council of State Public Welfare Administrators of the American Public Welfare Association, May 11, 1984.

65. *Id.*

66. *Id.*

67. *Id.* *See also* Bopp & Balch, *supra* note 12, at 104.

68. 45 C.F.R. §§ 84.55(b)(3), (4) (1985).

69. Bopp & Balch, *supra* note 12, at 104.

70. *See* Gross, *supra* note 21, at 452. The decision not to treat handicapped infants based on a "quality of life equation" in the Oklahoma experiment was made by a "myelom-ingocele team." The team consisted of a physician's assistant (a full-time program coordinator), a pediatrician, an orthopedist, a neurosurgeon, a urologist, a nurse clinician, a social worker, physical and occupational therapists, and a psychologist. *Id.*

71. *Id.*

72. Remarks by J. Robertson and N. Fost, at the First National Conference on Hospital Ethics Committees, sponsored by Concern for Dying and the American Society of Law & Medicine, in Washington, D.C. (May 1983), *discussed in* Annas, *Refusal of Lifesaving Treatment for Minors*, 23 J. FAM. L. 217, 228 (1984-85); *See also* American Academy of Pediatrics, *Guidelines for Infant Bioethics Committees* (1984), *discussed in* Annas, *Ethics Commit-*

grounded on a structural, mathematical formula called a “quality of life equation.”⁷³ One such hospital review committee made the decision to treat handicapped infants in the “Oklahoma Experiment”⁷⁴ based on a “quality of life formula.” The actual formula was $QL = NE \times (H + S)$.⁷⁵ QL is quality of life, NE is the patient’s physical attributes and I.Q., H is the parent’s financial status, and S is the cost to society.⁷⁶ The “Oklahoma Team” demonstrated that an infant born in need of immediate life-saving treatment, such as spina bifida, who requires sac closure surgery to prevent a fatal infection, will die if surgery is not performed and antibiotics are not administered.⁷⁷ The “Oklahoma Team” was unconcerned with the survival rate of sixty-seven percent of the same infants if treatment was not based on a “quality of life formula” and the infants were given active treatment.⁷⁸

The hospital review committee dismisses criticism of this type with public policy arguments.⁷⁹ They justify the use of the formula,⁸⁰ so heavily dependent on assessment of prejudicial criterion,⁸¹ by examining the long-term case of the spina bifida infant.⁸² The “Oklahoma Team” stresses the increased pressure families undergo in raising a disabled infant.⁸³ In addition, they emphasize the possibility of an unavailability of government funding for the infant’s future care.⁸⁴ Therefore, the “Oklahoma Team” does not tell the families of the criteria used by the hospital review committee to arrive at its decision for or against treatment.⁸⁵ They argue that a decision based on socio-economic criteria actually relieves low-income families of false hope for the future.⁸⁶ The hospital review committees have not proven effective in prohibiting discrimination against disabled infants.

tees in Neonatal Care: Substantive Protection or Procedural Diversion?, 7 AM. J. PUB. HEALTH 843 (1984).

73. See *supra* note 31 and accompanying text.

74. See Gross, *supra* note 21 and accompanying text.

75. See *supra* note 31 and accompanying text.

76. See Gross, *supra* note 21, at 456.

77. See Gross, *supra* note 21, at 455.

The ‘untreated survivor’ has not been a significant problem in our experience. All 24 babies who have not been treated at all have died at an average of 37 days. . . . Four of the six babies for whom nontreatment was suggested but was rejected by the parents are still alive. . . . One of the infants treated ‘late’ at four months of age is still alive but in crisis management.

Id.

78. See Gross, *supra* note 21, at 456.

79. *Id.*

80. See *supra* note 31 and accompanying text.

81. *Id.*

82. See Gross, *supra* note 21, at 456.

83. *Id.*

84. *Id.*

85. See Gross, *supra* note 21, at 455.

86. *Id.*

As a result of the failure of HHS, state child abuse agencies and hospital-based committees to protect the handicapped infant from discrimination, the parents and physicians are allowed wide latitude in making decisions affecting disabled newborns.⁸⁷ Unfortunately, when parents and physicians make a decision for or against treatment, they often consider factors other than the best interests of the infant. The parent and physician autonomy approach has proven inappropriate because of the circumstances under which such decisions are usually made.⁸⁸ Parents, emotionally shocked by the birth of their disabled infant and counseled by unfamiliar professionals in an unfamiliar hospital environment, often are in no position to make life or death decisions for their child.⁸⁹ Similarly, a national survey of physicians has shown that eighty-five percent of the nation's pediatricians would acquiesce to the parent's desires when the infant was born with a disability.⁹⁰ Only three percent of the physicians surveyed would get a court order for the necessary surgery over the parent's objections, while eighty-eight percent would do so if the child was not disabled.⁹¹ Therefore, the decision made by parents and physicians has not always been based on the disabled infant's best interests. As such, the decision discriminates against the handicapped infant in need of life-saving treatment.

The "Baby Doe" regulations proved ineffective in protecting the disabled newborn denied immediate medical treatment.⁹² The regulations decreased the protection for handicapped infants⁹³ when they increased the deference given to parents and physicians in the decision-making process.⁹⁴

87. Section 504 Baby Doe Regulations, *supra* note 43.

88. Diamond, *Treatment Versus Non-Treatment for the Handicapped Newborn*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 55, 62 (M. Delahoyd & D. Horan eds. 1982); Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 76 *PEDIATRICS* 321, 322-23 (1981); Sherlock, *Selective Non-Treatment of Newborns*, 5 *J. MED. ETHICS* 139 (1979); Waldman, *Medical Ethics and the Hopelessly Ill Child*, 88 *J. PEDIAT.* 890, 890-91 (1976); Editorial, *Severely Handicapped Infants*, 7 *J. MED. ETHICS* 115 (1981).

89. Gerry, *supra* note 63, at 21. The child abuse and child neglect laws in every state have significantly limited the presumption that parents act in the best interests of their children, *see also* Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 *STAN. L. REV.* 213, 215 (1975).

The shock of learning that one's child is defective overwhelms parents with grief, guilt, personal blame, and often hopelessness. They are suddenly confronted with an uncertain future of financial and psychological hardship, with potential devastating effects on their marriage, family and personal aspirations. If asked to approve a medical or surgical procedure necessary to keep the child alive . . . the parents view life of nominal interaction and development . . . refuse to provide consent.

Id.

90. SENATE COMM. ON LABOR AND HUMAN RESOURCES, S. Rep. No. 246, 98th Cong., 2nd Sess. 4, *reprinted in* 1984 U.S. CODE CONG. & ADMIN. NEWS 2918, 2925.

91. *Id.*

92. *See supra* notes 60 and 63 and accompanying text.

93. *See* Section 504 Baby Doe Regulations, *supra* note 43.

94. *Id.*

The regulations authorized HHS, state child abuse agencies and hospital review boards to prevent discrimination against handicapped newborns in the decision-making process.⁹⁵ The agencies proved ineffective in prohibiting discrimination against the infants.⁹⁶ Despite the ineffectiveness of the "Baby Doe" enforcement procedures, the Child Abuse Amendments of 1984 authorized the same procedures.⁹⁷

THE CHILD ABUSE AMENDMENTS OF 1984

Congress has recently enacted the Child Abuse Amendments of 1984,⁹⁸ federal legislation concerning the withholding of treatment from disabled infants.⁹⁹ Unfortunately, the Amendments have many of the same deficiencies as the "Baby Doe" regulations.¹⁰⁰ The Amendments give the physician a significant role in the decision-making process.¹⁰¹ They also contain the same enforcement provisions¹⁰² which had proved ineffective in

95. *Id.*

96. *See supra* notes 59-77 and accompanying text.

97. *See* Child Abuse Amendments of 1984, *supra* note 9.

98. *Id.*

99. *Id.*

100. Section 504 Baby Doe Regulations, *supra* note 43.

101. Child Abuse Amendments of 1984, *supra* note 11.

102. Child Abuse Amendments of 1984, *supra* note 9, at § 5103(K). Section 5103(K) provides, in relevant part:

(K) within one year after Oct. 9, 1984, have in place for the purpose of responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction. . . .

Id. at § 5103(K).

Section 5103 note (Supp. 1986) states in part:

(a)(1) Not later than 60 days after the date of the enactment of this Act [Oct. 9, 1984], the Secretary of Health and Human Services (hereinafter in this part referred to as the "Secretary") shall publish proposed regulations to implement the requirements of section 4(b)(2)(K) of the Act (as added by section 122(3) of this Act).

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a process of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish final regulations under this subsection.

(b)(1) Not later than 60 days after the date of the enactment of this Act [Oct. 9, 1984], the Secretary shall publish interim model guidelines to encourage the establishment within health-care facilities of committees which would serve the purposes of educating hospital personnel and families of disabled infants with life-threatening conditions, recommending institutional policies and guidelines concerning the withholding of medi-

the "Baby Doe" regulations. Although the Amendments have many positive aspects,¹⁰³ they lack effective enforcement provisions and as such will fail to prevent discrimination against handicapped infants.¹⁰⁴

Initially, the Amendments define the unlawful denial of life-saving treatment for disabled infants.¹⁰⁵ Under the Amendments, it is unlawful to withhold food, water, nutrients or medication from newborn infants.¹⁰⁶ Such prohibition is necessary to prevent cases such as "Infant Doe"¹⁰⁷ and the "Oklahoma Experiment"¹⁰⁸ from reoccurring. Also, this provision directly contravenes the position held by some doctors who espouse active euthanasia to hasten the death of disabled infants.¹⁰⁹ In addition, the Amendments mandate "medically indicated treatment" for infants with "life-threatening" conditions.¹¹⁰ However, an infant in need of immediate medical treatment may be excluded from treatment if, in the physician's "reasonable medical judgment," the denial of treatment is warranted.¹¹¹

As a result of the current diversity in medical opinion on the issue of treatment, the advice of physicians can vary immensely.¹¹² The Amendments allow physicians, exercising "reasonable medical judgment," to with-

ally indicated treatment (as that term is defined in clause (3) of section 3 of the Act (as added by section 121(3) of this Act) from such infants, and offering counsel and review in cases involving disabled infants with life-threatening conditions.

(2) Not later than 180 days after the date of the enactment of this Act and after completion of a period of not less than 60 days for notice and opportunity for public comment, the Secretary shall publish the model guidelines.

Id. at § 5103 note (Supp. 1986).

103. Child Abuse Amendments, *supra* note 10.

104. Child Abuse Amendments, *supra* note 102. *See also supra* notes 59-79 and accompanying text.

105. Child Abuse Amendments, *supra* note 10.

106. *Id.*

107. *In re* Treatment and Care of Infant Doe, No. GU 8204-004A, slip op. at 2 (Monroe County Cir. Ct. Apr. 12, 1983), petition for writ of mandamus and prohibition, *denied, sub nom* State of Indiana *ex rel* Infant Doe v. Monroe Circuit Court, No. 482 S 140 (Ind. Apr. 14, 1982), *appeal dismissed, sub nom. In re* Guardianship of Infant Doe, No. 1-782 A 157 (Ind. Ct. App. Feb. 3, 1983), *petition for transfer denied*, No. 1-782 A 157 (Ind. June 15, 1983), *cert. denied*, 104 S. Ct. 394.

108. Gross, *supra* note 21.

109. *See supra* notes 31-34. *See also* Freeman, *Is There a Right to Die — Quickly?* 80 J. PEDIAT. 904, 905 (1972) ("[I]n those rare instances where the decision has been made to avoid 'heroic' measures and to allow 'nature to take its course,' should society not allow physicians to alleviate the pain and suffering and help nature take its course—quickly?"); Reid, *Spina Bifada: The Fate of the Untreated*, 7 HASTINGS CENTER REP. 16, 19 (Aug. 1977) ("It is not a valid argument that man has managed without euthanasia for most of his civilized existence and therefore should continue to manage without it. . . . When ethical values become no longer acceptable, they must be replaced.").

110. Child Abuse Amendments, *supra* note 10.

111. Child Abuse Amendment, *supra* note 11.

112. *See supra* notes 31-38 and accompanying text.

hold treatment from handicapped infants in three situations: (1) when the infant is chronically and irreversibly comatose; (2) when treatment would prolong dying; (3) when treatment would be inhumane.¹¹³ The language “reasonable medical judgment” suffers from the same vagueness problem as the language found in the “Baby Doe” regulations.¹¹⁴ Since the term “reasonable medical judgment” is not clearly defined under the Amendments, it is subject to broad interpretation.¹¹⁵ As such, the physician is allowed great deference in making decisions affecting disabled newborns.¹¹⁶ Other procedural safeguards are similarly lacking.¹¹⁷

The Child Abuse Amendments granted decision-making power to the same agencies which had proven ineffective in prohibiting discrimination against disabled infants in the “Baby Doe” regulations.¹¹⁸ The Amendments require state child abuse agencies receiving federal funds to establish procedures or programs to report instances of denial of medical treatment.¹¹⁹ They also require HHS to issue regulations to implement the Amendments and to publish model guidelines for voluntary hospital review committees.¹²⁰ In as much as these reporting agencies have proven ineffective in the past,¹²¹ they are not now likely to provide effective procedural safeguards for the infant denied immediate medical treatment.

State child abuse agencies have traditionally been in a mutually dependent relationship with the medical profession.¹²² As such, it is likely that state child abuse agencies will merely defer to the attending physician, thus nullifying the Amendments’ reporting provisions. In addition, HHS has, in the past, failed to respond to reports of treatment denial for disabled infants.¹²³ Hospital review committees have also failed to prohibit discrimination against disabled infants.¹²⁴ In fact, they are often the discriminating party.¹²⁵ As a result, whether an infant receives life-saving treatment and survives,¹²⁶ or is denied this treatment and allowed to die,¹²⁷ will depend

113. Child Abuse Amendments, *supra* note 11.

114. 45 C.F.R. § 84.55(b)(3), (4) (1985). *See also* 42 U.S.C.A. § 5102(B)(3) (Supp. 1986).

115. 45 C.F.R. Part 1340 App. (1985).

116. Campbell & Duff, *supra* note 8, at 893-94.

117. Child Abuse Amendments, *supra* note 102.

118. *Id.* *See also supra* notes 59-77 and accompanying text.

119. Child Abuse Amendments, *supra* note 102.

120. *Id.*

121. *See supra* notes 59-77 and accompanying text.

122. *See supra* notes 64 and 67.

123. *See supra* note 63 and accompanying text.

124. *See supra* notes 31, 70 and 72 and accompanying text.

125. *See Gross, supra* note 70 and accompanying text.

126. *See McLone, supra* note 35 and accompanying text.

127. Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele* in INFANTICIDE 69, 70 (M. Delahoyd & D. Horan, eds. 1982) (“If the meningomyelocele (spina

more on the treating physician's personal medical views than on the Amendments' seemingly protective provisions.

Although the Amendments were a key step in a long struggle to prohibit the denial of life-saving treatment for infants,¹²⁸ the agencies granted decision-making power by the Amendments are not likely to protect the handicapped newborn from discrimination.¹²⁹ The Amendments allow the physician great deference in making the decision to treat the infant or allow the infant to die under one of the Amendment's exceptions.¹³⁰ The Amendments' enforcement provisions had proven ineffective in past regulations in protecting the infant from discrimination;¹³¹ thus, the question of whether the Amendments have provided constitutionally adequate procedures for the handicapped infant denied life-saving medical treatment is raised.

PROCEDURAL DUE PROCESS

Procedural due process is required by the fifth amendment whenever a federal government action attempts to deprive "any person of life, liberty or property without due process of law."¹³² The fifth amendment requires that the Child Abuse Amendments provide adequate procedural due process for the handicapped infant denied life-saving medical treatment.¹³³ A determination of whether the Child Abuse Amendments have violated the due process clause requires a two-part analysis. First, it must be shown that the disabled newborn denied life-saving treatment has a constitutionally protected interest at stake.¹³⁴ Secondly, it must be demonstrated that the

bifada) child is left untreated . . . then the mortality rate ranges from 90-100 percent in the first year or two of life.") *Id.*

128. Child Abuse Amendments, *supra* note 10.

129. See *supra* notes 59-79 and accompanying text.

130. Child Abuse Amendments, *supra* note 11.

131. Child Abuse Amendments, *supra* note 102. See also *supra* notes 59-79 and accompanying text.

132. The fifth amendment states: "No person shall . . . be deprived of life . . . without due process of law. . . ." U.S. CONST. amend. V. See also Van Alstyne, *Cracks in "The New Property": Adjudicative Due Process in the Administrative State*, 62 CORNELL L. REV. 445, 450-52 (1977). "The essence of a procedural due process complaint,—it builds in such a large margin of probable mistake as itself to be intolerable in a humane society." *Id.* See also Monaghan, *Of "Liberty and Property,"* 62 CORNELL L. REV. 405 (1977); Tribe, *Structural Due Process*, 10 HARV. C.R.-C.L. L. REV. 269 (1975); Note, *Entitlement, Enjoyment and Due Process of Law*, 1974 DUKE L.J. 89 (1974).

133. U.S. CONST. amend. V.

134. *Goss v. Lopez*, 419 U.S. 565 (1975) (students may not be temporarily suspended without minimum procedures); *Morrisey v. Brewer*, 408 U.S. 471 (1972) (a preliminary hearing required at place of arrest for parole violation); *Bell v. Burson*, 402 U.S. 535 (1971) (hearing required before a driver's license was revoked); *Goldberg v. Kelly*, 397 U.S. 254 (1970); *Snidach v. Family Financing Corp.*, 395 U.S. 337 (1969) (before garnishing a wage earner's salary a prior hearing was necessary).

Amendments had failed to adequately protect that interest.¹³⁶ Then, if the Amendments are determined to have impaired the handicapped infant's protected interest, the issue becomes what process is due¹³⁸ to ensure full protection for the infant denied life-saving medical treatment based on his handicap. Thus, to determine whether the Amendments have violated the handicapped infant's constitutional due process rights, this two-part analysis must be applied.

A. Handicapped Infants' Constitutionally Protected Interest

The handicapped infant denied immediate life-saving medical treatment has a life interest at stake.¹³⁷ The infant has a constitutional right to life which vests at birth.¹³⁸ In *Roe v. Wade*,¹³⁹ the Court held that from the moment of live birth there exists a human being entitled to the fullest protection of the law and the most basic rights enjoyed by every human being.¹⁴⁰ Therefore, the handicapped infant as a human being possesses a right which must be afforded full constitutional protection.

The handicapped infant also has a right to life-saving treatment.¹⁴¹ Although the right is not expressly stated in the Constitution, the Child Abuse Amendments ground the right to life-saving treatment in a federal law.¹⁴² In *Cleveland Board of Education v. Loudermill*,¹⁴³ the Supreme Court held that while the legislature may elect not to confer an interest, it may not constitutionally authorize deprivation of such an interest once conferred without procedural safeguards.¹⁴⁴ The legislature elected to confer a right to immediate medical treatment for handicapped infants when they enacted the Child Abuse Amendments.¹⁴⁵ Therefore, the legislature may not constitutionally exclude an infant from life-saving treatment without adequate procedures.¹⁴⁶

135. *Mathews v. Eldridge*, 424 U.S. 319, 321 (1976).

136. *Little v. Streater*, 452 U.S. 1 (1981) (refusal to pay for an indigent's blood grouping test violated due process); *Addington v. Texas*, 441 U.S. 418 (1979); *Memphis Light, Gas and Water Div. v. Craft*, 436 U.S. 1 (1978) (the utility customer's interest in continued service and the not insubstantial "risk of computer errors" and erroneous terminations outweighed the efficiency interests of the government utility); *Goldberg v. Kelly*, 397 U.S. 254 (1970).

137. See *supra* notes 77 and 127 and accompanying text.

138. *Roe v. Wade*, 410 U.S. 113, 157 (1973). See also *supra* note 27.

139. 410 U.S. 113 (1973).

140. *Id.* at 157.

141. Child Abuse Amendments, *supra* note 10.

142. See *Cleveland Board of Educ. v. Loudermill*, 105 S. Ct. 1487 (1985); *Logan v. Zimmerman Brush Co.*, 445 U.S. 102 (1982) (the hallmark of property is an individual entitlement grounded in a federal or a state law).

143. 105 S. Ct. 1487 (1985).

144. *Id.* at 1493.

145. Child Abuse Amendments, *supra* note 10.

146. See *Loudermill*, 105 S. Ct. at 1493 (the right to due process is conferred by consti-

B. Constitutionally Adequate Procedures

In order to determine whether the dictates of procedural protection have been met by the Child Abuse Amendments, a balancing test must be applied to the Amendments. In *Mathews v. Eldridge*,¹⁴⁷ the Court requires consideration of three factors: (1) the private interest that will be affected by the official action; (2) the risk of an erroneous deprivation of such interest through procedures used, and the probable value, if any, of additional or substitute safeguards; and (3) the fiscal or administrative costs of the substitute procedures.¹⁴⁸

First, in applying the *Eldridge*¹⁴⁹ balancing test to the Child Abuse Amendments, the strength of handicapped infants' interest must be evaluated. The infant denied immediate life-saving treatment has a life interest at stake.¹⁵⁰ The handicapped infant erroneously included in one of the Amendments' three exceptions to treatment will be allowed to die.¹⁵¹ Therefore, the newborn's individual interest at stake is at its highest.

Second, the risk of an erroneous deprivation of the handicapped infant's life through the procedures contained in the Child Abuse Amendments are also at their highest. The Amendments allow physicians exercising "reasonable medical judgment" to withhold treatment from a newborn.¹⁵² Because the treatment of disabled newborns is subject to much debate in the medical profession,¹⁵³ the attending physician's decisions to withhold treatment based on "reasonable medical judgment" depends on his personal and professional views. Since the Amendments grant decision-making power to the same agencies that had proved ineffective in the "Baby Doe" regulations, the infant is not protected from this discrimination.¹⁵⁴ The additional value of substitute procedures would be to prevent discrimination against infants based on their handicap.¹⁵⁵

The last factor in the *Eldridge*¹⁵⁶ balancing test as applied to the Amendments is the fiscal costs of the substitute procedures for the government. Since the infant's life is at stake,¹⁵⁷ even if the costs were as great as

tutional guarantee, not by legislative grace).

147. 424 U.S. 319 (1976).

148. *Id.* at 321.

149. *Id.*

150. See *supra* notes 77 and 127 and accompanying text.

151. See *supra* notes 77 and 127 and accompanying text.

152. Child Abuse Amendments, *supra* note 11.

153. See *supra* notes 31-38 and accompanying text.

154. Child Abuse Amendments, *supra* note 102. See also *supra* notes 59-79 and accompanying text.

155. See *supra* notes 77 and 127 and accompanying text.

156. 424 U.S. at 347.

157. See *supra* notes 77 and 127 and accompanying text.

the costs of providing prosecutors, judges, and defense counsel to ensure fairness of a criminal procedure, the cost would not be too high.¹⁵⁸ The government's interests are not served by an erroneous decision, especially where an individual's constitutional right to life is involved.¹⁵⁹

The handicapped infant has a constitutional right to adequate procedural safeguards.¹⁶⁰ The application of the *Eldridge*¹⁶¹ balancing test demonstrates that procedural protection has not been provided by the agencies granted decision-making power in the Amendments. Therefore, the Child Abuse Amendments should provide the newborn substitute procedures which will guarantee the handicapped infant his constitutional right to procedural due process.¹⁶²

WHAT PROCESS IS DUE?

The fifth amendment guarantees the handicapped infant due process and fair treatment.¹⁶³ Therefore, to protect the infant from discrimination in the decision-making process, the infant has a right to a prior evidentiary hearing,¹⁶⁴ appointed counsel,¹⁶⁵ a "clear and convincing" evidence standard¹⁶⁶ and a record of the proceedings.¹⁶⁷ Such substitute procedures are essential for full constitutional protection of the disabled infant denied treatment.

Due process requires a prior evidentiary hearing when the decision to be made involves an "immediately desperate" situation.¹⁶⁸ For example, in *Goldberg v. Kelly*,¹⁶⁹ the Court found an "immediately desperate" situation where a welfare recipient denied benefits was deprived of his very means to live. Based on this crucial factor, a prior evidentiary hearing was mandated.¹⁷⁰ Because a handicapped infant who is denied life-saving treatment also faces an "immediately desperate"¹⁷¹ situation, the disabled infant

158. *Lassiter v. Dep't of Social Services*, 452 U.S. 18, 60 (1981) (Stevens, J., dissenting); see also *Goldberg*, 397 U.S. at 266.

159. See *Loudermill*, 105 S. Ct. at 1495.

160. *Id.* at 1493.

161. 424 U.S. at 321.

162. See *Loudermill*, 105 S. Ct. at 1493.

163. See *supra* note 132 and accompanying text.

164. See *Goldberg*, 397 U.S. at 264.

165. See *Lassiter*, 452 U.S. at 25.

166. See *Addington v. Texas*, 441 U.S. 418, 431-33 (1979).

167. See *Goldberg*, 397 U.S. at 271; but cf. *Lassiter*, 452 U.S. at 50-51 (Blackmun, J., dissenting) (The dissent disagrees with the majority that a review of the record would establish whether a defendant, proceeding without counsel, has suffered an unfair disadvantage).

168. *Goldberg*, 397 U.S. at 264.

169. 397 U.S. 254, 264 (1970).

170. *Id.* at 266-271.

171. See *supra* notes 77 and 127 and accompanying text.

should likewise be granted a prior evidentiary hearing.

Due process requires the appointment of counsel when a person's own liberty is at stake.¹⁷² In *Lassiter v. Department of Social Services*,¹⁷³ the Court held that appointed counsel was necessary for indigents when they stood to lose their liberty.¹⁷⁴ However, the disabled newborn may lose more than his liberty, he may lose his life. Also, counsel should be appointed when there is great disparity between the parties,¹⁷⁵ when the issues are complex and when the loss is irrevocable.¹⁷⁶ There is great disparity between the disabled newborn and the decision-makers.¹⁷⁷ Legal and medical issues involved in a denial of life-saving treatment are very complex. Because the infant who is denied immediate treatment may lose his life, the infant's loss is irrevocable.¹⁷⁸ Accordingly, appointed counsel would ensure the handicapped newborn his constitutional right to be heard.¹⁷⁹ Therefore, a disabled infant should be appointed counsel.

When official action imperils an interest of great magnitude, such as loss of life, due process requires a "clear and convincing" evidence standard.¹⁸⁰ In *Addington v. Texas*,¹⁸¹ the Court held an indigent's interest in the outcome of a civil commitment proceeding to be of "great weight." In light of the risk of error, the Court held that due process requires more substantial evidence than a mere preponderance. The Court insisted on a "clear and convincing" evidence standard.¹⁸² Similarly, the infant's interest in the decision of whether immediate medical treatment is withheld is of "great weight."¹⁸³ Due to the risk of error in the decision-making process, life-saving treatment should not be denied unless the medical evidence is "clear and convincing."

A record of the decision-making proceedings should also be kept, so that courts can conduct a retrospective review of the transcript to ensure a high standard of decision-making practices.¹⁸⁴ As such, the proceeding held

172. *Lassiter*, 452 U.S. at 25.

173. 452 U.S. 18 (1981).

174. *Id.* at 25.

175. *Lassiter*, 452 U.S. at 30.

176. *Lassiter*, 452 U.S. at 45 (Blackmun, J., dissenting).

177. See Gross, *supra* notes 21 and 70.

178. See *supra* notes 77 and 127 and accompanying text.

179. See *Goldberg*, 397 U.S. at 267.

180. *Addington*, 441 U.S. at 424-432 (1979); *Santosky v. Kramer*, 455 U.S. 745, 769 (1982) (due to the high risk of error a "clear and convincing" standard of evidence must be mandated).

181. 441 U.S. 418 (1979).

182. *Id.* at 427, 433.

183. See *supra* note 77 and accompanying text.

184. See *Goldberg*, 397 U.S. at 271; but cf. *Lassiter*, 452 U.S. at 50-51 (Blackmun, J., dissenting).

to determine whether a handicapped infant should be included in one of the Amendment's exceptions, thereby denied immediate life-saving treatment, should be recorded. A transcript of the deliberations should be kept, including a synopsis of any other treatment cases considered relevant to the decision at hand. The medical evidence offered for or against treatment should be recorded.¹⁸⁵ In this way, a record of the proceedings would provide the reviewing court with information as to whether the handicapped infant was afforded appropriate procedural safeguards.

In summary, the Child Abuse Amendments should include the following procedures: (1) a prior evidentiary hearing to provide a neutral fact-finder;¹⁸⁶ (2) appointed counsel to provide the infant a voice in the proceedings;¹⁸⁷ (3) a "clear and convincing" evidence standard to avoid an erroneous decision;¹⁸⁸ and (4) a record of the proceedings to ensure adequate review. Therefore, the portions of the Child Abuse Amendments which grant decision-making power to the Department of Health and Human Services, state child abuse agencies receiving federal funds and voluntary hospital review boards¹⁸⁹ should be stricken. In lieu thereof, the following binding enforcement procedures should be inserted:

Section One: Prior Evidentiary Hearing¹⁹⁰

(A) Before a decision is made to withhold life-saving treatment, a prior evidentiary hearing must be held.

(1) In cases of myelomeningocele (spina bifida), a prior evidentiary hearing must be held within 24 hours;¹⁹¹

185. Dep't of Health and Human Services, Office of Human Development Services, *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers to Establish Infant Care Review Committees*, 50 Fed. Reg. 14,896, (Model Guidelines). These suggestions were the subject of some controversy during the comment period, as discussed in Bopp & Balch, *supra* note 12, at 126.

From one perspective, commentators urged that records not be available to government agencies and others outside the hospital. From another perspective, it was suggested that tapes or written minutes be made for each meeting and transmitted to the [state child protection agencies] for review. [The Department of Health and Human Services] rejected both views.

Bopp & Balch, *supra* note 12, at 126.

186. See *Goldberg*, 397 U.S. at 264.

187. See *Lassiter*, 452 U.S. at 25, 30; see also *Lassiter*, 452 U.S. at 45-46 (Blackmun, J., dissenting).

188. See *Addington*, 441 U.S. at 425, 431-32.

189. Child Abuse Amendments, *supra* note 102.

190. See *Goldberg*, 397 U.S. at 264.

191. Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 69, 71 (M. Delahoyd & D. Horan eds. 1982) (The spina bifida infant's open sac should be closed within twenty-four hours. The failure to close the sac within twenty-four hours will result in irreparable harm.)

- (2) In all other cases, which range from Down's Syndrome to anencephal, a prior evidentiary hearing must be held within the time limit mandated by specific physical symptoms;¹⁹²
- (3) Appointed counsel must be provided timely and adequate notice of the proceeding;¹⁹³
- (4) Appointed counsel will be provided an opportunity to present medical evidence in favor of the handicapped infant;¹⁹⁴
- (5) Appointed counsel will be given the opportunity to confront adverse witnesses;¹⁹⁵ and
- (6) Appointed counsel will have an opportunity to present an oral argument on behalf of the handicapped infant.¹⁹⁶

Section Two: Appointed Counsel

(A) Counsel should be appointed to advocate for the handicapped infant's life interest.¹⁹⁷

- (1) Appointed counsel will gather and present medical evidence on behalf of the handicapped infant;¹⁹⁸ and
- (2) Appointed counsel will identify the material issues involved.¹⁹⁹

Section Three: "Clear and Convincing" Evidence

(A) Before the decision is made to withhold life-saving medical treatment from a handicapped infant, the medical evidence must be "clear and convincing."²⁰⁰

Section Four: Records

(A) Records of the proceedings at which the decision to withhold immediate life-saving treatment must be maintained,²⁰¹ including but not limited to:

- (1) summary descriptions of specific cases consid-

192. (i.e. "Infant Doe" needed surgery to correct a blocked esophagus and thereby allow food to reach his stomach. The failure to treat the infant resulted in his death within six days.)

193. See *Goldberg*, 397 U.S. at 267.

194. *Id.* at 269.

195. *Id.* at 269-270.

196. *Id.* at 268-69.

197. See *Lassiter*, 452 U.S. at 25.

198. *Id.* at 30.

199. *Id.* at 45 (Blackmun, J., dissenting).

200. See *Addington*, 441 U.S. at 431-32.

201. See *supra* note 185 and accompanying text.

- ered in the decision;²⁰²
(2) medical evidence presented for and against active treatment.²⁰³

CONCLUSION

As a result of the conflict between the handicapped infant's parents, the state and the medical community regarding the handicapped infant's right to immediate life-saving treatment, in significant numbers handicapped infants have been allowed to die. In response, the Child Abuse Amendments of 1984 were signed into law.

Admittedly, the Amendments were a key step in the long struggle to ensure immediate life-saving treatment for handicapped newborns. However, the Amendments granted decision-making power to the Department of Health and Human Services, state child abuse agencies and voluntary hospital review committees. These agencies had previously proven ineffective in preventing discrimination against newborns. As a result, the Amendments failed to adequately protect the handicapped infants' constitutional right to life.

Accordingly, the legislature should now take the second step in the struggle to protect the handicapped infant from treatment denial. The infant denied life-saving treatment should be provided a prior evidentiary hearing, appointed counsel, protected by a "clear and convincing" standard of evidence and afforded a record of the proceedings. These procedures would guarantee the handicapped infant his constitutional due process rights. To do any less would allow thousands of future handicapped infants to die.

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202. See *Goldberg*, 397 U.S. at 271.

203. A record of the decision-making proceedings should be kept so the fairness of the decision can be reviewed.