

1984

Quality of Life, Sanctity of Creation: Palliative or Apotheosis?

George P. Smith II

Catholic University of America, Columbus School of Law, smithg@law.edu

Follow this and additional works at: <https://digitalcommons.unl.edu/nlr>

Recommended Citation

George P. Smith II, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 Neb. L. Rev. (1984)

Available at: <https://digitalcommons.unl.edu/nlr/vol63/iss4/6>

This Article is brought to you for free and open access by the Law, College of at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Nebraska Law Review by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.

Quality of Life, Sanctity of Creation: Palliative or Apotheosis?

TABLE OF CONTENTS

I. Introduction	709
II. The Federal "Baby Doe" Regulations	712
A. The March 7, 1983 Version.....	712
1. Background	712
2. Challenge in <i>American Academy of Pediatrics v. Heckler</i>	713
B. July Reissuance	716
C. The Final Rules	718
III. Baby Jane Doe	721
A. Action Against the Parents	721
B. The Federal Response to Baby Jane Doe.....	722
IV. Searching for a Workable Standard	724
A. Technical/Medical Criteria	724
B. The Role of Parents in Decisionmaking	729
C. Quality of Life and Extraordinary Care.....	732
D. The Role of the Federal Government	738
V. Conclusion	740

I. INTRODUCTION

A six-pound baby boy in Bloomington, Indiana, who lived but six days, has invoked a national rethinking of infanticide, parental power under the common law to exercise jurisdiction over the care of children, and the crucial issue of whether quality of life standards are more significant and fundamental than principles of sanctity of life. "Baby Doe" was born a mongoloid, with consequent mental retardation, and had a malformed esophagus that prevented food from reaching his stomach.¹ Rather than authorize

* B.S., 1961, J.D., 1964, Indiana University; LL.M. 1975, Columbia University. Professor of Law, Catholic University of America. This article was written while Professor Smith was a Visiting Fellow at Clare Hall, Cambridge University, England, and the Fullbright Visiting Professor of Law and Medical Jurisprudence at The University of New South Wales, Sydney, Australia, 1984.

1. See Van der Dussen, *Givan: Court's 'Doe' Action Set No Legal Precedent*,

corrective surgery, the parents chose to withhold food and medical treatment—save pain killers—from their son.²

The county prosecutor learned of the parents' decision to stop feeding the infant, and brought suit to remove Baby Doe from the parents' custody.³ Since the parents' decision was based on the medical opinions of advising physicians, however, the Monroe County Circuit Court determined that no probable cause existed for finding that Baby Doe had been neglected.⁴ On appeal, the Indiana Supreme Court prevented interference with the parental decision by affirming the circuit court orders.⁵ Before an emergency appeal could be made to the United States Supreme Court, Baby Doe died.⁶ Disclaiming the attachment of any judicial significance to the case, Chief Justice Givan of the Indiana Supreme Court stressed that the ruling was unwritten and, thus, could in no way be used as legal precedent.⁷ Firm legal precedent or not, the case sparked action by the federal government to prevent hospitals receiving federal assistance from participating in future decisions of a similar nature.⁸

Bloomington Herald-Telephone, Apr. 23, 1982, at 1, col. 1 [hereinafter cited as Van der Dussen, *No Precedent*]; Van der Dussen, *No Charges Will Be Filed in Infant Doe Case*, Bloomington Herald-Telephone, Apr. 19, 1982, at 1, col. 1 [hereinafter cited as Van der Dussen, *No Charges Will Be Filed*]; Van der Dussen, *Infant's Death Ends Feverish Appeal for Life*, Bloomington Herald-Telephone, Apr. 16, 1982, at 1, col. 1 [hereinafter cited as Van der Dussen, *Death Ends Appeal*]; Van der Dussen, *High Court May Be Asked to Save Baby*, Bloomington Herald-Telephone, Apr. 15, 1982, at 1, col. 1.

2. See generally *In re Baby Doe*, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982).

3. *Id.*

4. *Id.*

5. State *ex rel.* Infant Doe v. Baker, No. 482 5140 (Ind. Apr. 16, 1982), *cert. denied* 103 S. Ct. 394 (1983). A special guardian *ad litem* was appointed to perfect the appeal. The legal issues to have been raised were: did the child have a right under the fourteenth amendment to continue living; did the child have the same rights as all others to procedural due process protections; and finally, was this child denied equal protection because of its handicap? See generally Van der Dussen, *No Charges Will Be Filed*, *supra* note 1.

6. See Van der Dussen, *Death Ends Appeal*, *supra* note 1.

7. See Van der Dussen, *No Precedent*, *supra* note 1.

8. Proposed Rules for Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30,846 (1983). In 1983, during the first session of the 98th Congress, Senator Roger W. Jepsen introduced S. 467 as a bill "to establish [a] governmental policy with regard to respect for human life." S. 467, 98th Cong., 1st Sess., 129 CONG. REC. 51,080 (daily ed. Feb. 3, 1983). Section 8 of the proposal sought to protect handicapped infants by forbidding federally funded institutions from withholding "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 treatment medically contraindicated." *Id.* at 51,081. No definition of handicap was set out in

This Article will suggest an approach to facilitate decisionmaking where the concepts of quality of life and sanctity of life appear to clash. It is hoped that a reconciliation of these two ideas will provide an alternative to the increasing federal intervention in the process of family decisionmaking *vis-a-vis* handicapped infants.

The construct will combine deontological standards with situational, or consequential, ethics. This unique synthesis will then be placed within a sphere of expanded family advisers—medical, social, spiritual, legal, etc.—who are called into being with the birth of a genetically defective newborn. The force of the construct arises from the basic goal of man to minimize suffering, maximize the social utility or purposes of life,⁹ and give living expression to love of God and of mankind.¹⁰

The actual utilization of the construct can be likened to a balancing test, where the gravity of the harm in allowing life-sustaining actions for a handicapped infant is balanced against the utility of the benefits stemming from the life-sustaining actions. The gravity of harm is measured in terms of social, economic, religious and philosophical costs, while the utility of the benefits is measured in terms of the positive consequences that flow to the threatened individual, its parents, and society. To assist the balancing process, there must be a weighing of factors such as the infant's long-range capacity for entering into relationships with others.

Imperfect as considerations forming this construct may be, they may help the family tackle the painful problems of a grossly deformed neonate or a genetically defective infant. Acting within this spirit, the standards of quality of life and sanctity of creation in no way challenge or obstruct one another. They serve neither as palliatives or mitigating shields, nor as an apotheosis or glorified ideal. Rather, they are mere aspects that complement each other in a unified approach to decisional efforts. As such, they are grafted to the proposed analytical construct which—if implemented—would act to limit or possibly preclude government intrusions into the privacy and autonomy of the family unit in its process of anguished decisionmaking.

the proposed legislation, which never passed in the Senate, nor was the requirement of medically contraindicated treatment set out with clarity.

9. See G. SMITH, *GENETICS, ETHICS AND THE LAW* 1-4 (1981).

10. See McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, in *HOW BRAVE A NEW WORLD* 339 (R. McCormick ed. 1981).

II. THE FEDERAL "BABY DOE" REGULATIONS

A. The March 7, 1983 Version

1. Background

In addition to spawning an outburst of public emotion, the Indiana Supreme Court's Baby Doe decision acted as a catalyst for political action. On April 30, 1982, President Reagan referred specifically to the case of *In re Infant Doe* and pointedly reminded the Attorney General of the United States and the incumbent Secretary of Health and Human Services that Section 504 of the Rehabilitation Act¹¹ prohibits discrimination against all handicapped individuals.¹² Section 504 provides that "[n]o otherwise qualified handicapped individual in the United States . . . 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. . . ."¹³

The Secretary accordingly issued a notice to health care providers on May 18, 1982, reminding them of the applicability of Section 504 to handicapped infants.¹⁴ While recognizing that hospitals who receive federal grant monies do not always have complete or final control over treatment in the face of contrary parental directives, the Secretary nevertheless required that any parental efforts to withhold care from a handicapped infant should not be aided by the hospital. If a federally funded hospital were to withhold treatment from such newborns, the institution would risk discontinuation of federal assistance.¹⁵

The regulation promulgated pursuant to Section 504 was published March 7, 1983, and became effective as a final interim rule on March 22, 1983.¹⁶ The rule proposal was so closely linked to the highly publicized Baby Doe case that the popular media dubbed the regulations as the "Baby Doe Rules."¹⁷ The rules sought to provide the full spectrum of medical care and food to all newborns in the more than 6,400 hospitals receiving federal aid.¹⁸ This goal was to be achieved by requiring federally funded hospitals and medical institutions to post warnings in conspicuous places throughout maternity wards, pediatric wards, nurseries, and inten-

11. 29 U.S.C. § 794 (1982).

12. The origins of the Baby Doe Regulations are set out in *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 397-98 (D.D.C. 1983).

13. 29 U.S.C. § 794 (1982).

14. 47 Fed. Reg. 26,027 (1982).

15. *Id.*

16. 48 Fed. Reg. 9,630 (1983).

17. See, e.g., Kamen & Russell, *Court Strikes Down U.S. 'Baby Doe' Rule*, Wash. Post, Apr. 15, 1983, at 1, col. 2.

18. 48 Fed. Reg. 9,630 (1983).

sive care nurseries. These warning signs explained that the failure to feed and care for handicapped infants violated federal law, and provision was made for a toll-free "hotline" telephone number to make timely reportings of suspected violations.¹⁹ Additionally, the Baby Doe Rules authorized the Department of Health and Human Services to dispatch a "civil rights investigation squad" to investigate all alleged violations. These investigators were given the right to demand complete twenty-four hour access to all hospital records and an opportunity for immediate and direct questioning of all concerned parties.²⁰

2. *Challenge in American Academy of Pediatrics v. Heckler*

The American Academy of Pediatrics and the National Association of Children's Hospitals joined forces with the Children's Hospital National Medical Center to maintain an action challenging the validity of the Baby Doe Rules in *American Academy of Pediatrics v. Heckler*.²¹ These medical providers charged first that the regulation was arbitrary and capricious, and that it intruded unnecessarily into confidential relations between the family and the physician.²² The group of challengers charged further that the Secretary of Health and Human Services had acted beyond her statutory authority, and had improperly dispensed with the federally prescribed assurance of public comment before the regula-

19. *Id.* The warnings were to read as follows:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED BY FEDERAL LAW.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline

U.S. Dept. of Health & Human Services

Washington, D.C. 20201

Phone 800-368-1019 (available 24 hrs. a day)

In the City of Washington, D.C. 863-0100

(TTY capability)

or

Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of The Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

Id. at 9,631.

20. *Id.* See also *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 398 (D.D.C. 1983).

21. 561 F. Supp. 395 (D.D.C. 1983).

22. *Id.* at 396.

tion's issuance.²³

This challenge of the federal Baby Doe Rules came at a particularly controversial point in time. Public debate over the plight of severely mentally or physically defective newborns had reached a zenith, partly as a result of new advances in neonatology that prolong the life of infants who would otherwise die shortly after birth. Federal District Judge Gesell pointed out, however, that such life-sustaining methods often preserve the life of an "infant who continues nevertheless to suffer from mental or physical defects so great as seriously to impair the infant's expected quality of life and chances for an independent existence."²⁴

Acknowledging the need for courts to be deferential to administrative decisionmaking,²⁵ Judge Gesell nonetheless concluded that the action undertaken by the Department of Health and Human Services was "an arbitrary and capricious agency action"²⁶ that failed to "satisfy the test of rationality."²⁷ The court particularly questioned the failure of the record to establish that various issues of central concern had been considered prior to the promulgation of the questioned rule. The court expressed concern that the agency had failed to address issues such as: the "disruptive effects of a 24 hour toll-free 'hotline' upon ongoing treatment of newborns"; the potential for abuse by anonymous tipsters in triggering a sudden descent of "Baby Doe" squads; the effects of such a squad in "monopolizing physician and nurse time" and disrupting efforts to maintain high quality infant care; and, finally, the regulation's ultimate effect of forcibly removing a child from a hospital, under the threat of subsequent termination of all federal assistance, when parents direct the withholding of medical treatment.²⁸

The court, in *American Academy of Pediatrics*, recognized that the power to make difficult, heart-wrenching decisions on whether to forego life-preserving measures has traditionally rested within the privacy of the family, in consultation with a physician.²⁹ Judge

23. *Id.*

24. *Id.*

25. 5 U.S.C. §§ 551, 706 (2) (A) (1977). The Administrative Procedure Act requires a right of notice, consultation, and comment before the promulgation of a rule; however, the *American Academy of Pediatrics* court was "well aware that agency rulemaking must be considered deferentially and that this Court is prohibited from substituting its own judgment for that of the agency if a rational basis exists for the agency's decision." *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 399 (D.D.C. 1983).

26. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 399 (D.D.C. 1983).

27. *Id.* at 399.

28. *Id.*

29. *Id.* at 396 ("Traditionally, the difficult decision of when to withhold life-sus-

Gesell outlined some of the factors that influence parental-physician decisions to treat handicapped infants: the risks of treatment to the infant; the infant's quality of life if the newborn survives treatment; the utility or value of prolonging such life-sustaining measures when imminent death is inevitable; and, finally, the economic and social costs of maintaining the infant in light of the impact on the stability of the family unit.³⁰ The court continued by observing that there had been no weighing of these various factors, nor any further balancing of the issues against various risks of malpractice suits and professional discipline, which could well be imposed upon both physicians and hospitals who find themselves caught between this federal regulation and "established legal and ethical guidelines."³¹ Judge Gesell further explained:

The Secretary did not appear to give the slightest consideration to the advantages and disadvantages of relying on the wishes of the parents who, knowing the setting in which the child may be raised, in many ways are in the best position to evaluate the infant's best interests. [N]one of these sensitive considerations touching so intimately on the quality of the infant's expected life were even tentatively noted. No attempt was made to address the issue of whether termination of painful, intrusive medical treatment might be appropriate where an infant's clear prognosis is death within days or months or to specify the level of appropriate care in such futile cases. Means of funding the extensive care mandated by the regulation and for allocating scarce medical resources between defective newborns and other newborns or other patients were also apparently not considered.³²

By encroaching upon the privacy of parental decisionmaking, the rule would seek to change the whole course of previously established law. The Department of Health and Human Services had, in essence, built an intrusive structure to control the parental decision to withhold treatment of handicapped infants, an area traditionally placed beyond the government's regulation reach. Recognizing that the treatment of severely defective newborns does not follow *any* customary standard of care, Judge Gesell concluded that "the regulation thus purports to set up an enforcement mechanism without defining the violation, and is virtually without meaning beyond its intrinsic *in terrorem* effect."³³

Finally, Judge Gesell even noted some concerns over the possibility that the Baby Doe Rules exceeded the scope of Section 504 of the Rehabilitation Act. The court, in *American Academy of Pediat-*

taining treatment of a newborn has been one made within the privacy of the physician-patient relationship, without interference by state or federal authorities.").

30. *Id.*

31. *Id.* at 399-400.

32. *Id.* at 400.

33. *Id.*

rics, found nothing in the legislative history of the Act to suggest that Section 504 could be used as a monitor of the medical treatments provided for defective newborn infants; nor could the court identify anything remotely posturing a standard for preserving a particular quality of life.³⁴ The court did, however, acknowledge that the statute was, on its face, subject to a very broad interpretation that may well authorize "some regulation of the provision of some types of medical care to handicapped newborns."³⁵ Judge Gesell left the issue of Section 504's scope undecided, explaining that further congressional action is needed to chart the extent to which Section 504 should be applied in "such a sensitive area of moral and ethical concerns."³⁶

B. July Reissuance

On July 5, 1983, the Department of Health and Human Services (Department) reissued its "Baby Doe" Regulations in light of the Gesell opinion.³⁷ This time, the Secretary directed that public comments were to be submitted by September 6, 1983.³⁸ With four exceptions, the new proposed rules were identical with the original final interim rule. First, the so-called "hotline" notice was to be posted only "in a conspicuous place in each nurses' station,"³⁹ whereas the original rule required permanent posting in conspicuous places throughout delivery wards, pediatric wards, nurseries, and intensive care nurseries.⁴⁰ Second, the notices were limited in size to eight and one-half by eleven inches in size,⁴¹ whereas the old regulation allowed the Department to send large posters of unlimited size to hospitals.⁴² Third, the new regulations made listing the local child protective agency's telephone number on the poster mandatory, rather than optional.⁴³ Finally, the proposed rules directed each state's child protective services agency to set up and

34. *Id.* at 401 ("The legislative history of the section focuses on discrimination against adults and older children and denial of access to federal programs.").

35. *Id.*

36. *Id.* at 402.

37. 48 Fed. Reg. 9,630 (1983) (to be codified at 45 C.F.R. § 84).

38. By November of 1983, over 16,000 comments were received and processed by the Department of Health and Human Services. Telephone interview with Susan Shalhoub, Office of Civil Rights, Department of Health and Human Services (Nov. 29, 1983). Another source reports that by the closing date, 11,000 comments were filed, of which "the overwhelming majority" were favorable. See Annas, *Baby Doe Redux: Doctors as Child Abusers*, 13 HASTINGS CENTER REP. Oct. 1983, at 26.

39. 48 Fed. Reg. 30,851 (1983) (to be codified at 45 C.F.R. § 84.61(b)).

40. 48 Fed. Reg. 9,630 (1983).

41. *Id.* at 30,851 (to be codified at 45 C.F.R. § 84.61(b)).

42. See Annas, *supra* note 38, at 28.

43. 48 Fed. Reg. 30,851 (1983) (to be codified at 45 C.F.R. § 84.61(b)).

maintain procedures designed "to prevent medical neglect of handicapped infants" within sixty days of the effective date of regulation.⁴⁴

In the "Supplementary Information" section of the proposed rules, care was taken to specify that Section 504 of the Rehabilitation Act would not mandate treatment of an infant when it would "not benefit medically from a particular treatment."⁴⁵ More specifically, "Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies."⁴⁶ Futile therapies that merely prolong—in a temporary manner—the process of death for a defectively born infant were not to be imposed.⁴⁷ A Section 504 violation would occur, however, when treatment is withheld "*because of the existence of a handicap and the handicap does not render the treatment medically contraindicated.*"⁴⁸

The Department of Health and Human Services failed to resolve the central problem pervading the whole of the final interim rule: namely, the vagueness in the standard physicians are directed to follow under the rules. Although the Department stated that the "customary medical care" standard does not require treatment that is "medically contraindicated," and, indeed, allows the withholding of treatment based upon "legitimate medical judgment,"⁴⁹ these terms ultimately do nothing but muddy the waters. The final interim rule later explained that ultimate physician responsibility "corresponds with the responsibilities of parents or guardians under State child abuse and neglect laws to provide medically indicated treatment for their children."⁵⁰ As one observer has noted:

The suggested definition is circular; 'customary medical care' is care that must be provided to avoid violation of the child abuse and neglect laws. The idea that standards are likely to be developed in any way but through individual cases being decided by courts of law seems farfetched. Certainly ad hoc Baby Doe squads descending on hospitals in the middle of the night are unlikely to be helpful to anyone. Nor does this 'standard' provide any guidance to the nurses who are expected to use the hotline to call for help in appropriate circumstances.⁵¹

In August of 1983, the Undersecretary of the Department of Health and Human Services personally tried to assist in the development of a mechanism that would assist health providers in coming to grips with the issue of whether adequate, customary, or

44. *Id.* at 30,851 (to be codified at 45 C.F.R. § 84.61(e)).

45. *Id.* at 30,852 (to be codified at 45 C.F.R. § 84).

46. *Id.*

47. *Id.*

48. *Id.* (emphasis in original).

49. *Id.*

50. *Id.*

51. See Annas, *supra* note 38, at 27.

acceptable care was being provided to defectively born infants.⁵² The Undersecretary suggested that *local* hospital committees—dubbed Bioethical Review Committees—be established to determine the question of whether proper medical treatment was being provided handicapped newborns.⁵³

The Undersecretary's proposal won the support of ten groups, including The American Academy of Pediatrics and The American Medical Association, which had opposed the Baby Doe Rules.⁵⁴ Such Bioethical Review Committees (much akin to ethical tribunals) would be composed of doctors, hospital administrators, clergy, and lay members, and would take on the duty of developing guidelines for the treatment of handicapped infants and other sensitive bioethical issues.⁵⁵ The committees could be convened automatically when disagreements arose over the withholding of treatment or upon the request of any hospital staff member, a family member, or even a concerned member of the public.⁵⁶ This is, at least in theory, a sound proposal that would go far toward providing a support mechanism to a beleaguered family unit faced with the ultimate responsibility for deciding the fate of a defective newborn.

The desire of the federal government to provide health care services to *all* citizens, and to prevent discrimination against the handicapped in the administration of these services, is admirable. But to formalize this into an overly broad and intrusive regulatory scheme, which has at best scant foundation in case law,⁵⁷ would threaten the privacy of the family and destroy the code of confidentiality existing between doctor and patient. Such regulations ignore valid legal mechanisms, such as child protection laws in the states,⁵⁸ that have not been tried and found deficient.

C. The Final Rules

The final Baby Doe Rules were printed in January of 1984, and were the product of nearly 17,000 comments submitted to the Department of Health and Human Services.⁵⁹ Although the Department effected some changes in its attempt "to forge a cooperative

52. See Hilts, *HHS Moves to End 'Baby Doe' Controversy on the Handicapped*, Wash. Post, Aug. 24, 1983, at A2, col. 1.

53. *Id.*

54. *Id.*

55. *Id.*

56. *Id.*

57. The regulations were founded upon only four documented cases of "discriminatory" denial of care for defective infants. 48 Fed. Reg. 30,848 (1983).

58. See Annas, *supra* note 38, at 27.

59. 49 Fed. Reg. 1,622 (1984).

approach,"⁶⁰ the final rules still provided for the same basic mechanisms of federal intervention without provisions for a meaningful standard. The changes were thus aimed more at muting the controversy surrounding federal intervention, than at providing workable guidelines for the treatment of handicapped infants.

The new standard to be used in caring for defective infants was stated as follows: "nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments."⁶¹ This new standard would appear to permit more room for discretion in withholding treatment, as the language speaks of "reasonable" medical judgments, and seems to allow *some* consideration of the infant's defective condition. The basic problem with the old proposed standard of customary medical care remains: the standard is still too vague to justify the sanctions visited upon the parties involved.

Acknowledging concerns reflected in public comments to the effect that the proposed warning signs posted in nurses' stations could "have a disruptive effect on the provision of health care to newborn infants," the Department responded by changing the requirements for the sign.⁶² These changes were largely cosmetic, however, as the Department's basic approach remained unaltered. The sign no longer needed to be posted in nurses' stations, but must still be placed "at any location where nurses and other medical professionals who are engaged in providing health care related services to infants will be aware of the content of the notice."⁶³ The sign has also continued to shrink in size, and must now be only five by seven inches.⁶⁴ In order to eliminate the possibility that viewers of the warning sign might believe that it implies past improper conduct by the hospital, the Department now allows a sign explaining that the hospital's policy is consistent with that of the government's nondiscrimination requirements embodied in Section 504.⁶⁵ Finally, minor changes have been made in the re-

60. *Id.*

61. *Id.* at 1,651 (to be codified at 45 C.F.R. § 84.54).

62. *Id.* at 1,625.

63. *Id.* at 1,626. This action was taken to remedy the concern expressed by medical providers that "posting [the signs] in the nurses' stations would continue to make the notice conspicuous to distressed parents." *Id.*

64. *Id.*

65. *Id.* at 1,625. This alteration was suggested by the Catholic Health Association; in order to be allowed to put up such a sign, the hospital must first have a procedure in use for "review of treatment deliberations and decisions concerning health care for handicapped infants." *Id.*

quired wording of the sign.⁶⁶

There were two significant changes in the rules. Although not required, the establishment of Infant Care Review Committees (ICRC's) was encouraged in the 7,000 health care providing hospitals receiving federal assistance.⁶⁷ These ICRC's consist of at least seven members from the hospital staff, with one designated to act as "special advocate" for the infant.⁶⁸ Under the final rules, the ICRC's were encouraged to develop and recommend to participating hospitals guidelines for the withholding or withdrawal of medical treatment for infants suffering from life-threatening conditions. The ICRC's also provide counsel in specific cases under review where treatment is, in fact, withheld or withdrawn. The final rules permitted only an advisory role for the ICRC's however, and thus greatly limit the potential intrusion of a hospital review board.⁶⁹

The second important change in the final rules was the language found in the section called "Guidelines Relating to Health Care for Handicapped Infants."⁷⁰ This section provided "interpretive guidelines" that boldly stated that no federal intervention will occur where either of the following standards or conclusions were met: (1) where reasonable persons with medical training conclude that the treatment would be futile, or (2) where the treatment's success is too unlikely, and thus the considered treatment will not be of medical benefit to the infant (and could even harm the infant).⁷¹

66. *Id.* at 1,626. The Department of Health and Human Services explained that such changes reflected the "deference to reasonable medical judgments."
Id. One example of the wording change is found in the heading of the sign: the new sign's heading reads "Principles of Treatment of Disabled Infants."

67. *Id.* at 1,562 (to be codified at 45 C.F.R. § 84.54).

68. *Id.*

69. Originally, the American Academy of Pediatrics suggested the hospital review boards as a substitute for government mechanisms to enforce Section 504. The Department rejected this suggestion for the reason that the "essential element of this alternative proposal—that it separates the process from the established legal framework governing decisionmaking by parents and physicians, with no meaningful provision to ensure that they function in accord with this framework—makes the proposal unacceptable." *Id.*

More recently, the Child Abuse Amendments of 1983, *see* H.R. 1904, 98th Cong., 1st Sess. (1983), and S. 1003, 98th Cong., 1st Sess. (1983), seek to direct the withholding of federal funds from those hospitals that withhold treatment of handicapped at risk newborns to the infant's neglect or abuse. Treatment could be withheld only if the baby in distress were irreversibly comatose or if treatment would merely prolong dying and thus be considered inhumane. *See generally* H.R. REP. NO. 98-159, 98th Cong., 2d Sess. (1984).

70. *Id.* at 1,653-54 (to be codified at 45 C.F.R. § 84).

71. *Id.* On May 23, 1984, the new regulations were found invalid. *See American Hosp. Ass'n v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984). The government has, however, decided to appeal this decision. *See* Wash. Post, Aug. 18, 1984, at A2, col. 3.

III. BABY JANE DOE

A. Action Against The Parents

On October 11, 1983, another "Baby Doe" was born with a variety of tragic disorders including spina bifida (a failure of the spinal column to close properly) and excess fluid in the brain. Dubbed "Baby Jane Doe," she was born at the Stony Brook Hospital on Long Island, New York. Attending physicians acknowledged that she would die within two years without corrective surgery. Even with surgery, she could survive only in a severely retarded and bedridden condition. After consultation with other physicians and members of the clergy, the parents refused to allow corrective surgery.⁷²

Subsequently, a Vermont "right-to-life" attorney having no direct interest or relationship to the parties petitioned the New York Supreme Court to intervene on the child's behalf.⁷³ The plaintiff circumvented the standing problem by appointing a guardian *ad litem*, who then sought a judicial authorization for surgery to override the parents' decision to disallow remedial surgery.⁷⁴ Although the trial court actually ordered the operation, the appellate division of the supreme court reversed and upheld the rights of the parents in *Weber v. Stony Brook Hospital*.⁷⁵

The New York Court of Appeals found that the state legislature had, through the passage of Article 10 of The Family Court Act, established detailed provisions designed to protect children from injury and mistreatment, and to promote their general well-being.⁷⁶ Under this legislation, the primary responsibility for initiating child neglect proceedings is vested in specific child protective agencies which—with proper court supervision—are directed to thoroughly investigate allegations of child neglect and report their findings to the court before judicial proceedings are initiated.⁷⁷ The decision warned that "judicial proceedings touching the family relationship should not be casually initiated."⁷⁸

The court further observed that there was a total failure to follow the statutory scheme that the Legislature had designed specifically for the protection of children:

As the guardian conceded on oral argument, acceptance of the proposition

72. See Margolick, *Battle for 'Baby Doe'*, N.Y. Times, Oct. 25, 1983, at B1, col. 5.

73. *Id.*

74. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 209, 456 N.E.2d 1186, 1187, 469 N.Y.S.2d 63, 64 (1983).

75. 95 A.D.2d 587, 467 N.Y.S.2d 685, (1983).

76. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 210, 456 N.E.2d 1186, 1188, 469 N.Y.S.2d 63, 65 (1983).

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

78. *Id.*

he espouses would be to recognize the right of any person, without recourse to the strictures of the Family Court Act, to institute judicial proceedings which would catapult him 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.⁷⁹

Refusing to enumerate the circumstances that would trigger judicial protection of a child's interest, the decision merely observed that there may be occasions where court involvement is appropriate.⁸⁰

Other New York courts have, in various instances, given guidance as to the parameters of parental autonomy in deciding to discontinue the treatment of their children. Lower courts in New York have determined that the adequacy of medical treatment may be used as a norm or standard in considering cases of child neglect.⁸¹ Furthermore, where a child has a "reasonable chance" to lead a fulfilling and useful life, parental inaction in the face of needed surgical interventions will not be permitted.⁸² Interestingly, however, the New York Court of Appeals has held that where treatment designed to prolong life offers no hope of recovery, life sustaining efforts may be terminated.⁸³ In a case where excessive pain would not be encountered by the patient, however, the same court ordered blood transfusions to sustain the life of a terminally ill and profoundly retarded cancer patient.⁸⁴

B. The Federal Response to Baby Jane Doe

The privately instituted action against the parents was only half of the ordeal stemming from the Baby Jane Doe's case. On November 2, 1983, the federal government argued in court that the failure by a federally supported hospital to order surgery for an infant with severe birth defects violated the civil rights accorded the child under the Rehabilitation Act of 1973.⁸⁵

79. *Id.*

80. *Id.*

81. *In re Hofbauer*, 65 A.D.2d 108, 411 N.Y.S.2d 416 (N.Y. App. Div. 1978) (parents had the right to choose laetrile therapy under a licensed physician for their eight-year-old child).

82. Application of Cicero, 101 Misc. 2d 699, 702, 421 N.Y.S.2d 965, 968 (N.Y. Sup. Ct. 1979) (court ordered surgery for an infant born with spina bifida).

83. *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981).

84. *Id.* "[A] court should not in the circumstances of this case allow an incompetent patient to bleed to death because someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease." *Id.* at 382, 420 N.E.2d at 73, 438 N.Y.S.2d at 275-76.

85. See Barringer, *U.S. Seeks Records of 'Baby Jane Doe,'* Wash. Post, Nov. 3, 1983, at 1, col. 6.

In the United States District Court in Brooklyn, the Justice Department sought access to the medical records of Baby Jane Doe in order to determine whether a violation of her federal civil rights (guaranteeing equal protection of the laws to disabled persons) had been violated. Stony Brook Hospital, where Baby Jane Doe was born and where she remained, refused to cooperate by providing the infant's medical records to Justice Department investigators, the Surgeon General of the United States, and investigators from the United States Department of Health and Human Services.⁸⁶

In this early test of reissued Baby Doe Rules, United States District Court Judge Leonard D. Wexler of New York ruled that the evidence in the case "conclusively established there is no discrimination."⁸⁷ The Judge observed that the parents had made a choice between two medically acceptable alternatives: surgery versus non-surgical care. He concluded that if the operations had been performed, "the infant would live longer—as a vegetable, paralyzed, disabled"⁸⁸

A new outburst of public sentiment followed the Baby Jane Doe decision. Meeting in Washington, D.C., on November 30, 1983, various doctors' groups and disability rights organizations issued a joint statement that the basis for deciding whether to withhold treatment should never be tied to a person's disability—even where uncertainty exists as to whether the treatment will have truly beneficial consequences.⁸⁹ The groups further agreed, however, that "it is ethically and legally justified to withhold medical or surgical procedures which . . . will only prolong the act of dying."⁹⁰ Finally, the groups contended that the determination of the course of treatment to follow should hinge solely on the medical condition of the individual at risk, rather than on the limited potential of such an individual or the lack of available community resources needed to compensate for the handicap.⁹¹

The tragic saga of Baby Jane Doe will continue to be rewritten daily; some cases will be noticed, others will not. It is hoped that these stories can be reckoned with, not in an atmosphere of jour-

86. *Id.*

87. See Barringer, *Judge Rejects Federal Role in 'Baby Doe' Case*, Wash. Post, Nov. 24, 1983, at A5, col. 4.

88. *Id.* The Justice Department unsuccessfully appealed the decision of Judge Wexler to a federal appeals court. See *United States v. University Hosp.*, 729 F.2d 144 (1984). See also Barringer, *'Baby Doe' Ruling Appealed by Justice Department*, Wash. Post, Nov. 24, 1983, at A5, col. 4.

89. See Barringer, *'Baby Doe' Takes Turn for Worse; Legal Fight Accelerates*, Wash. Post., Nov. 30, 1983, at A2, col. 1.

90. *Id.*

91. *Id.*

nalistic sensationalism and bureaucratic intermeddling, but rather in an informed medical and familial setting, where love and humaneness are basic elements of the decisionmaking process. Barring the most extreme circumstances of parental disability,⁹² decisions affecting Baby Doe families should not be made by those outside the immediate circle of family concern. As one commentator has explained, "the inevitable agony will be much less if these decisions, and any mistakes, are left to the families involved; most often the families will decide on the basis of love, and in any event it is the family that must live with the resulting burden or guilt."⁹³

IV. SEARCHING FOR A WORKABLE STANDARD

A. Technical/Medical Criteria

The Baby Doe Rules warn against discriminatory denial of "nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgment)"⁹⁴ and "customary medical care."⁹⁵ This naive concept of customary medical care is simply a mirage in the frequently difficult and tragic cases of severely handicapped infants; such a standard does not presently exist. Responding to such uncertainties, this Article will try to provide a framework for determining a standard of medical care for infants born with birth defects and, in turn, establish the roots of a more workable process of principled decisionmaking. It should be stressed that this Article does not propose a rigid, monolithic standard of medical care. Any standard for determining the treatment of defective infants must steer a course between the absence of standard (as exists under the federal regulations) and the adoption of an overly rigid standard. Flexibility is important in this sensitive undertaking.

Neonatal intensive care units, developed largely in university medical centers, now permit care to save all infants except the very premature—those weighing less than one and one-half pounds.⁹⁶ Those infants weighing more than one and one-half

92. See *infra* notes 114-126 and accompanying text.

93. Wall St. J., Oct. 31, 1983, at 30, col. 1.

94. 49 Fed. Reg. 1,651 (to be codified at 45 C.F.R. § 84.54).

95. *Id.*

96. Steinmann, *The Baby Savers*, N.Y. Times, May 11, 1975, § 6 (Magazine), at 68. As early as 1975, one of the most advanced newborn intensive care units in the country (with thirty-six beds, staffed by eight pediatricians, two pediatric anesthesiologists, a neurologist, and fifty-seven specially trained nurses), was opened at The Babies Hospital in The Columbia Presbyterian Medical Center. *Id.* At Jackson Memorial Hospital in Miami, Florida, seventy beds comprise a similar unit. See Sternberg, *Lying Hopelessly Ill, Infant Tests New Law of Hospital Survival*, Wash. Post, Apr. 3, 1983, at A4, col. 1.

pounds are considered to be "salvageable" and almost no medical technique and assistance will be denied to such infants.

Statistics indicate that American physicians tend to follow this birth weight standard in determining whether intensive, or aggressive treatment (e.g. machine-assisted respiration) should be undertaken. A recent report of infant births in the United States disclosed the fact that infants in the 501-750 gram range (1 lb. 1½ oz. to 1 lb. 10¼ oz.) are oftentimes treated aggressively. Those in the 751-1,000 gram range (1 lb. 10¼ oz. to 2 lb. 3 oz.) are commonly treated in an aggressive manner, while those infants weighing more than 1,000 grams (2 lb. 3 oz.) at birth are routinely treated aggressively.⁹⁷

In contrast, intensive care in Britain and Sweden is generally reserved for infants over 750 grams.⁹⁸ Conversely, when an infant weighs less than 750 grams, it is seldom subjected to aggressive care. As a consequence of this general policy, fewer disabilities result in British and Swedish infants of low birth-weight from aggressive treatment than in the United States.⁹⁹

An infant with a very low birth-weight is susceptible to brain injuries, which in turn may result in associated handicaps such as mental retardation and cerebral palsy, and sustained treatment may only be obtained at considerable financial expense.¹⁰⁰ It has therefore been suggested that a cut-off weight be set at 1,000 grams (about two pounds, three ounces), below which aggressive treatment could be justifiably withheld.¹⁰¹ Another viable alternative would be to withhold aggressive infant care when a birth weight of 1,000 grams or less is recorded for those born in a state of severe asphyxiation.¹⁰²

It should be emphasized that nonaggressive care does *not* mean "no care." Rather, it has been termed as conservative care, and is recognized to be a less intensive mode of therapy designed to promote the newborn's comfort and well-being. Nonaggressive care

97. Young, *Caring for Disabled Infants*, 13 HASTINGS CENTER REP., Aug. 1983, at 15.

98. *Id.*

99. *Id.*

100. One recent report of typical costs for infants who were born with a weight greater than 500 grams, and who were admitted at the University of California, San Francisco, Moffitt Hospital from July 1976 to 1978, showed the average total charge was \$8,069, while the median total charge was \$3,610. In five cases out of 1,185 admissions, total charges were greater than \$100,000. In nineteen cases, the total charges were in the range of \$50,000 to \$99,999. In 153 cases, the bill ranged from \$10,000 to \$19,000. Strong, *The Tiniest Newborns*, 13 HASTINGS CENTER REP., Feb. 1983, at 14, 16.

101. *Id.* at 14 (discussing the suggestion made by an obstetrician in Kirkley, *Fetal Survival*, 137 AM. J. OBSTETRICS AND GYNECOLOGY 873 (1980)).

102. *Id.* at 15.

may be performed by maintaining the distressed infant's warmth, periodically providing fluids, and placing the infant under an oxygen hood in order to prevent cyanosis.¹⁰³

It should also be stressed that an infant's birth weight is only *one factor* to be weighed into the decision to withhold intensive treatment. Selective non-treatment should be administered on the basis of a determination, made by the family and its physicians, which would focus on factors other than just weight, such as the potential for quality of sustained life and economic considerations of cost-effectiveness in saving and promoting a particular life.¹⁰⁴

Genetic factors are also frequently considered. The most commonly agreed upon genetic factors that would justify the withholding or discontinuation of aggressive therapies are tied to severe abnormalities, diseases, or damages to an infant's central nervous system. "Severe afflictions" would include cases of hydranencephaly,¹⁰⁵ severe neural tube defects,¹⁰⁶ gross hydrocephalus¹⁰⁷ (if complicated by infection), and specific chromosomal disorders such as trisomy 13 and 18.¹⁰⁸ Additional cases might include infants with extensive and fully documented brain damage after asphyxia and hemorrhage.¹⁰⁹

Examples abound of instances where action was taken by the government to force parents or physicians to treat or sustain infants in the most tragic of conditions.¹¹⁰ On April 11, 1983, in Coos County, Oregon, the Baby Doe saga was repeated. On that date, an infant girl was born suffering from multiple defects: her skull was formed with a membrane sac containing fluids and brain parts

103. *Id.*

104. *Id.* at 17.

105. This may be described as a developmental disorder of the nervous system which results in large fluid-filled cavities within the brain. BLAKISTON'S GOULD MEDICAL DICTIONARY 632 (1979).

106. This may be described as a disorder characterized by distention of the brain with cerebrospinal fluid. *Id.* at 633.

107. The neural tube is the embryonic tube that "differentiates into brain and spinal cord." *Id.* at 905.

108. Trisomy 13 and 18 are chromosomal defects characterized by severe mental retardation, seizures, and various physical deformities. *Id.* at 1405.

109. See Young, *supra* note 85, at 15.

110. For example, the leading English case of *In re B (Minor)* overruled a lower court decision respecting a parental decision which "in the kindest . . . interests of the child" forbade surgical correction of an intestinal blockage of a mongoloid infant. The court ruled that the infant was entitled to a "happy life" insofar as a person suffering from mongolism could enjoy such a life, and that the corrective surgery would assure that life. While not structuring a conclusive standard for subsequent decisionmaking in such cases, the court indicated that there may well be "awful" cases where the life of the child would be so full of pain and suffering that it would be better to end it. C.A. 1981, 1 W.L.R. 1421, 1424.

hanging from the back of her head. As a consequence of her massive brain damage, a number of her bodily functions were curtailed. She was unable to see or hear, she had neither sucking nor swallowing reflexes, and was unable to eat without special intravenous or forced feeding.¹¹¹

Acting on a telephone call regarding the alleged nonfeeding of the infant, the Oregon Right to Life group took immediate action. The group not only alerted the state health department, but also used the Baby Doe Hotline to fly a federal team of investigators to Oregon from the United States Department of Health and Human Services. While there was no disagreement among the interested parties that the baby's death was imminent, in spite of the treatment that she could receive, the Oregon Right to Life group sought "to show that the child should not be starved to death."¹¹² A spokesman for the group explained: "We felt it was no more appropriate to starve the child than to inject it with something that would kill her outright, which everyone agrees is not proper."¹¹³ Although refusing to find the parents' medically supported orders to end the feeding of the infant to be negligent, the Circuit Court directed intravenous feeding to be attempted while an appeal was perfected to the Oregon Court of Appeals. Mercifully, the baby died before further court action.¹¹⁴

Other instances also suggest that miracles of modern medicine may be but curses to those who are recipients. Consider, for example, the case of Andrew Stinson, who was born fifteen and one-half weeks premature, and who weighed only one pound, twelve ounces, at birth. Because of "heroic" medical efforts, six grueling months elapsed before the infant finally found peace through death.¹¹⁵ Mrs. Stinson felt that the use of so-called "heroic and experimental technology" on her son was a moral outrage and was applied in callous disrespect for the sacredness of human life, rather than in respect for it.¹¹⁶

Another example of a case where modern medicine could be said to have acted more as a curse than a miracle can be found in the vivid description of the agony of a small child, kept alive through the grace of modern technology:

111. See Hiltz, *Brain-Damaged Baby Dies Amid Court Fight Over Treatment*, Wash. Post, Apr. 23, 1983, at A2, col. 1 [hereinafter cited as Hiltz, *Baby Dies*].

112. *Id.*

113. *Id.* See also G. WILLIAMS, *THE SANCTITY OF LIFE AND THE CRIMINAL LAW* 25-35 (1958).

114. See Hiltz, *Baby Dies*, *supra* note 111.

115. See Stinson & Stinson, *On the Death of a Baby*, 244 ATL. MONTHLY 64 *passim* (1979). See generally R. STINSON & P. STINSON *THE LONG DYING OF A BABY* (1983) [hereinafter cited as STINSON & STINSON].

116. See generally STINSON & STINSON, *supra* note 115.

The child lies motionless inside the Plexiglass incubator. . . . She weighs 24 ounces and is two months old. Tubes, five in all, carry nutrients into her body and carry wastes away. She is covered with scabs. Her skin is yellow and slowly dying. Two weeks ago, infection ravaged her small intestine. Her body is stiff: poor circulation and blood teeming with bacteria have caused a condition similar to rigor mortis. When this little girl begins to die, she will not be resuscitated, her parents and her doctor have decided. She is taking up a bed that could be used for a potential survivor.¹¹⁷

This baby, termed Jackson Miami's "Baby Doe," was the subject of heroic life-sustaining measures since its birth.¹¹⁸ Typically, the costs of such care run from \$6,000 to \$80,000.¹¹⁹ Even greater than the economic costs are the physical costs to the infant itself. As one of the nurses caring for the Jackson Baby Doe put it, "that poor baby is suffering."¹²⁰

These tragic cases underscore the importance of considering the potential benefit to be derived from intensive treatment. A vast array of surgical techniques can now preserve life for weeks or even months, in spite of severe defects. For example, prompt surgery can save children with spina bifida (exposure of the spinal cord) from death, but treatment rarely can save them from lives of partial paralysis, mental retardation, and a complete dependence upon others for assistance in discharging the simplest body functions.¹²¹ The lives of grossly premature infants who have severe cases of mental retardation (due to oxygen deprivation during birth) can also be saved as a consequence of modern neonatal intensive care procedures. While surgery is successful in otherwise correcting life-threatening cardiac and intestinal defects which are commonly associated with Down's Syndrome, the same surgical gift cannot alter mental retardation which, in turn, is caused by Down's Syndrome.¹²²

A study conducted in the early 70's at Children's Hospital in Sheffield, England, provides another set of guidelines for determining when care may be withheld from handicapped infants.¹²³ The Sheffield study focused on the presence of those conditions that dictate that the infant will either die early (e.g., within nine months), regardless of the care given, or will suffer severe multi-system handicaps that preclude the child from living an independent, dignified life, or enjoying meaningful interpersonal relations.

117. See Sternberg, *supra* note 96, at A4, col. 1.

118. *Id.*

119. *Id.*

120. *Id.*

121. See American Academy of Pediatrics v. Heckler, 561 F. Supp. 345, 396 n.2 (D.D.C. 1983).

122. *Id.*

123. See McCormick, *supra* note 10, at 339.

The following defects were found to merit the withholding of treatment:

1. Thoracolumbar or thoracolumbosacral lesion (lesion on the thoracic and lumbar parts of the spine).
2. Gross paralysis with a neurologic segmental level at L3.
3. Kyphosis or scoliosis (abnormal curvature of vertebral column).
4. Gross hydrocephalus (accumulation of fluid within the brain) with a head circumference at least two centimeters above the ninetieth percentile related to birth weight.
5. Other gross congenital defects, such as cyanotic heart disease (cardiac malformation causing insufficient oxygenation of the blood).
6. Intracranial (brain) birth injury.¹²⁴

The recent statistical studies that have disclosed that the number of disabled babies born in the United States has doubled within the last twenty-five years are sobering.¹²⁵ The study released by the National Center for Health Statistics revealed that 140,000 babies born this year will suffer from some type of physical abnormality, mental retardation, or learning disability.¹²⁶ In the late 1950's, there were only about 70,000 such abnormal births.¹²⁷ The medical, social and economic implications of this increase in disabled infants are significant, since it translates into a substantial financial commitment and, indeed, burden to society. The full effect of the cost outlay has yet to be calculated. For example, there has been a 15 percent increase in the number of children enrolled in some form of special education since 1975—with federal service costs at over one billion dollars a year.

B. The Role of Parents in Decisionmaking

While the most universal relation in nature is that between parent and child,¹²⁸ there is a discernible modern legislative trend toward replacing the traditional deference to parental authority with a new emphasis on child welfare.¹²⁹ In 1973, the dominant judicial attitude in settling disputes concerning children was to inquire whether the best interests or welfare of the child would be served.¹³⁰ In 1979, however, a neo-conservative attitude was advocated, and is gaining respect, which directs judicial restraint and

124. Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, 4 BR. MED. J. 201, 204 (1973). See also PEDIATRIC NEWS, Nov. 1974 at 8, 11.

125. Lyons, *Disabilities in U.S. Babies Found to Have Doubled in 25 Years*, Int'l Herald Tribune, July 21, 1983, at 1, col. 1.

126. *Id.*

127. *Id.*

128. 1 W. BLACKSTONE, COMMENTARIES ON THE LAWS OF ENGLAND *446.

129. See, e.g., Dickens, *The Modern Function and Limits of Parental Rights*, 97 L.Q. REV. 462, 463-65 (1981).

130. See *id.* at 467. See also J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *BEYOND THE BEST INTERESTS OF THE CHILD* (1973).

discourages state intervention when "children issues" arise.¹³¹ As one commentator has noted, state intervention must be tempered: "[s]o long as the child is part of a viable family, his own interests are merged with those of the other members. Only after the family fails in its function should the child's interests become a matter for State intrusion."¹³² Thus, before a child's interest can be protected individually, the government must make a showing that the parent, or parents, are operating in a fashion that is not consistent with principles of family solidarity and privacy.¹³³

Modern parents, under the neo-conservative analysis, should exercise autonomy over the medical needs of their children.¹³⁴ The crucial task is to find the point at which parental choices so harm the child's welfare as to justify state intervention.¹³⁵ It has been suggested that unless death is a likely consequence of the parental decision, there is no justification for governmental intrusion.¹³⁶ An ameliorated position could state that only *unreasonable* parental actions warrant intervention. Introducing the standard of reasonableness gives wider significance and respect to parental autonomy. It is also a more realistic approach to decisional matters in this sphere of consideration.

The standard of reasonableness is always flexible and responsive to individual factual applications. This flexibility may be enhanced through interpretation and application of social policies emerging from each particular situation. Forces of reasonableness and social policy are balanced as justice or equity is sought in individual cases. The element of reasonable discretion must be accorded to the family in its unique position of knowledge. Determinations of the best interests of one family member must by necessity be based upon individual family beliefs in social, economic, and spiritual values. Each case must be considered individually, according to the context in which it arises. The proposed construct for decisionmaking is thus a mere aid to the difficult process, not an unyielding *a priori* ethic.

As a concert master in an orchestra assists his fellow musicians in tuning and seeks to establish whether they are in pitch before performing, he has—unless suffering from tone deafness—developed an innate ability to determine the tonality or pitch (or, as the case may be, "intonality") of the group. It may be a sense developed over years of early musical training, but every acknowledged

131. See Dickens, *supra* note 129, at 467.

132. J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *supra* note 130, at 1.

133. See Dickens, *supra* note 129, at 1.

134. See J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *supra* note 130, at 112.

135. See Dickens, *supra* note 129, at 472.

136. See J. GOLDSTEIN, A. FREUD, & A. SOLNIT, *supra* note 130, at 92.

concert master has it, and most other musicians have it as well. Similarly, one does not need to read laws or interpret judicial decisions holding forth on what is or is not pornographic. As one Supreme Court Justice asserted, one knows obscenity when he sees it—and most average, ordinary, reasonable people would agree.

When a parent exceeds the standard of reasonable conduct regarding a newly born handicapped infant, decisive action should be taken by the state to protect the infant. An inherent sense of conscience, decency, or humaneness directs all loving parents. This assumes, of course, that the parents are themselves intelligent and contributing members of society. Obviously in those cases where the parents are not competent members of society, the state must stand ready to pierce the familial veil of privacy where the parents are incapable of making mature, reasonable, and loving judgments regarding the medical treatment of their newborn. One could, for example, well imagine a case of a fourteen year-old, drug dependent, and economically insecure young girl giving birth to a neonate. Due to her illness, modest economic circumstances, and lack of sophistication, such a mother may decide to try to prevent heroic measures from being undertaken on an infant determined "salvageable" by her attending physicians. In this situation, the state would be justified—indeed, compelled—to act. Similarly, when confused religious purposes supposedly "compel" parents to withhold emergency blood transfusions or surgical interventions, the state must intervene to protect the infant.¹³⁷

While familial self-determination cannot remain unfettered and unchallenged, intrusions by the state should only be tolerated when familial judgment—based on consultation with wise and faithfully objective medical providers—"so exceeds the limits of reason" that the best interests of the incapacitated member are being flagrantly disregarded.¹³⁸ Stated conversely, a parent will be considered *prima facie* inadequate when he or she suffers a disabling mental illness, retardation, drug addiction, or major character defect.¹³⁹ These criteria evince an objectivity that has been lacking in past judicial evaluations, which were based on the best interests of the child.¹⁴⁰

137. See, e.g., *Jehovah's Witness v. King County Hosp.*, 390 U.S. 598 (1968) (sustaining state law ordering treatment for children who are medically neglected by their religious parents). See also G. SMITH, *supra* note 9, at 41-44; L. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 850-59 (1978).

138. McCormick, *supra* note 10, at 378.

139. See Garrison, *Why Terminate Parental Rights?*, 35 STAN. L. REV. 423, 489 (1983).

140. See, e.g., *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48, (court refused to

C. Quality of Life and Extraordinary Care

From a Judaeo-Christian theological perspective, the meaning, the substance, and, indeed, the consummation of life is tied to two inextricable expressions of love: love of God and love of neighbor. It is through love of others that God is recognized and loved.¹⁴¹ The meaning of life under this interpretation, then, is to be found in human relationships and the qualities of respect, concern, compassion, and justice that support such relationships.¹⁴²

Traditional philosophical thought on preserving life acknowledges that grave hardships may occur that make the preservation of life an extraordinary and, hence, nonobligatory function.¹⁴³ An extraordinary situation may arise when the infant suffers the "grave inconvenience" of living a life in a grossly mutilated body and when the future offers only pain with little or no chance of recovery.¹⁴⁴ The means for saving life also become extraordinary when the life that would be saved is lacking in quality in one form or another. A life is lacking in quality if continued existence would severely jeopardize the oppressed individual's opportunity to grasp and seek the overall meaning of life. This life goal has been termed the "relational-potential," and is described as the "growth in love of God and neighbor" through human relationships.¹⁴⁵ Under these circumstances, the individual's ability to nurture and maintain human relationships is so threatened and strained by the tragic physical condition of the infant that this goal can not be fulfilled.¹⁴⁶ Finally, where the financial cost of preserving life is so overwhelming that it would create grave hardship for the family,

order treatment for a child with a heart defect and Down's Syndrome, on the ground that there was not clear and convincing evidence that the child was not being provided with the necessities of life), *cert. denied*, 445 U.S. 949 (1980).

141. St. John wrote: "If any man says I love God and hates his brother, he is a liar. For he who loves not his brother, whom he sees, how can he love God, whom he does not see?" 1 *John* 4:20-21 (King James). See McCormick, *supra* note 10, at 346.

142. See also McCormick, *supra* note 10, at 346; Morison, *Implications of Prenatal Diagnosis for the Quality of, and Right to, Human Life*, in *BIOMEDICAL ETHICS AND THE LAW* 329 (J. Humber & R. Almeder eds. 1976).

143. See McCormick, *supra* note 10, at 347.

144. It has been urged that society and medicine stop "perpetuating the fiction that withholding treatment is ethically different from terminating life. It is time that society begins to discuss mechanisms by which we can alleviate the pain and suffering for those individuals whom we cannot help." Freeman, *Is There a Right to Die—Quickly?*, in *MORAL PROBLEMS IN MEDICINE* 354, 356 (S. Gorovitz ed. 1976).

145. McCormick, *supra* note 10, at 349.

146. *Id.* at 347. Extraordinary measures undertaken to prolong a life of suffering are unjust to the individual in question and to the societal standard of decency and humanity. G. SMITH, *supra* note 9, at 9.

medical care should be considered extraordinary, and therefore, nonobligatory.

Social justice demands that each individual be given an opportunity to maximize his individual potential. Yet, a point is often reached where maintenance of an individual is in defiance of all concepts of basic humanitarianism and social justice. When an individual's condition is such that it represents a negation of any "truly human" qualities or "relational-potential,"¹⁴⁷ then the best form of treatment should be no treatment at all.

Life should not be viewed as an end in and of itself, but rather as something that should be preserved so that other values can be fulfilled. Life should only be preserved when it holds a potentiality for human relationships. Although this standard does not admit of mathematical precision and must be applied with great humility and caution, it is nonetheless a beginning from which particular medical formulations may be developed.

Little disagreement is likely to be found with the conclusion that an anencephalic infant (one without a brain) has no capacity to develop a "relational-potential." The same conclusion could not be said of an infant with Down's Syndrome.¹⁴⁸ In the final analysis, a "relational-potential" test is needed which is applied "to presumptive biological systems for the gray area between such extremes."¹⁴⁹ Even with this, however, the decisions will have to be made by the parents, relying on the integrity and professionalism

147. See McCormick, *supra* note 10, at 349.

148. *Id.* at 350.

149. *Id.* A number of specific factors may be considered in testing the capacity or potential for social relationship: the relative likelihood of success of the corrective surgical intervention; the patient's life expectancy; the familial circumstances (i.e., financial and psychological stability); and the potential for the individual's contributions. Rescher, *The Allocation of Exotic Medical Lifesaving Therapy*, in *MORAL PROBLEMS IN MEDICINE* 523, 526-29 (S. Gorovitz ed. 1976).

One study showed conclusively that physicians normally evaluate the chronically or terminally-ill in terms of not only the physiological aspects of the case, but also in terms of the extent to which the patient is capable of interacting with others. Patients determined unsalvageable are typically not treated heroically. In determining salvageability, the patient's potential capacity to perform its social roles is crucial. Salvageability, then, is based upon a physician's determination of whether his patient can be restored to health or can, in a chronic state, be maintained for an indefinite period of time. The quality of life that the patient may enjoy if maintained or rehabilitated is a significant—if not crucial—determination. See D. CRANE, *THE SANCTITY OF SOCIAL LIFE: PHYSICIANS TREATMENT OF CRITICALLY ILL PATIENTS* 11, 14, 119 (1975).

Of course, the important point to be remembered is that the exact manner, weight and application of these factors in the balancing test must depend upon the *situation* of each case.

of medical personnel.¹⁵⁰ If a grossly deformed infant enjoys no potential for developing or enjoying relationships with others, or if there is a potential but it would remain undeveloped in a basic struggle to survive, then it can be said that that infant's life has achieved its greatest potential.¹⁵¹ Under these circumstances, it may be concluded that such an infant should be allowed to die because no extraordinary means are merited. Since the condition of the infant is extraordinary, the means of treatment are, in turn, extraordinary.¹⁵²

The concepts of ordinary versus extraordinary life-sustaining processes are highly relative, not only to time and locale, but also in their application to individual cases.¹⁵³ The concepts of ordinary and extraordinary treatment, in essence, serve as value judgments which determine whether a given mode of treatment poses an undue hardship on the patient or provides hope for a direct benefit.¹⁵⁴ If a particular mode of medical or surgical intervention either imposes too great a hardship on the patient, or could offer no reasonable hope of benefit, the treatment could be correctly viewed as extraordinary and, thus, nonobligatory.¹⁵⁵

Concern must be expressed regarding the patient's comfort in the remaining days of his life, if such an extraordinary act is undertaken or withheld. This determination of whether contemplated treatment is ordinary or extraordinary is essentially a quality of life statement.¹⁵⁶ In coming to this quality of life statement, we knowingly or unknowingly use a substituted judgment to conclude that, if we were in a similar situation, we would (or would not) wish to survive in such a state of impairment. Decisions of this nature are made within a vortex of deep emotionalism. They can be aided—but certainly never validated—by using the construct posited here.

Since the binding force of life is love, then it can be argued that man should endeavor to maximize a response to love in whatever life situations man finds himself.¹⁵⁷ If an act renders more harm than good to the individual concerned, and to those around him, the act would properly be viewed as unloving. The crucial point of understanding is that a basic cost/benefit analysis is almost always undertaken—consciously or unconsciously. Of course, the

150. McCormick, *supra* note 10, at 350.

151. *Id.* at 349. See generally Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975).

152. *Id.*

153. R. MCCORMICK, NOTES ON MORAL THEOLOGY, 1965 THROUGH 1980, at 565 (1981).

154. *Id.*

155. *Id.*

156. *Id.*

157. See Fletcher, *Love is the Only Measure*, 83 COMMONWEAL 427 (1966).

methodology utilized in this assessment will be situational and incapable of absolute determination.¹⁵⁸ Of necessity, the basic norm or standard to be used will be love.

Moral obligations must arise from more than mere situations or consequences.¹⁵⁹ The measurement of a defective infant's potential for developing human relationships serves as a valuable and rational construct for determining the newborn's future. The situation ethic of love is complemented and magnified when engrafted onto the relational-potential standard.

In a recent statement, President Reagan deplored the outcome of the original Indiana "Baby Doe" case.¹⁶⁰ "The real question today," the President suggested, "is not when human life begins, but, *What is the value of human life.*"¹⁶¹ The three pivotal words in this statement are "value," and "human life." Value should be evaluated in relation to the infant, its parents, and society. Agreed medical standards of "life," and its potential for humanity, can be crucial in this probing.

Every *person* is, to be sure, of equal value. If a proper relationship is established, however, between the words, "life," "equal," and "value," then it cannot be maintained that every *life* is of equal value.¹⁶² If "life" is taken to mean the continuation of vital processes, "value" to mean a good life to the concerned individual, and "equal" to mean either "identical" or "the same" (especially as to treatment), then it is incorrect to maintain that "every life is of equal value."¹⁶³ The concept of "equal value" is valid, as it simply means that all efforts must be made in order to avoid unjust discrimination in providing health care and life support mechanisms. Not all discrimination, or inequality of treatment, is unjust. The threat of unjust discrimination is bypassed totally if the process of decisionmaking focuses on *patient benefit*, in terms of a quality-of-life standard.¹⁶⁴

While a person has a value of incalculable worth, there are situ-

158. See R. McCORMICK, *supra* note 153, at 77.

159. See *id.* at 650.

160. Reagan, *Abortion and the Conscience of the Nation*, 9 HUMAN LIFE REV. 7 (1983).

161. *Id.* at 9 (emphasis in original).

162. See McCormick, *supra* note 10, at 350, 397. One of the world's greatest genetecists, the late Professor Theodosius Dobzhansky of Columbia University, observed that human equality is but an ethical precept, not a biological phenomenon. T. DOBZHANSKY, *GENETIC DIVERSITY AND HUMAN EQUALITY* 4 (1973).

163. McCormick, *supra* note 10, at 397.

164. *Id.* No absolute prohibition against the taking of human life can be inferred from recognition of the premise that life is sacred. See D. CALLAHAN, *ABORTION: LAW, CHOICE, AND MORALITY* 453-54 (1970); R. VEATCH, *DEATH, DYING AND THE BIOLOGICAL REVOLUTION* chs. 3, 5 (1976).

ations in which continued physical existence offers no benefits. As such, to maintain "life" could well be regarded as an assault on the infant, itself, and on its very dignity.¹⁶⁵

Dr. Joseph Fletcher has assembled a profile of those fifteen qualities, attitudes, or indicators of humanhood. According to Dr. Fletcher, to be considered "human" a child must possess: minimal intelligence, as those below a 20 I.Q. mark in a Stanford-Benet test are not considered persons; self-awareness; self-control; time consciousness; a sense of futurity tied to a theological assertion; a sense of the past, or memory; a capability to relate to others; an ability to express concern for others; an ability to communicate; the ability to assert control in life-directing situations and not dis-

165. McCormick, *supra* note 10, at 396.

Various groups have considered these and related problems. In Canada, it was suggested recently that decisions to treat or not to treat defective newborns should be made according to the medical facts of each case, should be reasonable, in the best interests of the patient, and in conformity with pertinent standards set out by the criminal law. Acceptable quality of life is essentially a question of fact that differs in each case. Yet it is also a question of sound medical judgment, based in turn upon medical experience, as well as consultations with the concerned party or parties such as parents, spouse, family, and next of kin. See LAW REFORM COMM'N OF CANADA, EUTHANASIA, AIDING SUICIDE AND CESSATION OF TREATMENT 24-26 (1983).

The A.M.A. has adopted the following position:

Quality of Life. In the making of decisions for the treatment of seriously deformed newborns . . . the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. In desperate situations involving newborns, the advice and judgment of the physician should be available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. . . .

The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AM. MEDICAL ASS'N 9 (1982).

A Presidential Commission reached conclusions similar to those of the A.M.A. The Commission went on to recommend that specific procedures be established for internal review of decisions regarding nontreatment for the handicapped at risk newborn. To that end, the formation of ethic review committees was suggested. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO TREATMENT 226-28 (1983).

play utter helplessness; the ability to display curiosity instead of indifference; changeability; rationality; the ability to be emotive and intuitive; the ability to be idiomorphous or distinctive; and finally, the capacity for neo-cortical functions.¹⁶⁶ Dr. Fletcher especially stressed the importance of the infant's ability to use its brain: "In the absence of the synthesizing function of the cerebral cortex, the *person* is non-existent. Such individuals are objects not subjects. . . . Personal reality depends on cerebation and to be dead 'humanly' speaking is to be ex-cerebral, no matter how long the body remains alive."¹⁶⁷

Dr. Fletcher's profile provides a test for determining the potential for sustaining human relationships. The deontological ethic thus merges creatively with the situation ethic.

On a case-by-case, or situational, basis bounded by medically

166. Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, 13 HASTINGS CENTER REP., Nov. 1972, at 1.

167. *Id.* at 3. The essential quality of humanness is the possession of the *potential* for participating in human activities which comes from possessing a functioning brain. See B. BRODY, ABORTION AND THE SANCTITY OF HUMAN LIFE: A PHILOSOPHICAL VIEW 114 (1975).

In order to continue to exist as a human—another viewpoint holds—one must possess an actually or potentially functioning heart, lung, or brain. Thus, it is only when a human possesses none of these that he ceases to exist. This view holds that a fetus may be regarded as a member of humanity when it acquires *one* of these. P. RAMSEY, THE PATIENT AS PERSON 96 (1970).

Yet another standard is posited for decisionmaking:

As long as we have any means of combatting the primary disease with any hope of success, we will use every mode of therapy available to maintain life. However, when there is no therapeutic approach of any value left, we feel that we must let the patient die as peacefully and comfortably as possible. Be it injection or hemorrhage, cardiac or respiratory arrest, we will not use extreme measures to combat it, only to let the child the next day die from the same or from another cause.

Toch, *Too Young to Die*, in PSYCHOSOCIAL ASPECTS OF TERMINAL CARE 65, 74 (B. Schoenberg, A. Carr, D. Peretz, & A. Kutscher eds. 1972).

Still another view regarding the status of personhood is that a human being becomes a person only when the attainment of higher mental capacities is recognized and charted. Being a subject of non-momentary interests makes a person, together with the possession of a sense of time, a concept of a continuing subject of mental states and a capacity for thought episodes. Humans, thus, may become quasi-persons reasonably at about three months. Empirical evidence concerning the psychological and neurophysiological development of human beings thus leads to the conclusion that it is most unlikely that the very new born infants are even quasi-persons, let alone persons. At best—according to this view—infanticide may destroy but a quasi-person. M. TOOLEY, ABORTION AND INFANTICIDE 34-36, 411, 419-21 (1983).

For children with diseases that involve pain and for which no hope for survival exists, prolongation of life should not be sought. Englehardt, *Ethical Issues in Aiding the Death of Young Children*, in BENEFICIENT EUTHANASIA 180, 187, 189 (M. Kohl ed. 1975).

approved guidelines, the decisionmakers will balance the gravity of the harm caused by extraordinary care, against the utility of the good that will come from such extraordinary actions. Decisionmakers should be ever-mindful of the ethical imperative to minimize human suffering at all levels when making their ultimate decisions. Father McCormick has suggested that decisionmakers should evaluate the infant's "potential" for the development of human relationships in light of the possibility that this hard-won potential—even assuming it exists—may be lost in the extraordinary care's drain on time, attention, and social-economic resources. This balancing test validates a cost-benefit analysis.¹⁶⁸

D. The Role of the Federal Government

Federal involvement in the decision to administer or withhold life-sustaining measures for defective newborns need not necessarily be in the form of intervention. If the federal government expressed its legislative concern for protecting human life in less intrusive ways, federal actions could, instead, be designed to provide cooperative assistance.

Rather than the Bioethical Review Committees envisioned in the federal Baby Doe regulations,¹⁶⁹ local hospitals should utilize their expertise in health care issues to promote "ethics advisory committees." These ethics advisory committees would assist the parents of newly born handicapped children by reaching independent assessments of whether conditions are so extraordinary that heroic action would be useless. The etiology of such committees could be traced to present clinical pathological conferences, which serve as an integral part of standard hospital procedures. Routinely, the clinician who cared for a diseased patient describes the rationale for his diagnosis and the course of therapy that he followed; then the pathologist describes the post mortem findings. Thus, any errors in diagnostic judgment are discovered, but they are discovered *after* the fact.¹⁷⁰ Introducing an ethical perspective in order to determine the ethical bases of treatment or non-treatment, and aggressive or conservative treatment, would shape the development of an ethical tribunal.

These ethics advisory committees could be composed of a wide sampling of independent individuals representing legal, ethical, medical, social, religious, and lay interests. Their opinions would never be imposed, but would instead only be triggered upon a fam-

168. See Cohn, *Let Deformed Babies Die*, *G U Jesuit Says*, Wash. Post, July 7, 1974, at A6, col. 1.

169. See *supra* notes 52-55 and accompanying text.

170. Dagi, *The Ethical Tribunal in Medicine*, in 1 *ETHICAL, LEGAL AND SOCIAL CHALLENGES TO A BRAVE NEW WORLD* 201, 208 (G. Smith ed. 1982).

ily request for their services. The ethics advisory committee would become an adjunct to the already existing family support mechanism of advisers, giving their counsel either before, or during, a crisis. The family unit itself, however, would make the ultimate decision regarding disposition of the case. The obvious advantage of this proposal is that it could function independent of a complex regulatory scheme. Through custom and usage, the committees could provide the direction and stability necessary to establish a standard medical practice for the treatment of handicapped newborns.

The ICRC's contemplated in the federal Baby Doe regulations differ radically from the proposed ethics advisory committees. Enforcement of a federal regulatory scheme through the "Baby Doe" regulations is offensive, in part because of its superimposition onto a federal scheme. As it appears to be emerging, an investigation by ICRC's could be triggered upon request by any committee member or a concerned member of the public. This would be an intrusion into the privacy and autonomy of the family. Committee "action" should be considered efficacious only if requested by the family or its designated agents (e.g., physicians). Furthermore, the ICRC's would serve as little more than an information gathering body for federal investigations.

Government concern and direction would be welcome if it were designed to decrease the number of premature infants born each year by increasing the funding for programs that provide food and prenatal care for expectant mothers. Coordinated state and federal legislative schemes to promote voluntary educational programs for genetic screening before marriage would also reduce the tragedy of handicapped infants.¹⁷¹ Federal regulation of contaminants and chemical pollutants could also reduce the incidence of genetic deformity. The federal government could establish a federal advisory task force charged with the responsibility of suggesting guidelines for a classification of birth diseases and problems which would merit a standard of acceptable medical treatment. There must be an unequivocal governmental policy that ensures that all handicapped individuals—regardless of age—will not be denied medical services on the basis of any handicap whatsoever. An even more far-reaching and needed position would be the legislative recognition that no citizen—handicapped or otherwise—should be denied needed medical services because of an inability to pay.¹⁷²

171. See generally J. FLETCHER, *COPING WITH GENETIC DISORDERS* (1982); P. REILLY, *GENETICS, LAW AND SOCIAL POLICY* (1976).

172. See Annas, *Disconnecting the Baby Doe Hotline*, 13 HASTINGS CENTER REP., June 1983, at 14, 16.

V. CONCLUSION

All life is sanctified by creation and, as such, is qualitative to the individual in crisis, and to mankind in general. Indeed, mankind occupies a position of "sacredness in the natural, biological order."¹⁷³ The purpose of life, as previously propounded, is to express love of God through fellowship with his fellow creatures. A parallel human goal is to minimize suffering and maximize the social good or utility of life.¹⁷⁴ One human endeavor should not be balanced against the other. Rather, after acknowledging the sanctity of all life, the questions to be addressed are: (1) whether the handicapped infant possesses a sustained ability to fulfill a "relationship-potential"; and (2) whether the course of medical treatment minimizes suffering and maximizes the potential utility of life. It is only at this point that a balancing process should be undertaken to judge the neurophysiological capacity and the long range capacity for quality living. The decision must then be made as to whether ordinary measures are sufficient to nurture this potential, or whether the case is so extraordinary in shared medical opinion that little can be accomplished in seeking to advance the potential.

Decisions in this sensitive area should be placed within the sole province of the family, acting under a standard of reasonableness. The family may, upon request, employ the guidance of medical, social, religious, ethical and legal advisors (i.e., an ethics advisory committee), but need not face an inquisitorial federal government.

Aided by medically approved standards like the Sheffield List and birth weight minimums for neonates, and by the acknowledged parental attitude of love, compassion, and well-being, hard decisions can and should be made within familial privacy. Viewed within this total context, sanctity of creation and quality of life are neither a palliative nor an apotheosis. Instead of being considered grandiose principles, they should be considered as intertwined guidelines that set the parameters for permissible action of families in these times of trauma. Implemented in the manner in which this Article proposes, these two guidelines remove the federal government's incentive to regulate, and intrude upon, issues of family planning.

173. P. RAMSEY, *THE PATIENT AS PERSON* xiii (1970).

174. See G. SMITH, *supra* note 9, at 1-4.