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## Baby Doe Decisions: Modern Society's Sins of Omission

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# Baby Doe Decisions: Modern Society's Sins of Omission

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*The quality of a culture is measured by its reverence for all life.*<sup>1</sup>

## I. INTRODUCTION

Curing mankind of its physical ills is medicine's noble pursuit. The advances in the field over the last generation have been staggering, and the benefits to society immeasurable. However, an unfortunate side-effect of the advance is our ability to forestall death, without being able to alleviate all sickness that in years past would have precipitated death. We can hold death at bay; we can keep life, sometimes. But we cannot assure that those who are saved will live healthy lives.

The painful consequence of this getting ahead of ourselves is nowhere more poignantly illustrated than in the case of a baby born with birth defects. If the child suffers from incurable defects, but can be kept alive, the inquiry may become whether the child *should* be kept alive, and under what circumstances. Medical and legal professionals labor with the inquiry, and certainly no answer is completely satisfactory—the issue is such a troubling one. But the answers the courts have risked in their judicial decisions are, at best, clumsy and inconsistent.

The public's attention was recently captured by a decision which sparked such a new and furious debate on the rights of families, the duty of physicians, the role of the courts, and the responsibility of governments, that it rages even now. The child called "Baby Doe" has lent his name to all babies whose lives are similarly at stake.

It began quietly enough. On April 9, 1982, "Infant Doe"<sup>2</sup> was born, the third child to his parents, in Bloomington Hospital, Indiana. Baby Doe suffered from two different birth defects: he was afflicted with Down's Syndrome,<sup>3</sup> a condition from which he would

1. Attributed to Albert Schweitzer. While perhaps apocryphal, the statement expresses eloquently the animus that pervades both Schweitzer's life and this Article.
2. The child is known as "Infant Doe," born to "John and Mary Doe." Records of the subsequent proceedings are sealed in accordance with Indiana law, although limited facts and findings are available. The child's mother was 31 years old at the time of birth, and according to the parents' attorney, she had apparently been thought too young to undergo amniocentesis during her pregnancy. See generally Longino, *Withholding Treatment from Defective Newborns: Who Decides, and on What Criteria?*, 31 KAN. L. REV. 377, 382 (1983); Letter from Dr. John Pless of Bloomington Hosp., 309 NEW ENG. J. MED. 554 (1983) [hereinafter cited as Pless Letter]. Presumably, pre-natal detection of Baby Doe's defects would have enabled his parents to consider abortion.
3. Once commonly referred to as "mongolism," Down's Syndrome is mental retardation, the severity of which is impossible to estimate at birth, and the precise extent of which cannot be determined in early infancy. See Bannon,

never recover, and from tracheoesophageal fistula, a surgically correctable condition.<sup>4</sup> This defect of the esophagus hampered breathing and prohibited swallowing, as the passage from the mouth to the stomach had not properly developed. Any oral feeding would probably have suffocated the child. Two pediatricians (one of which was the Doe family pediatrician) advised immediate transfer to another hospital for surgery to correct the esophageal defect. A third doctor (the attending obstetrician) recommended that Baby Doe remain at Bloomington Hospital, forego any corrective surgery to effectuate oral feeding, and receive only that treatment that would keep him relatively comfortable and free of pain until he inevitably died of either pneumonia or starvation.<sup>5</sup>

John and Mary Doe chose "nontreatment."<sup>6</sup> The next day, hos-

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*The Case of the Bloomington Baby*, 8 HUM. LIFE REV. 63, 63 (1982); Zellweger & Ionasescu, *Genetics of Mental Retardation*, in MEDICAL ASPECTS OF MENTAL RETARDATION 160 (2d ed. 1978). Down's Syndrome occurs in approximately one in every 700 live births. Often, other congenital defects, especially heart problems, are also present. See W. NYHAN & N. SAKATI, GENETIC AND MALFORMATION SYNDROMES IN CLINICAL MEDICINE 1, 21 (1976). See also *infra* note 4 and accompanying text.

4. According to a recent report by a Presidential Commission to study withholding medical treatment, the two most common defects present in a Down's Syndrome infant are congenital heart problems and gastrointestinal blockage, which includes Baby Doe's affliction of tracheoesophageal fistula. Left untreated, a child similarly afflicted will die of pneumonia or starvation. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 203 (1983) [hereinafter cited as PRESIDENT'S COMM'N REP.]. Surgery on such gastrointestinal defects is typically successful. *Id.* Conflicting opinions on Baby Doe's chances for surviving the operation ranged from "probably successful," to a 50-50 chance for success, to minimal chance of surviving the operation. See *In re* Infant Doe, No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982) (Declaratory Judgment); Bannon, *supra* note 3, at 63; Longino, *supra* note 2, at 382 n.30. In fact, Baby Doe's condition was surgically "reparable"—at least on day one of his life. See Pless Letter, *supra* note 2, at 664.
5. The Monroe County Circuit Court Judge described Baby Doe's fate euphemistically: to 'succumb [sic] due to inability to receive nutriment. . . ." *In re* Infant Doe No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982).
6. Withholding treatment from defective newborns, at least to the extent that heroic steps are not taken in cases where the prognoses are bad, is known as "passive" or "involuntary" euthanasia, or sometimes "dysthanasia." These terms attempt to distinguish between cases where treatment is withheld under certain circumstances, from cases where an affirmative act of "mercy-killing" (what may traditionally be considered "euthanasia") takes place under similar circumstances. In the first instance, treatment is never administered; in the second instance, present treatment is withdrawn or removed, in an affirmative act of "pulling the plug." See Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 214 n.16 (1975). Cf. Colletter, *Death, Dying and the Law: A Prosecutorial View of the Quinlan Case*, 30 RUTG. L. REV. 304, 309 & nn.21-23 (1977).

pital representatives requested a court hearing to determine the extent to which the hospital would be liable if Baby Doe "succumbed" pursuant to the parents' wishes. The Circuit Court for Monroe County, Indiana, concluded that "after having been fully informed of the opinions of two sets of physicians," the parents had the right to choose a "medically recommended course of treatment" for Baby Doe.<sup>7</sup>

The court directed the hospital to allow the "treatment" prescribed by the obstetrician and chosen by the parents.<sup>8</sup> The county prosecutor learned of the decision, and filed an emergency petition with the juvenile court seeking to remove Baby Doe from his parents' custody, and to authorize lifesaving treatment.<sup>9</sup> The court denied the petition,<sup>10</sup> finding that "the State has failed to show that this child's physical or mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parents to supply the child with necessary food, and medical care."<sup>11</sup> The Supreme Court of Indiana refused to reverse.<sup>12</sup> Baby Doe was baptized and given last rites, but he was not given lifesaving surgery, and he was not fed intravenously. He died April 15, 1982, at six days, as lawyers prepared an appeal to the United States Supreme Court.

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7. *In re Infant Doe*, No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982). The court noted that "Mr. Doe was lucid and able to make an intelligent, informed decision." See *infra* notes 27, 196 & 224 and accompanying text (parental autonomy and parents' desire not to be shielded from painful decisionmaking).
  8. The Monroe County Child Protection Team, and the appointed guardian Monroe County Department of Public Welfare, apparently conducted a hearing and decided not to appeal the decision. *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982) (Finding 11).
  9. *Id.* IND. CODE ANN. § 31-6-4-4 (Burns 1979) authorizes removal of a child from parental custody. Some local couples sought to adopt Baby Doe, one of whom had a three-year old daughter with Down's Syndrome. N.Y. Times, Apr. 17, 1982, at A6, col. 2.
  10. The court stated that: "[I]n order for the Court to issue such an order it must be shown that the child is a child in need of services pursuant to I.C. 31-6-4-3." *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982) (Finding 13).
  11. *Id.* A Petition for Temporary Restraining Order was also denied. The language of Finding 14 is from IND. CODE ANN. § 31-6-4-3 (Burns Cum. Supp. 1982).
  12. *Indiana ex rel Infant Doe v. Monroe Cir. Ct.*, No. 482 5140 (Ind. Apr. 16, 1982), *cert. denied sub nom. Doe v. Bloomington Hosp.*, 104 S. Ct. 394 (1983). See Longino, *supra* note 2, at 382 n.30. Upholding the rulings of the Circuit Court and Juvenile Court judges, the Indiana Supreme Court, on April 14, 1982, ruled that Baby Doe's parents could withhold treatment. See N.Y. Times, Apr. 15, 1982, at D21, col. 5. Baby Doe died hours before a stay of the Indiana Supreme Court ruling was to be heard by Justice Stevens of the United States Supreme Court.

The public response to the Indiana decision was generally unfavorable. Right-to-life groups,<sup>13</sup> those concerned with human rights in general,<sup>14</sup> and those involved with rights of the handicapped in particular,<sup>15</sup> expressed strong disapproval. President Reagan, through the Department of Health and Human Services, emphasized his intent to enforce existing laws,<sup>16</sup> and promulgated a new rule for federally funded hospitals that attempted to make actions of this sort prohibited acts of discrimination against the handicapped.<sup>17</sup> The new rule was short-lived, however,<sup>18</sup> and the adequacy of existing laws and the fate of current regulations are in serious doubt.<sup>19</sup>

The *Baby Doe* judges wrestled with a narrow issue: the right of

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13. See Wallis, *The Stormy Legacy of Baby Doe*, TIME, Sept. 26, 1983, at 58.

14. See generally Bannon, *supra* note 3.

15. See *supra* note 9; *infra* notes 137-76 and accompanying text.

16. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination solely on the basis of handicap by federally assisted programs and institutions. 29 U.S.C. § 794 (1982). Department of Health and Human Services (DHHS) Director Richard Schweiker warned federally funded hospitals that section 504 would apply in cases involving the medical care of infants with birth defects, and that violations might warrant termination of federal assistance. 47 Fed. Reg. 26,027 (June 16, 1982). See Russell & Babcock, "Hospitals Warned on Handicapped Babies," The Wash. Post, May 19, 1982 at A21, col. 4. This was apparently the first time section 504 had been applied to the medical treatment of handicapped infants. *Id.* at A21, col. 5.

17. 45 C.F.R. §§ 84.51-.52. The new rule required federally assisted medical institutions to post a sign in all pre- and post-partum wards, nurseries, delivery rooms and pediatrics wards warning that "Discriminatory Failure to Feed and Care for Handicapped Infants in this Facility is Prohibited by Federal Law," and offering a toll-free confidential "Handicapped Infant Hotline" to the DHHS or to a State Child Protective Agency. 48 Fed. Reg. 9,630 (1983) (to be codified at 45 C.F.R. § 84.61) (proposed Mar. 7, 1983, effective date Mar. 22, 1983).

18. Judge Gerhard Gesell struck down the rule as "arbitrary and capricious." American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 403 (1983). Although the regulation was not properly promulgated in accordance with the Administrative Procedure Act, 5 U.S.C. § 551-59 (1982), American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 398-99 (1983), the court added that the hotline would be intrusive and disruptive to the doctor-patient treatment process. *Id.* at 401.

19. The Second Circuit struck a nearly fatal blow to the newest federal regulations only weeks after they became effective. See *infra* notes 151-61 and accompanying text. United States v. University Hosp. at Stony Brook, 729 F.2d 144 (2d Cir. 1984), held that section 504 of the Rehabilitation Act of 1973, prohibiting handicapped discrimination (under which the new regulations were promulgated), does not encompass treatment decisions for handicapped infants. See *infra* notes 147-50 and accompanying text. Therefore, according to the court, the Department of Health and Human Services lacks any statutory authority to investigate nontreatment cases or to compel production of medical records. See *infra* note 151. The government may be reluctant to appeal the decision to the United States Supreme Court. If it loses the appeal, it will very likely be forced out of the arena entirely.

parents to choose a medically recommended course of treatment or nontreatment for their child.<sup>20</sup> That question, and a broader one addressing the policies of withholding medical care from defective newborns, have received varied treatment from commentators. "Nontreatment" has been both decried<sup>21</sup> and acclaimed.<sup>22</sup> Perhaps the *Baby Doe* decision is simply an unpopular and relatively rare one. It may be viewed as a trend toward the devaluation of handicapped life (and perhaps all weaker lives) and toward increasing emphasis on those interests that compete with the infant's interest in life-sustaining care.<sup>23</sup> Perhaps, too, the decision reflects the narrow values and priorities of an increasingly selfish society.

Part II of this Article will examine those current statutes and case law that should have helped Baby Doe, but which failed him and may well fail others like him. Part III then provides a series of standards which, if enacted, may save future Baby Doe infants.

## II. THE LAW AS IT IS

The constitutional "right-to-life" is violated only when a state wrongfully acts to abridge it.<sup>24</sup> Clearly, no state action denied

20. *In re Infant Doe*, No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982); *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982). See also Interview with attorney for Baby Doe's parents (Andrew C. Mallor), quoted in Longino, *supra*, note 2, at 382 n.30.

21. One commentator observed: "The absence of due process for the infant is all the more striking given the emotional circumstances of the parental decision and the lack of publicly certified guidelines or criteria for withholding care. We thus have a situation . . . in which arbitrary and unjustified killings can and have occurred." Robertson, *supra* note 6, at 268. See also *In re Storar*, 78 A.D.2d 1013, 434 N.Y.S.2d 46 (1980), within which one judge called withholding treatment from a 52-year-old mentally retarded cancer victim "an unwarranted and unconscionable intrusion upon the sanctity of human life." *Id.* at 1016, 434 N.Y.S.2d at 48 (Cardamone, J., dissenting).

22. For example:

It may . . . be that death has finally begun to emerge from our psychic closet and that we may now be able to thoughtfully address the potentially tragic by-product of medical science's assault upon death [the ability to keep the very seriously ill alive]. As one who participated in the [*Quinlan*] case I fervently hope for that result. After all, the dying is the one minority to which we all belong.

Colleston, *supra*, note 6 at 328. Cf. American Academy of Pediatrics Committee on Bioethics, *Treatment of Critically Ill Newborns*, 72 PEDIATRICS 565, 566 (1983) (supporting careful, thoughtful nontreatment decisions: "When the infants prospects are for a life dominated by suffering, the concerns of the family may play a larger role. Treatment should not be withheld for the primary purpose of improving the psychological or social well-being of others, no matter how poignant those needs may be.").

23. See *infra* notes 197-201 & 224-30 and accompanying text.

24. The Constitution guarantees that "nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person

Baby Doe life or equal protection; the decision was made by private citizens.<sup>25</sup> Each state has enacted sanctions against those citizens who take another's life.<sup>26</sup> In addition, the Constitution assures parents some degree of privacy in making certain decisions by restricting state intrusions into that decision-making process.<sup>27</sup> In Baby Doe's case, however, state laws arguably designed to protect his well-being<sup>28</sup> were apparently insufficient to subvert the parents' right to make a private decision concerning that well-being.<sup>29</sup>

State laws reflect and articulate state interests. Thus, it is important to examine those laws that bear directly on the nontreatment issue. Various theories have been advanced. Child neglect

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within its jurisdiction the equal protection of the laws." U.S. CONST. amend XIV. As one of the *Baby Doe* judges noted:

Clearly, infants are afforded the same protection as adults, but the important point to remember is that these Constitutional guarantees concern the relation of the states to their citizens, not relations between citizens. The individual states are then left to regulate the conduct of those within the state. This power is reserved to the states in the Tenth Amendment to the Constitution, as limited by the Fourteenth Amendment.

Letter from Judge John G. Baker, special judge and Judge Pro-Tempore, *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982) [hereinafter cited as Judge Baker Letter].

25. One may question whether judicial involvement is sufficient to constitute state action, but that question is outside the scope of this Comment. *But see* Judge Baker's remarks, *infra* note 29.
26. *See, e.g.*, NEB. REV. STAT. §§ 28-304 to -307 (1979). *See also infra* notes 178-85 and accompanying text.
27. Curiously, the same constitutional provisions that recognize a right to life have been interpreted to grant a penumbral right of privacy and a substantive due process protection for the liberty of parenthood. *See, e.g.*, *Pierce v. Society of Sisters*, 268 U.S. 510, 534 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 402 (1923). The concept of familial privacy with respect to the personal activities of consenting adults, combined with an interest in preserving what may traditionally be considered a "natural right" of parental decisionmaking, together may create a fundamental right in parents to determine what is best for the child, and will require an overriding compelling state interest before the right can be abridged. For a discussion of the policies for and against applying a "strict scrutiny" standard—a standard by which only the most compelling state interest may impinge upon a recognized fundamental constitutional right—to those state laws which compete with a family's private decision-making, see Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV. 1383, 1387-90 (1974).
28. *See supra* note 26.
29. One of the *Baby Doe* judges wrote that the case did not "deny that the State retains a valid interest in preserving life where there is a clash of values. The case of 'Infant Doe' simply was a difficult one where the State was required to yield to the valid choice made by the parents." Judge Baker Letter, *supra* note 24, at 3. The judge added: "This Court represented the position of the State, and my decision was not necessarily a reflection of my personal preferences as to the parents' decision." *Id.*



statutes have, for example, been most frequently invoked to counter parents' nontreatment decisions. At first glance, neglect law seems to provide sufficient protection for the newborn. The results in cases applying these laws suggest otherwise. A second theory asserts that the defective infant may be the victim of handicapped discrimination. This legal analysis is new, and as yet, relatively untried. A fresh approach to long-standing discrimination law and the arrival of new federal regulation indicate, however, that this theory will receive greater attention in future. Clearly, society has expressed its intent to protect the very young and the disabled, since it has legislated for that purpose. But the defective newborn controversy threatens to test the limits of that intent.

## A. Child Neglect

### 1. Generally

One of the statutory strictures that should have been adequate to protect Baby Doe was the Indiana child abuse and neglect law.<sup>30</sup> Perhaps the most widely understood definition of neglect, and the one which neglect statutes address, is a "chronic failure by adults to protect children from obvious physical danger."<sup>31</sup> Most statutory language refers to physical harm, since there are definable standards for measuring dangers of sickness, lack of basic physical needs, and life-threatening situations.<sup>32</sup> The following language explains this reality:

Broadly speaking . . . , child neglect occurs when the dominant expectations for parenthood are not met—when a parent fails to provide for a child's needs according to the preferred values of the community. The legal concept of neglect calls for consideration of rights and corresponding duties as they arise within the tripartite interaction between child, family and the state. The basic goal of any neglect statute is to prevent harm—physical always, sometimes also psychological and social—from occurring

30. "Child abuse or neglect," as defined by IND. CODE ANN. § 31-6-11-2 (Burns 1979), involves a child in need of services if:

(1) His physical or mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parent . . . to supply the child with necessary food, clothing, shelter, medical care, education, or supervision; (2) His physical or mental condition is seriously endangered due to injury by the act or omission of his parents, guardian, or custodian."

IND. CODE ANN. §§ 31-6-43(a)(1)(2) (Burns Supp. 1982).

31. Katz, Howe, & McGrath, *Child Neglect Laws in America*, 9 FAM. L. Q. 1, 4 (1975).

32. *Id.* See S. KATZ, WHEN PARENTS FAIL 22-23 (1971). NEB. REV. STAT. § 28-710 (Cum. Supp. 1982), defines abuse or neglect as "knowingly, intentionally, or negligently causing or permitting a minor child or an incompetent or disabled person to be: (a) Placed in a situation that endangers his or her life or physical or mental health; . . . (c) deprived of necessary food, clothing, shelter, or care. . . ."

to children. Determination of legal neglect is not merely, however, a question of medical or even psychiatric judgment, but is essentially a social policy issue. Primarily, neglect denotes conduct in conflict with the child-rearing standards of the dominant culture, and determination of neglect is based on social as well as legal judgments.<sup>33</sup>

The "standards of the dominant culture" must to some extent provide a commonly understood meaning of child neglect. Most states do not have a statutory definition of "neglect" or of "neglected child,"<sup>34</sup> and simply refer to the neglected child in rather broad terms.<sup>35</sup> The applicable state law in the Baby Doe case provided expressly for state intervention if the parent failed to provide, among other things, necessary food or medical care.<sup>36</sup> A number of states similarly structure their child neglect laws to specifically include a duty to provide medical assistance.<sup>37</sup> Those

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33. Katz, Howe, & McGrath, *supra* note 31, at 5.

34. *Id.* at 54-55. The article by authors Katz, Howe, and McGrath also provides a thorough survey of child neglect laws' procedural hearings requirements, statutory penalties, reporting requirements, and an analysis of parental fault-based statutes. *Id.* at 58-63. These subjects do not fall within the scope of this Article.

35. Arizona, for example, refers to a situation in which a child "lacks proper parental care necessary for his health and well-being." ARIZ. REV. STAT. ANN. § 8-531(1) (1974).

36. IND. CODE ANN. § 31-6-4-3 (Burns 1971), & 31-6-4-4 (Burns Cum. Supp. 1982). The State of Indiana filed a Petition for Emergency Detention pursuant to § 31-6-4-4, asking the Monroe County Dept. of Public Welfare to take immediate custody of Baby Doe and provide him emergency treatment. *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982). The applicable code provision states that "a child may be taken into custody by any law enforcement officer under the order of the court." IND. CODE ANN. § 31-6-4-4(a) (Burns Cum. Supp. 1982). Finding 13, *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct., Monroe County Apr. 13, 1982), determined that unless Baby Doe could be shown to be a "child in need of services" under IND. CODE ANN. § 31-6-4-3 (Burns Cum. Supp. 1982), the court would not intervene. That code section provides for a child whose "physical and mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parent . . . to supply the child with necessary food . . . [or] medical care. . . ." *Id.* Baby Doe was denied medical care: surgery, which, under normal circumstances would have enabled him to take nourishment, was withheld. Food was certainly denied as a result of the failure to provide medical care, as evidenced by the fact the Baby Doe starved to death. The application of the statute may really hinge on whether the denial of food and surgery was really any serious impairment or endangerment to Baby Doe's existing physical and mental condition.

37. A "typical" hypothetical model neglect law has been compiled:

First there will be a civil neglect purpose clause, stating that the intent of the law is to be liberally construed: to secure care, guidance and discipline for each child, preferably in his own home; to preserve and strengthen family ties whenever possible, removing him from the care, custody and discipline of his parents, only when his welfare or safety and the protection of the public cannot be adequately safeguarded without removal; and when removed, to secure care, custody

states that do not expressly require such medical assistance usually construe the law as though that express language were present.<sup>38</sup> There is much disagreement about whether a statutory definition of "neglected child" should be expanded to include those children who receive necessary minimum "protection, mainte-

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and discipline as nearly as possible equivalent to that which should have been given by his parents.

Second, there will be a "neglected child" definition that considers a child as a person under 18 years of age, abandoned, and/or lacking proper parental care, control or guardianship, and whose parent, guardian or custodian *refused* or was unable to *provide necessary medical, surgical or other special care made necessary by the child's particular condition*.

Third, the neglect hearing will provide for counsel, appointed counsel, and appeal, but no trial by jury. The hearing will be informal, closed to the general public and transcribed. All records will be deemed confidential. The statute will contain an evidentiary standard for determining neglect perhaps "by a preponderance of the evidence, in accord with civil rules of procedure." There will be a range of possible dispositional orders, including dismissal if the allegations are not proved; temporary order for support, custody and protection; protective supervision by the court in the child's own home; transfer of legal custody to a public agency, institution or department, or to a private licensed agency, or to a relative or other suitable person; and examination and/or treatment of the child. . . .

Fourth, there will be either a civil or a criminal penalty, imposing a fine, an imprisonment or both.

Fifth, the required reporting of abuse under a mandatory statute will include certain aspects of neglect. Immunities and waivers of privileges, *especially the physician-patient* and husband-wife, will be present.

Sixth, termination of parental rights will be possible following a proceeding, separate from the neglect hearing. . . .

And seventh, it may have as a special clause only the waiver of disability from an adjudication of the status of "neglected child." There will be no provisions for guardians ad litem, spiritual healing exemptions, or religious preference in placement clauses.

Katz, Howe, & McGrath, *supra*, note 31, at 70-71 (emphasis added).

38. See *State v. Perricone*, 37 N.J. 463, 181 A.2d 751 (1962), where Jehovah's Witness parents refused their newborn son recommended blood transfusions to treat heart and lung and possible neurological problems present at birth. The child's chances of dying were "two or three-times greater" if he did not have the blood transfusions. The transfusions probably would have saved the child's life, and probably would have alleviated the physical and neurological trouble, as well. *Id.* at 465, 181 A.2d at 754. This chance for improvement may provide a crucial distinction between *Perricone* and *Baby Doe*. See *infra* notes 107-12 and accompanying text. The *Perricone* child's death did not moot the issue of whether the parents were "neglectful" under state law, which provided that custody may be taken from parents when they neglect to provide "proper protection, maintenance, and education." N.J. STAT. ANN. § 9:2-9 (West 1948). Note that while New Jersey had a definition of child neglect that included failure to provide "medical attendance or surgical treatment," *id.* § 9:6-1, the court focused on the broader language, and did not need the specific "medical care" language to find the parents neglectful. *State v. Perricone*, 37 N.J. 463, 466, 181 A.2d 751, 755 (1962).

nance, and education,"<sup>39</sup> but who are unloved or unstimulated.<sup>40</sup> However, there is general agreement that failure to provide medical care, where that failure could result in death or serious injury, is clearly within the scope of child neglect law.<sup>41</sup>

## 2. *Exceptions to the Parental Duty*

### a. *Impossibility and Substantial Risk: The Established Exceptions*

There are, of course, certain exceptions to the parental duty<sup>42</sup> to provide medical care for minor children. A parent has no obligation to do the impossible.<sup>43</sup> Thus, a "father who cannot swim need not dive into deep water to rescue his drowning child."<sup>44</sup> If there is no treatment available for a child, then obviously, none can be attempted. This notion of "impossibility" may form the roots of a doctrine that withholding treatment from defective newborns constitutes "extraordinary care": that which need not, or arguably should not, be done.<sup>45</sup> It may be, then, that heroic efforts to save or

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39. See *supra* note 38.

40. Katz, Howe, & McGrath, *supra* note 31, at 4. See Areen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Neglect and Abuse Cases*, 63 GEO. L. J. 887, 927 (1975).

41. Katz, Howe, & McGrath, *supra* note 31, at 56. See *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County, 1974), where parents' refusal to consent to surgery to effectuate normal feeding and breathing was neglect. See generally, Robertson, *supra* note 6, at 222.

42. Clearly, there is a duty. *Stehr v. State*, 92 Neb. 755, 139 N.W. 676, *aff'd on reh'g*, 94 Neb. 151, 142 N.W. 670 (1913). In *Stehr*, the defendant was convicted of manslaughter for negligently causing the death of his four-year-old stepson when he allowed the fire in the house to go out, exposing the child to the elements. Although the parents tried home remedies, no doctor was summoned for over two weeks, and the boy died of gangrene. The court held that: "One charged with the support and control of a child of tender years . . . who negligently or willfully fails or refuses to obtain for it necessary medical aid, thereby causing its death, . . . may be guilty of manslaughter." *Id.* at 755, 139 N.W. at 676. The court noted further that manslaughter was a consequence of such culpable neglect, even though the death or serious bodily harm which resulted was unintentional, and that if a parent does not have the means to obtain medical aid, he has the duty to obtain public assistance. *Id.* at 760, 139 N.W. at 678.

43. In *Port Huron v. Jenkinson*, 77 Mich. 414, 43 N.W. 923 (1889), the court held unconstitutional an ordinance penalizing one who failed to do an impossible act.

44. W. LAFAVE & A. SCOTT, *CRIMINAL LAW* 188 (1972). "But impossibility means impossibility." *Id.* Thus, a poverty-stricken father would not be criminally liable for his child's death from starvation if it were impossible to get food, but he would be liable if he failed to seek available help to obtain the food. *Id.* at 188-89. *Accord Stehr v. State*, 92 Neb. 755, 766, 139 N.W. 676, 678 (1913).

45. See *infra* note 279.

to treat seriously defective newborns<sup>46</sup> that would have a minimal effect or produce negligible results may be neither morally compelled nor legally dictated by duty.<sup>47</sup>

A parent may not have an obligation to take measures to provide medical care that is highly risky or experimental. Certain treatments may be effective if successful, but may carry with them great risk of death or serious harm if unsuccessful. If the probability of harm outweighs the probability of success, there may be no duty to take the chance.<sup>48</sup> Likewise, when the effect of treatment is unknown, that is, it may help the child but the likelihood of benefit is unpredictable or uncertain, nontreatment could be justified.<sup>49</sup>

*In re Green*,<sup>50</sup> for example, involved a six-year-old victim of sickle-cell anemia whose mother refused to consent to blood transfusions for the child despite several doctors' recommendations.<sup>51</sup>

46. A "severely defective newborn" has been defined as an infant who is "not likely to survive without surgical and medical intervention and whose prognosis, even assuming this intervention, may be poor in terms of cognitive life and minimal functioning." Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J. LAW & MED. 393, 394 (1983). Although Ellis attempts to focus this definition by providing examples of severe defects (e.g., Myelomeningocele, Trisomy 21 or Down's Syndrome, Anencephaly, Trisomy 13, Encephalomeningocele, Severe Perinatal Trauma), he nonetheless admits that, due to the variety and degrees of severity of defects and limited medical knowledge, "[a] more precise definition is impractical and inappropriate at this point." *Id.*

47. See, e.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976). New federal regulation agrees, and "does not require that futile treatments, which will do no more than prolong the act of dying, be provided." 49 Fed. Reg. 1,643 (1984) (to be codified at 45 C.F.R. § 84.55). This distinction may have escaped those who have a tendency to regard every treatment case as an overtreatment case. See, e.g., Smith, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 NEB. L. REV. 709, 726-28 (1984).

48. See 49 Fed. Reg. 1,636 (1984) (to be codified at 45 C.F.R. § 84.55).

49. See, e.g., *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979) (allowing parents to administer experimental laetrile to their son pursuant to the advice of a doctor who believed in its efficacy). But see *In re Custody of a Minor*, 379 N.E.2d 1053, *aff'd*, 393 N.E.2d 836 (Mass. 1978), the famous Chad Green case, after which parents of the leukemia victim fled with him to Mexico to escape a court order for chemotherapy and forbidding further laetrile treatment.

50. 12 CRIME & DELINQ. 377 (Milwaukee County Ct. Wis. 1966).

51. The mother refused consent partly out of fear that her child would die, and partly on religious grounds, but the religious grounds were held not to be just cause for the refusal. *Id.* at 381. See also *Jehovah's Witnesses v. Kings County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967) *aff'd*, 390 U.S. 598 (1968); *People ex rel Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. denied*, 344 U.S. 824 (1952). The *Green* court distinguished these cases as involving "serious and acute medical problems demanding prompt attention with little or no alternative offered and usually optimistic prognostications as to recovery or benefit." *In re Green*, 12 CRIME & DELINQ. 377, 381 (Milwaukee County Ct. Wis.

The transfusions were experimental at that time. There was no reliable treatment for the disease. Although the blood disorder was incurable even with the transfusion treatments, transfusions could correct a dangerous blood deficiency during certain "crisis" periods when the boy became acutely ill. The risk of death absent treatment was extremely high during these "crisis" periods, but thus far, the child had survived.

The court upheld the mother's decision and refused to find child neglect.<sup>52</sup> The court agreed that "[w]here there is imminent possibility of loss of life or further serious disability due to inaction," treatment would be ordered.<sup>53</sup> Nonetheless, it held that where the efficacy of the proposed treatment is "doubtful,"<sup>54</sup> and the treatment itself risks serious harm or death to the child, a refusal to submit the child to that treatment will not constitute neglect.<sup>55</sup> Similarly, unless nontreatment means imminent harm or risk of death, a court may not intervene (even though without the prescribed course of treatment the child would be much less healthy, or might be permanently socially handicapped) so long as there is sufficient risk in the treatment itself.<sup>56</sup>

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1966) (emphasis added). Cf. *Custody of a Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978) (court ordered chemotherapy for a child who would die within several weeks without it, but had a 50-50 chance of survival with the treatment).

52. *In re Green*, 12 CRIME & DELINQ. 377, 384 (Milwaukee County Ct. Wis. 1966).

53. *Id.* See also *People ex rel Wallace v. Labrenz*, 411 Ill. 618, 104 N.E.2d 769, cert. denied, 344 U.S. 824 (1952) (ordering a transfusion because medical testimony indicated that the child would almost certainly die without it).

54. In *Green*, effectiveness of the treatment was found to be "seriously doubtful"; presumably, this "serious doubt" would be the catchphrase for the test, since mere "doubt" (rather than "serious doubt") could be cast on practically every medical procedure with any risk attached.

55. But see *In re Tuttendario*, 21 Pa. D. 561 (1912). In *Tuttendario*, although seven out of the ten children in the family had died in infancy (and thus there was some possibility of an inherent low resistance or weakness to disease or traumatic experience common to every child of those parents), an operation that probably could have provided recovery for a child suffering from ricketts was not ordered by the court when parents refused to consent to the operation because they feared losing another child.

The *Green* court also implied that if the mother's nonreligious reasons for refusing to consent to her son's treatment were "logical, reasonable, and made in good faith," the refusal might be afforded more weight. *In re Green*, 12 CRIME & DELINQ. 377, 385 (Milwaukee County Ct. Wis. 1966). A test of logic, reason, and good faith could, however, be problematic. It might too broadly allow nontreatment decisions for what certain circumstances might dictate are the "wrong" reasons (for example, financial hardship or marital stress), no matter how well-grounded in logic and good faith.

56. See, e.g., *In re Hudson*, 13 Wash.2d 673, 126 P.2d 765 (1942) (addressing a parent's good faith decision that it is unwise and dangerous to permit recommended surgery). In *Hudson*, a twelve-year-old girl had a congenital deformity in the form of a huge, heavy, abnormal growth on her left arm,

In the *Baby Doe* case, the surgical procedure recommended was neither impossible nor experimental.<sup>57</sup> Further, *Baby Doe* did not involve a situation in which the child could or would lead merely an inhibited, sickly or sub-normal life if the treatment were foregone. The risk of death to Baby Doe *without* the corrective surgery was imminent; in fact, it was inevitable.<sup>58</sup>

*b. Quality of Life Prognosis: An Emerging Exception*

Another possible exception to a parent's duty to provide medical care has emerged relatively recently.<sup>59</sup> The basis for this exception lies in the belief that there may be no duty to sustain life when the prognosis for "cognizant, sapient,"<sup>60</sup> productive life is very poor.<sup>61</sup> It follows that if the prognosis is "hopeless"—even

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which made it longer than the right arm and rendered it useless. Physicians recommended amputation because her affliction was, among other things, burdening her heart and increasing her susceptibility to infection. The court held that the girl was not a neglected child under state law, and that the court could not subject the child to an operation over the parent's objection. *Id.* at 712, 126 P.2d at 783. The dissenting opinion vigorously argued that the child had a right to as normal a life as possible and that the parents had a duty to provide medical and surgical care and to make their decision about the operation free from selfish, personal interests. *Id.* at 733, 126 P.2d at 791 (Simpson, J., dissenting).

57. In fact, such surgery is typically successful. PRESIDENT'S COMM'N REP., *supra* note 4, at 203. A Bloomington Hospital doctor described Baby Doe as "an infant with . . . reparable esophageal atresia and tracheoesophageal fistula." Pless Letter, *supra*, note 2.
58. The risk of death to Baby Doe *with* the corrective surgery that his parents refused is open to debate. Some authorities assert that the child very probably would not have survived the operation. Others argue that the child had at least a 50-50 chance for survival, and therefore the risk of harm through treatment may have been less than the risk of harm through nontreatment. See PRESIDENT'S COMM'N REP., *supra* note 4, at 203; Bannon, *supra* note 3, at 67; Longino, *supra* note 2, at 382, n.30. The risks of surgery were not expressly mentioned by the *Baby Doe* courts, nor was any evidence admitted regarding the success rate of the operation. The court accepted only that surgery was one medically recommended course of treatment. Regardless of the risks involved, it is certain that whatever Baby Doe's chances of survival were with the surgery, they were better than nothing—which was his chance for survival without surgery.
59. The "quality of life" assessment has an appealing ring to it, but is an extremely difficult term to define. One author equates it with the "substituted judgment" doctrine (the concepts are related), Smith, *supra* note 47, at 734 and later implies that parents and courts must have a "feel" for it. *Id.* at 730-31. The first assertion is inexact, and the second, although perhaps accurate, is dreadfully inadequate.
60. *In re Quinlan*, 70 N.J. 10, 55, 355 A.2d 647, 671 (1976).
61. In 1949, a doctor commented on the absurdity of medical care which is based on:

rational principles and economy and not on humane compassion and devine law. To be sure, American physicians are still far from the

though, technically, life itself is sustainable<sup>62</sup>—a parent may not be guilty of neglect when the quality of that child's life will be extremely poor<sup>63</sup> even with treatment. This "quality of life" analysis attempts to determine the kind of life the child will have, and the degree to which he will experience life, if he is given treatment.<sup>64</sup> Accordingly, a quality of life analysis presumes that a parent's failure to provide medical care is justified if the infant's life with treatment would have no measurable value.<sup>65</sup>

This "poor prognosis" exception is distinguishable from the impossible,<sup>66</sup> the experimental,<sup>67</sup> or the dangerous measures<sup>68</sup> par-

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point of thinking of killing centers, but they have arrived at a danger point in thinking, at which likelihood of full rehabilitation is considered a factor that should determine the amount of time, effort and cost to be devoted to a . . . patient.

Alexander, *Medical Science Under Dictatorship*, 241 NEW ENG. J. MED. 39, 41 (1949).

62. Advances in medicine now make it possible to sustain lives that would have until recently been unsavable, "although some will be severely handicapped and limited in their potential for human satisfaction and interaction." Robertson, *supra* note 6, at 214. The President's Commission stated that: "For almost any life-threatening condition, some intervention can now delay the moment of death. Frequent dramatic breakthroughs . . . have made it possible to retard and even to reverse many conditions that were until recently regarded as fatal." PRESIDENT'S COMM'N REP., *supra* note 4, at 1. See Comment, *Withholding Treatment from Defective Newborns: Substituted Judgment, Informed Consent, and the Quinlan Decision*, 13 GONZ. L. REV. 781, 781-82 (1978).
63. Of course, every quality of life judgment requires some subjective assessment of what is "poor" life and what is not. An infant's quality of life may be materially affected by the seriousness of his mental impairment or his physical deformity, the pain he must endure, and the potential he has for sharing various human experiences. See Note, *Birth Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599, 620-21 (1978). Quality of life may be extremely difficult to define and to consistently apply. For example, one illustration suggests an evaluation of which child would have a better quality of life prognosis: a defective infant or a ghetto child with alcoholic parents? In other words, the values by which we define quality of life have not been comfortably agreed upon. *Id.* at 621, n.114 (citing S. Law, Constitutional Right to Privacy (unpublished paper)).
64. Implicit in a discussion of the quality of life evaluation with respect to nontreatment decisions is consideration both of the extraordinary nature of the medical care, and of the medical feasibility of the treatment. See *infra* note 279.
65. See Note, *supra* note 63, at 599-600 (citing Tooley & Phibbs, *Neonatal Intensive Care: The State of the Art*, in ETHICS OF NEWBORN INTENSIVE CARE 22 (1976)). But cf. *In re Hudson*, 13 Wash. 673, 126 P.2d 765 (1942), where treatment would have greatly improved the child's physical, psychological and emotional well-being, but the court upheld the mother's refusal to consent because the treatment was not lifesaving, and because the child could make the decision herself in a few short years. The implications of a quality of life analysis become much more serious in a life-threatening situation.
66. See *supra* notes 43-45 and accompanying text.



ents may reasonably refuse. The treatment may be possible, safe, and even have proven successful for the ailment being treated. However, it may still not improve appreciably the child's chances for any quality of life commensurate with some capacity for those human experiences that give life its depth and texture.<sup>69</sup> Increasingly, this "quality of life" argument is advanced to justify terminating treatment for defective newborns.<sup>70</sup> Its proponents argue that the prognosis is not good for "meaningful" life, or, alternately, that prolonged life would mean prolonged misery, characterized by continuous, intrusive, painful treatments, and little else.<sup>71</sup>

The quality of life standard first surfaced in a controversial case involving a twenty-year-old girl who lapsed into an irreversible coma.<sup>72</sup> Karen Quinlan remained in a "debilitated and allegedly moribund state,"<sup>73</sup> and continued to physically deteriorate. She was not, however, "brain dead,"<sup>74</sup> so the doctors caring for her re-

67. *In re Green*, 12 CRIME & DELINQ. 377 (Milwaukee County Ct. Wis. 1966). See *supra* notes 50-55 and accompanying text.

68. See *supra* notes 52-55 and accompanying text. The notion of weighing the substantial benefit of treatment against the risk of serious harm with or without treatment is closely akin to a quality of life prognosis, though more exact.

69. A much-cited doctor asserts that capacity for "meaningful humanhood"—determined by such factors as the capacity to love and to understand, and the potential for independence and to plan a future—should be considered in a treatment decision. Comment, *supra* note 62, at 788 (citing Dr. Raymond Duff's theories in Kelsey, *Which Infants Should Live? Who Should Decide?*, 5 HASTINGS CENTER REP., Apr. 1975, at 5, 6). Other commentators have established various tests for determining "personhood," both from a quality of life perspective and perhaps ultimately in a conditional sense. One argues that a sense of self is necessary for personhood, since birth does not automatically bestow that characteristic. This sense of self stems from a desire "to continue existing as a subject of experiences and other mental states," and thus, "an entity that lacks such a consciousness . . . does not have a right to life," that is, a right to something is necessarily connected to the desire to have it. Tooley, *Abortion and Infanticide*, 2 PHIL. & PUB. AFFAIRS 37, 49 (1972). Another suggests that a minimal level of intelligence, measured by I.Q., be a requirement before an entity be labeled "person." Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, 2 HASTINGS CENTER REP., Nov. 1972, at 1, 1-4. One theory has traditionally maintained that the immortal soul cannot enter the body until that body is sufficiently formed (40-90 days). Atkinson, *Persons in the Whole Sense*, 22 AM. J. JURIS 86, 91 (1977). See also Robertson, *supra* note 6, at 248. Yet another doctor confesses that before he decides to forego treatment, he determines what sort of life the infant will have with treatment by judging whether the child is "able to give and receive love." Dr. David Abramson, quoted in Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699, 704 (1982).

70. See Note, *supra* note 63, at 620.

71. See PRESIDENT'S COMM'N REP., *supra* note 4, at 219.

72. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

73. *Id.* at 12, 355 A.2d at 651.

74. A team at Harvard Medical School defined "brain death," and the standards for determining "brain death" have been part of the legal definition of

fused her parents' request to remove her from a life-sustaining<sup>75</sup> respirator. On appeal, the New Jersey Supreme Court granted the request, convinced that "the focal point of decision should be the prognosis as to the reasonable possibility of return to cognitive and sapient life, as distinguished from the forced continuance of a biological vegetative existence" to which the court felt Karen was "doomed."<sup>76</sup>

The *Quinlan* decision implies that "quality of life" is a higher good to which traditional notions about the sanctity of human life must yield. If circumstances allow society to refuse to sustain a life so that nature may terminate it,<sup>77</sup> if this emerging "exception" means that only *quality lives* are worthy of protection beyond parental discretion, then the *Baby Doe* progeny are the children doomed. A quality of life standard assumes that at some point a defective baby would no longer wish to be sustained,<sup>78</sup> and that

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"death" in many states. See Ufford, *Brain Death/ Termination of Heroic Efforts to Save Life—Who Decides?*, 19 WASHBURN L.J. 225, 229-35 (1980). The Harvard definition requires: (1) unresponsiveness to normally painful stimuli; (2) absence of spontaneous movements or breathing; (3) absence of reflexes; and (4) no change 24 hours later. See generally *A Definition of Irreversible Coma*, 205 J. A.M.A. 85 (1968). Brain death has also been defined as "the permanent loss of all integrated neuronal brain function." Ufford, *supra*, at 227-28. Testimony in *Quinlan* revealed that no physician would have failed to put Karen on a respirator initially, and no physician would be willing to terminate the respirator, once it had been administered as lifesaving treatment, absent brain death. However, the court looked at testimony that implied a quality of life assessment: "The subject has lost human qualities . . . [M]ajor surgical procedures would [probably] be out of the question even if they were known to be essential for continued physical existence." *In re Quinlan* 70 N.J. 10, 18, 355 A.2d 647, 657 (1976).

75. At least one commentator distinguishes between lifesaving care and life-prolonging or -sustaining care, which is therapeutic or emergency treatment that "amounts to no more than efforts to prolong the life of a terminally ill, noncognitive patient." Clarke, *The Choice to Refuse or to Withhold Medical Treatment: The Emerging Technology and Medical-Ethical Consensus*, 13 CREIGHTON L. REV. 795, 823 (1980). After several unsuccessful attempts to wean Karen from the respirator, she was successfully weaned after the court upheld her father's decision to withdraw treatment. Brown & Truitt, *Euthanasia and the Right to Die*, 3 OHIO N.U.L. REV. 615, 628 (1976).
76. *In re Quinlan*, 70 N.J. 10, 51, 355 A.2d 647, 669 (1976). In addition to its "quality of life" language, *Quinlan* is also frequently cited with respect to the "right to die" as a necessary consequence of the right to privacy. See Brown & Truitt, *supra* note 75, at 628. See *infra* notes 187-201 and accompanying text, for discussion of a child's best interests including consideration of a right to die. Consistent with the right to die is some consideration of *Quinlan* as a pioneer case permitting euthanasia.
77. See Sharp & Crofts, *Death With Dignity, the Physician's Civil Liability*, 27 BAYLOR L. REV. 86, 87 (1975) (citing Fletcher, 75 AM. J. NURSING 671 (1975)).
78. Distinct but implicit here is the doctrine of "substituted judgment," whereby anyone with decisionmaking rights regarding the treatment of another will make the decision standing in the shoes of the other, and make the choice the

nontreatment is acceptable, even desirable. A philosophy of care premised upon this assumption leads to the inevitable conclusion that death at that point is better than life.<sup>79</sup> One *Baby Doe* judge reached just that conclusion: "It is a harsh view that no life is preferable to life, but the great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was non-existent."<sup>80</sup>

*Quinlan* is, however, readily distinguishable from *Baby Doe*, and the same rationale need not invariably apply. Baby Doe was not in a vegetative mental state; he was mentally retarded. He required surgery to correct his physical defect, not life-prolonging, continuous attachment to machinery. Finally, the standard for determining what Baby Doe's quality of life would have been was summoned from the perspective of an ordinary, healthy human being deciding for the infant. This standard might, arguably, have been appropriate to evaluate the prospective life of a once-healthy young woman who had lived a normal life for twenty years. It is, however, inappropriate when applied to a mentally retarded child who has not had the opportunity to experience life to the extent

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other would probably have, to the extent that is possible. Substituted judgment must be asserted on behalf of the incompetent in his or her best interests. See Comment, *supra* note 62, at 791. The "substituted judgment" doctrine exists ostensibly to guard an incompetent patient's right to privacy in medical treatment (and therefore, often the "right to die"), and has been asserted to be "the only practical way to prevent destruction of [that] right." *In re Quinlan*, 70 N.J. 10, 41, 355 A.2d 647, 664 (1976).

79. It may be logically and legally absurd to assert that nonexistence is preferable to defective life. See Tedeschi, *On Tort Liability for Wrongful Life*, 1 ISRAEL L. REV. 513, 537 (1966) (using *Quinlan* as precedent). It has been held that infant plaintiffs have no cause of action in "wrongful life" cases to be compensated for the physical and mental suffering they endure for having been born. *Becker v. Schwartz*, 46 N.Y.2d 401, 386 N.E.2d 807 (1978). Such a cause of action would demand "a calculation of damages dependent upon a comparison between . . . life in an unimpaired state and nonexistence." *Id.* at 412, 386 N.E.2d at 812. Another court denied a claim for wrongful life, not on the difficulty in measuring damages, but because the child had suffered no injury which the law recognized, since "life—whether experienced with or without a major physical handicap—is more precious than non-life." *Berman v. Allan*, 80 N.J. 421, 429, 404 A.2d 8, 12 (1979).
80. Judge Baker Letter, *supra* note 24, at 2. It is extremely difficult to resolve Judge Baker's determination that Baby Doe's quality of life was "non-existent" for even a "minimally adequate" prognosis, considering the facts that the severity of the Down's Syndrome could not have been reliably forecast at the time of the hearing (April 15, 1982), see *supra* note 3 and accompanying text, and that the other Baby Doe affliction (esophageal trouble) was "reparable." See Pless Letter, *supra* note 4, and accompanying text. The difficulty of such a resolution illustrates that quality-of-life standards, without more, are simply too subjective and broad to be workable. See *supra* notes 59-71 & 77-80 and accompanying text.

that he is able, and may never fully realize how "unhappy" his lot in life is, compared to that of the "normal" lives around him.<sup>81</sup> This absence of an appropriate vantage point from which to make accurate judgments about the quality of individual lives,<sup>82</sup> coupled with a potential for error,<sup>83</sup> provide strong reasons to avoid adopting a quality of life exception to neglect.<sup>84</sup> This will be particularly true without narrower strictures to limit the discretionary power of the decisionmakers—be they doctors, parents or courts.

### c. *The Next Exception*

It is too early to determine if the Bloomington, Indiana decision was merely anomaly,<sup>85</sup> or whether it may pave the way for the formal adoption of an exception to a parent's responsibility to care for his or her minor children. This exception would permit parents of a child born with both a permanent handicap and a life-threatening correctible defect to refuse the corrective treatment. The more advanced medical science becomes, the greater the essential knowledge and the opportunity to keep alive newborns who would not previously have survived.<sup>86</sup> As the opportunity grows, the number of nontreatment decisions will conceivably escalate proportionately. Judicial endorsement of such decisions can only in-

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81. Studies show that handicapped persons commit suicide far less often than non-handicapped persons, and psychological tests reveal that they are glad rather than sorry they were born and that they are hopeful about their future. See Diamond, *The Deformed Child's Right to Life*, in DEATH, DYING AND EUTHANASIA 133 (1977).
  82. See also *In re Phillip B.*, 92 Cal. App. 2d 796, 156 Cal. Rptr. 48 (1979), cert. denied, 445 U.S. 949 (1980) (see *infra* note 221 for a discussion of *Phillip B.*).
  83. See D. WALTON, ETHICS OF WITHDRAWAL OF LIFE-SUPPORT SYSTEMS 84 (1983). Karen Quinlan was eventually successfully weaned from her "life-prolonging" respirator. See Collester, *supra* note 6, at 305.
  84. See Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699, 704 (1982).
  85. One author remarked that *Baby Doe* is the first instance where courts have approved a course of action in which withholding treatment from a defective newborn would lead to certain death. Longino, *supra* note 2, at 382 n.30. But see Comment, *supra* note 62, at 787, where it was reported that a Maryland Down's Syndrome baby with an intestinal blockage died of starvation over fifteen days when parents refused to consent to corrective surgery for the intestinal problem. In Horan, *Euthanasia, Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice?*, 27 BAYLOR L. REV. 76, 77 (1975), a case "in Decatur" is noted, where a child with an esophageal problem, believed also to have Down's Syndrome, was not given treatment. Brown & Truitt, *supra* note 75, at 632, discuss a Detroit, Mich., child with intestinal problems precluding feeding who was denied corrective surgery pursuant to a decision by the parents in consultation with the pediatrician. The child received surgery upon court order, after an anonymous report to the police via a newspaper "action line."
  86. See Note, *supra* note 63, at 599-600 (citing Tooley & Phibbs, *Neonatal Intensive Care: The State of the Art*, in ETHICS OF NEWBORN INTENSIVE CARE 22 (1976)).

crease the frequency with which parents will invoke this new exception.

Just a decade ago, in *Maine Medical Center v. Houle*,<sup>87</sup> a trial court in Maine exercised its jurisdiction under the doctrine of *parens patriae*<sup>88</sup> "to care for infants and protect them from neglect,"<sup>89</sup> and overruled the parents' decision to withhold medical care from a child much like Baby Doe. The child was born with certain birth defects: no left eye, rudimentary left ear without an ear canal, malformed left thumb, and tracheoesophageal fistula.<sup>90</sup> Since, as with Baby Doe, the esophageal problem precluded normal feeding, the child was fed intravenously,<sup>91</sup> and surgery was recommended. Within forty-eight hours, the child's father asked that the intravenous feedings<sup>92</sup> be stopped, and that corrective surgery be foregone. The court, however, issued an order to maintain the child "in a stable and viable condition,"<sup>93</sup> and restrained the parents from ordering any course "which, in the opinion of the attending physician, would be injurious to the current medical situation of said child."<sup>94</sup> Within the next few critical days, the child suffered seizures and required some artificial respiratory aid. In addition, since the first nontreatment request by the parents, medical evaluation revealed "virtual certainty of some brain damage."<sup>95</sup> After this more recent evaluation, the attending physician

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87. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County 1974).

88. The *parens patriae* doctrine enables the state to act as "the general guardian of all infants, idiots and lunatics." *Hawaii v. Standard Oil Co.*, 405 U.S. 251, 257 (1972). The statutory scheme of any individual state's child neglect laws, together with the common law right and duty of *parens patriae*, is the basis for judicial intervention or approbation in nontreatment decisions. See Clarke, *supra* note 75, at 814.

89. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County 1974). No particular statute was invoked since the state's *parens patriae* authority provided the power for intervention. See *supra* note 88.

90. See *supra* note 4. Baby Doe also was born with this esophageal ailment.

91. According to the limited information available, Baby Doe was not fed intravenously pending any surgical decisions. See Pless Letter, *supra* note 2.

92. The largely academic question may be raised: to what extent were the *Houle* baby's intravenous feedings simply a life-prolonging measure, like Karen Quinlan's respirator, the withdrawal of which might be termed active euthanasia? See *supra* notes 72-76 and accompanying text.

93. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County 1974).

94. *Id.* Note that, in contrast to Baby Doe's situation, there was no dispute among physicians (at first), and the parents' desire to withhold treatment—at least initially—was not made pursuant to any medically recommended course of treatment, a seemingly crucial element in *Baby Doe*. See *supra* note 4.

95. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County 1974).

concluded that without surgery the child would certainly die, and that with surgery the child could survive, albeit brain-damaged to some unknown degree.<sup>96</sup> The physician recommended "that all life supporting measures . . . be withdrawn."<sup>97</sup>

The only appreciable distinction between the facts in *Houle* and those in *Baby Doe* is that the *Houle* child was given some life-maintaining medical care—intravenous feeding and periodic artificial respiration—pending resolution in the courts. Medical attention provided to the *Houle* baby was surely the result of quick judicial response favorable to treatment, and an initial absence of medically recommended nontreatment.<sup>98</sup> The case did not remark on the fact that nontreatment would mean a withdrawing of life-saving treatment already administered,<sup>99</sup> as well as a refusal to undertake any further treatment. Instead, the *Houle* court focused on and expressly discarded any quality of life consideration: "[T]he issue . . . is not the prospective quality of the life to be preserved, but the medical feasibility of the proposed treatment compared with the almost certain risk of death should treatment be withheld."<sup>100</sup>

This analysis is clearly consistent with those decisions that weigh the risk of harm with the substantial benefit to the child in determining whether to treat.<sup>101</sup> What factors, then, could permit a situation whereby the parents of one mentally defective baby with a surgically correctable esophagus problem could withhold lifesaving treatment, when the parents of a different mentally defective

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96. *Id.*

97. *Id.*

98. See *supra* note 7. It has been suggested that while Baby Doe's esophageal defect was reparable, his chances of surviving the operation may have been no greater than 50 percent by the time he died; but, had the surgery been ordered over the parents' wishes at first opportunity, chances of survival would have been quite good. See Bannon, *supra* note 3, at 68; Longino, *supra* note 2, at 382 n.30. See also *supra* note 4 and accompanying text.

99. This was perhaps comparable to the *Quinlan* situation, where it was simply unthinkable for the doctors to fail to initiate respiratory support, but once the life-sustaining treatment was administered, withdrawing it would be contrary to medical standards, practice and ethics. *In re Quinlan*, 70 N.J. 10, 18, 355 A.2d 647, 657 (1976). The focus probably should be on the necessary treatment initially provided, and *not* on whether that treatment may legally permissibly be discontinued. Otherwise, health care personnel might hesitate to give treatment in the first place, preferring to risk doubtful liability for passive nontreatment rather than probable liability for active euthanasia. See *Barber v. Superior Court of Los Angeles County*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983) (doctors acquitted of murder when IV's supplying food and water were equated with life-support equipment).

100. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct. Cumberland County 1974).

101. See *supra* notes 48-56, and accompanying text.

baby with the same correctable problem would undoubtedly have been guilty of child neglect for the same deliberate omission? The situation cries out for uniformity in the law and uniformity in application of that law. Without it, broad statutory language is ignored, or interpreted to fit a neglect controversy that the lawmakers may have never anticipated.<sup>102</sup>

### 3. Problems with Neglect Law

#### a. Interpretation

The difficulty in defining child neglect for nontreatment situations may be the result of problems with interpretation, both of statutory language and of case law. In *In re Cicero*,<sup>103</sup> for example, the court appointed a guardian to consent to treatment for an infant born with spina bifida.<sup>104</sup> This infant would probably have died within six months without corrective surgery, but had a handicapped life expectancy of perhaps twenty years with surgery.<sup>105</sup> The court did not specifically find neglect on the part of the parents. It did use the state neglect law as authority for intervention since the infant fell within the purview of the statutory "neglected child" definition. The law defined such a child as one who is in "imminent danger of becoming impaired" as a result of the parents' failure to exercise a "minimum degree of care" in supplying the child with "adequate surgical care."<sup>106</sup> Although that language was interpreted by the *Cicero* court to require treatment for the spina bifida baby, it is certainly not clear that another court would reach the same conclusion.

The statute invoked in *Baby Doe* also contained the language

102. It is hoped that new handicapped discrimination regulation will help establish this much-needed uniformity: 49 Fed. Reg. 1,622 (to be codified at 45 C.F.R. § 84.55). See *infra* notes 152-56 and accompanying text.

103. 101 Misc. 2d 699, 41 N.Y.S.2d 965 (Sup. Ct. 1979).

104. Spina bifida involves abnormal development of the brain or spinal cord. It may be marked by an external saccular protusion from the spine, and causes physical and/or mental handicaps widely ranging in severity and frequently involving many organ systems, urinary tract deficiency, paralysis of the lower extremities, and hydrocephaly (increase of free fluid in the cranial cavity resulting in a marked enlargement of the head and many and varied other complications and defects). See PRESIDENT'S COMM'N REP., *supra* note 4, at 202; Robertson, *supra* note 6, at 213 nn.4 & 6 (citing J. WARKANY, CONGENITAL MALFORMATIONS 217-18, 272, 286-88 (1971)). Some spina bifida victims have normal intelligence and can lead independent lives. PRESIDENT'S COMM'N REP., *supra* note 4, at 202.

105. *In re Cicero*, 101 Misc. 2d 699, 700, 41 N.Y.S.2d 965, 965 (Sup. Ct. 1979). See also *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983) (the *Infant Jane Doe* case).

106. *In re Cicero*, 101 Misc. 2d 699, 41 N.Y.S.2d 965 (Sup. Ct. 1979).

"imminent danger of becoming impaired."<sup>107</sup> Similar "impairment" terms in other states' laws<sup>108</sup> might also not apply to situations in which a child is born seriously impaired, since that child is arguably in imminent danger only of living in continued impairment or of dying from the impairment.<sup>109</sup> The court in *Cicero* did not consider this analysis, but it might have: the spinal disorder certain to kill the *Cicero* baby if no treatment was administered may not have been "impaired" further by allowing the child to succumb<sup>110</sup> to death. Some would argue that, given the seriousness of the birth defect, death would be not an impairment but an improvement.<sup>111</sup>

With this analysis in mind, a child neglect statute—if it is truly intended to apply to the withholding of aggressive medical treatment from Baby Doe infants—might be considered underinclusive. Arguably, it is meant to protect not only those children in "imminent danger of becoming impaired," but also those defective newborns which cannot "become" any more impaired. The statutory language, however, simply does not adequately embrace those children. Neglect laws clearly contemplate protecting children who are relatively normal at the outset, but who later require and then are denied medical attention.<sup>112</sup> The defective newborn emerges from the womb in a less-than-healthy state, however, and may not be regarded as a child that the neglect statutes intended to protect. Indeed, a "Baby Doe" situation may not have even been imagined.

Neglect statute interpretation difficulties compound when a court favors an already liberal reading with an analysis of the child's prognosis with treatment. The *Baby Doe* courts probably made quality of prospective life a consideration,<sup>113</sup> and the *Cicero*

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107. *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct., Monroe County Apr. 13, 1982).

108. For example, Nebraska law couches abuse and neglect in terms of placing the child in a situation which would endanger his life or health or depriving the child of necessary care. NEB. REV. STAT. §§ 28-707 to -710 (1979).

109. Consider whether certain death can be deemed an "impairment" of an already existing very poor physical and/or mental condition. See *supra* notes 77-80 and accompanying text.

110. See *supra* note 5.

111. See *supra* note 109.

112. See generally IJA-ABA JOINT COMMISSION ON JUVENILE JUSTICE STANDARDS, STANDARDS RELATING TO ABUSE AND NEGLECT (1981); Katz, Howe & McGrath, *supra* note 31.

113. Judge Baker stated:

[T]he great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was non-existent. . . .

[Where religion is not an issue] the decision of the court will . . . depend on the prognosis for the patient if treatment is administered.

Judge Baker Letter, *supra* note 24, at 2.



court most certainly did.<sup>114</sup> The difficulty with such a consideration is that the child neglect statutes do not allow for the analysis. We may assume that defective newborns *are* within the contemplation of the statutes, and that a decision to withhold necessary medical treatment where there is a risk of death is within their purview. If that is true, then the guidelines for a quality of life determination are sadly inadequate,<sup>115</sup> and the courts should not be analyzing quality of life at all without these guidelines.<sup>116</sup> On the other hand, if we assume Baby Doe is representative of those infants who are *not* to receive protection under the neglect law, those statutes should specifically grant an exception so that parents, doctors, and hospitals will not risk liability under that law.

The judicial tendency to look beyond statutory language to "quality of life"<sup>117</sup> or "balancing interests"<sup>118</sup> tests seems to be gaining approval from commentators in both the legal and medical arenas.<sup>119</sup> This trend is disquieting, not only because the tests endorsed may be applied with broad judicial discretion, but also because those tests permit rather arbitrary labelling of a human being's worth. Life is placed on a continuum, ranging from least human/most defective<sup>120</sup> to most human/least defective, and the

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114. The court noted: "There is a hint in this proceeding of a philosophy that newborn, 'hopeless' lives should be permitted to expire without an effort to save those lives. Fortunately, the medical evidence here is such that we do not confront a 'hopeless' life." *In re Cicero*, 101 Misc. 2d 699, 702, 41 N.Y.S.2d 965, 968 (Sup. Ct. 1979). Treated, the child would probably lead a paralyzed invalid life, but might someday walk with braces and have normal intelligence: "This is not a case in which a court is asked to preserve an existence which cannot be a life." *Id.* at 701, 41 N.Y.S.2d at 968. Judge Baker even distinguished *Cicero* (compared to *Baby Doe*) as a case where the prognosis was for a relatively normal life. Judge Baker Letter, *supra* note 24, at 2.

115. See *supra* notes 64-84 and accompanying text.

116. There are some suggested alternatives to the present legislation to provide these guidelines. See *infra* notes 242-54 and accompanying text.

117. See *supra* note 69.

118. See Comment, *supra* note 62, at 786.

119. See Duff & Campbell, *Moral & Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973); Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L. J. 645 (1977); Shaw, *Genetically Defective Children: Emerging Legal Considerations*, 3 AM. J. LAW & MED. 333 (1977).

120. An ethicist recently wrote with candor:

Once the religious mumbo-jumbo surrounding the term "human" has been stripped away, we may continue to see normal members of our species as possessing greater capacities of rationality, self-consciousness, communication, and so on, than members of any other species; but we will not regard as sacrosanct the life of each and every member of our species, no matter how limited its capacity for intelligent or even conscious life may be. If we compare a severely defective human infant with a nonhuman animal, a dog or a pig, for example, we will often find the nonhuman to have superior capaci-

baby's fate is determined accordingly. Admittedly, the commentators' views reflect what a portion of society is willing to accept, and society itself may ultimately decide the issue. But lent such respectable professional signatures, the continuum tests may be even more frequently used *now* to define "adequate medical care," and the minimum degree of care in providing it. The inconsistency in application is striking. For the *Cicero* and *Houle* children, adequate medical care was corrective surgery. For Baby Doe, adequate medical care was nothing more than round-the-clock private duty nurses and doctor's orders for whatever pain medication was necessary.<sup>121</sup> "Adequate medical care" for Baby Doe did not demand corrective surgery to enable him to take nourishment.<sup>122</sup>

### b. Enforcement

Problems of enforcement raise yet another difficulty in bringing an action to intervene under child neglect law. There seem to be at least two explanations. First, withholding treatment from newborns is extremely difficult to uncover.<sup>123</sup> Doctors and parents work together and, regardless of their motivations and interests, if they mutually agree on a course of treatment, the neglect may go undetected unless someone outside that confidential doctor-patient-parent entity objects.<sup>124</sup> The fact that it was not until 1973 that the medical profession first openly acknowledged the relatively widespread practice of nontreatment indicates that society had been largely ignorant of the practice until then.<sup>125</sup>

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ties, both actual and potential, for rationality, self-consciousness, communication, and anything else that can plausibly be considered morally significant. Only the fact that the defective infant is a member of the species *Homo sapiens* leads it to be treated differently from the dog or pig. Species membership alone, however, is not morally relevant.

Singer, *Sanctity of Life or Quality of Life?*, 72 PEDIATRICS 28, 29 (1983).

121. *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982) (Finding 9).

122. The new "Baby Doe regulations" promise that this situation need never be repeated. 49 Fed. Reg. 1,622, 1,630, 1,657 (1984) (to be codified at 45 C.F.R. § 84.55).

123. See Ellis, *supra* note 46, at 398-99.

124. See Wald, *State Intervention on Behalf of "Neglected" Children—A Search for Realistic Standards*, 27 STAN. L. REV. 985, 1028-30 (1975).

125. See Duff & Campbell, *supra* note 119. Admittedly, withholding treatment had probably been a clandestine form of medical practice to any real extent for only a relatively short period of time before this revelation. Until medicine became sophisticated enough to be able to save certain defective newborns, there was obviously no dilemma involved in deciding whether to treat. If society becomes more accepting of passive euthanasia, doctors and parents may be more likely to come to a nontreatment decision *now* than they would have been 20 years ago when it was perhaps morally unthinkable. For example, a 1975 survey of pediatricians revealed that only 17 percent of them would

Of course, this discovery problem may not substantially differ from any other child neglect situation, since child neglect is a somewhat secreted family phenomenon.<sup>126</sup> Yet a neglected child of school age might have a better chance of getting help from teachers, social workers, neighbors and anyone else in the community who has an opportunity to see him.<sup>127</sup> The exposure is drastically reduced in the defective newborn's case. Further, the hospital community in which the child is born may be more tolerant of the practice of withholding medical treatment than the community at large might be of a practice of starving or battering an older child.<sup>128</sup> One safeguard some states employ is a child neglect

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do everything possible to save an infant like Baby Doe (Down's Syndrome with life-threatening intestinal obstruction); if the parents agreed with the doctor's decision, and no legal sanctions would ensue, 61 percent of the pediatricians polled would not have performed the lifesaving surgery. PRESIDENT'S COMM'N REP. *supra* note 4, at 208 (citing *Treating the Defective Newborn: A Survey of Physician's Attitudes*, 6 HASTINGS CENTER REP. 2 (1976)). Another study found 51 percent of the pediatricians surveyed in Massachusetts would not have recommended surgery for such a child. *Id.* (citing Todres, Krane, Howell, & Shannon, *Pediatricians' Attitudes Affecting Decisionmaking in Defective Newborns*, 60 PEDIATRICS 197 (1977)). See also Colletter, *supra* note 6, at 304-05 n.3 (reporting that in surveying physicians' attitudes regarding the Karen Quinlan controversy, a medical magazine discovered that 86 percent of the responding physicians had been confronted with whether to continue treating a "vegetative" patient, and 75 percent believed such patient should not be kept alive). These statistics certainly suggest that cases like *Baby Doe* may occur with greater frequency than we realize. See 49 Fed. Reg. 1,645 (1984). But see the finding of the President's Commission which states that "despite reports of occasional cases in which seriously erroneous decisions about the treatment of newborns were carried out, such events appear to be very rare," and are perhaps "inevitable in a society that treasures personal and familial autonomy." PRESIDENT'S COMM'N REP., *supra* note 4, at 209 & n.51 and accompanying text. Professor Smith believes that the "Baby Doe regs" were insufficiently based on "only four" documented cases of "discriminatory" denial. Smith, *supra* note 47, at 718 n.57. DHHS points out that "there is no requirement in law or policy to prove the magnitude of illegality before establishing basic mechanisms [to enforce] a clearly applicable statute." 49 Fed. Reg. 1,645 (1984) (to be codified at 45 C.F.R. § 84.55). Regardless of the frequency or rarity, or of the medical profession's attitude, the judiciary may remain uncomfortable with the practice. Early in the nontreatment controversy, a court remarked: "There is a strident cry in America to terminate the lives of *other* people—deemed physically or mentally defective. . . . Assuredly, one test of a civilization is its concern with the survival of the 'unfit-test'. . . ." *In re Weberlist*, 79 Misc. 2d 753, 757, 360 N.Y.S.2d 783, 787 (1974).

126. Paulsen, *Child Abuse Reporting Laws—Some Legislative History*, 34 GEO. WASH. L. REV. 42 (1966); Note, *The Legal Framework for Child Protection*, 66 COLUM. L. REV. 697 (1966).

127. All 50 states now have compulsory reporting statutes.

128. It has been suggested that doctors sometimes employ the practice of not informing parents of a severely defective child that there are any treatment options—either by calling the situation hopeless, or by simply telling the parents the child was stillborn. See, e.g., Ellis, *supra* note 46, at 398. The national

telephone "hotline."<sup>129</sup> Anyone who suspects neglect may phone the appropriate community department or law enforcement agency, and an investigation or prosecution will then ensue. The Reagan administration recently failed in an attempt to establish a nationwide hotline specifically for the protection of Baby Doe infants,<sup>130</sup> but another hotline, in a somewhat less conspicuous form, is now mandated by a new regulation.<sup>131</sup>

A second problem with neglect law enforcement involves a hesitation to hold parents morally blameworthy. The few states that have criminal as well as civil child neglect laws<sup>132</sup> have never initiated a criminal prosecution for withholding medical care from a defective infant.<sup>133</sup> When a child neglect law is invoked to protect

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attention drawn to two cases at Johns Hopkins in the early 1970's indicated that parents do make nontreatment decisions about children like Baby Doe (afflicted with mongolism and life-threatening, surgically correctable intestinal trouble), and neither the doctors nor the courts supervent these decisions. *Id.* at 399-400. *But see* Brown & Truitt, *supra* note 75, at 631 (indicating that often persons inside the health care setting will notify the "authorities" of a nontreatment decision).

129. Nebraska provides for such a "hotline" by statute, NEB. REV. STAT. § 28-711 (Cum. Supp. 1979), and it is designed to protect both children and handicapped persons: "When any physician, medical institution, nurse . . . or any other person has reasonable cause to believe that a *child* or an *incompetent* or *disabled* person has been subject to . . . neglect, he or she shall report such incident . . . on the toll-free number." *Id.* (emphasis added).

130. 48 Fed. Reg. 9,630 (1983) (to be codified at 45 C.F.R. § 84.61). The rule required all hospitals receiving federal funds to post a notice, informing whomever may be concerned of the policy of non-discrimination against the handicapped, in areas where care is provided to infants and handicapped persons. The notice provided a contact point at the DHHS for reporting violations via toll-free telephone. In *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983), the court struck down the regulation as arbitrary and capricious, in that there was no attempt by the government to investigate the appropriateness of nontreatment decisions, and no attempt to regulate its disruptive effects on the health care situation. Still, there are reports that the hotline system had been effective; it surfaced 33 accusations of improper care, 11 of which were investigated by a government team of doctors and civil rights personnel. Three handicapped newborns were apparently saved by new medical techniques as the result of the attention drawn to them through the hotline. *See* Wallis, *The Stormy Legacy of Baby Doe*, TIME, Sept. 26, 1983, at 58. Some 49 reports were investigated as of Dec. 1, 1983. Note that the federal hotline rule was backed by handicapped discrimination regulations and not by child neglect law. The hotline is not a brand-new method of uncovering nontreatment decisions. At least one child with Down's Syndrome and a gastrointestinal defect was saved when an anonymous report was made to a Detroit, Mich. newspaper regarding the child's condition. *See* Brown & Truitt, *supra* note 75, at 632.

131. 45 C.F.R. § 84.55 (1984).

132. *See* Katz, Howe & McGrath, *supra* note 31, at 14, 15, & 63, for a survey of the types of statutes and the penalties imposed.

133. *See* Mueller & Phoenix, *A Dilemma for the Legal and Medical Professions Eu-*

a defective newborn, it is usually, as in *Baby Doe* and *Cicero*, simply a vehicle to obtain an order for treatment, or for a guardian who may consent to treatment. It is not used as a weapon to penalize the parents. Both out of compassion for the plight of parents,<sup>134</sup> and with great deference to family autonomy,<sup>135</sup> many courts that eventually find neglect may find it rather reluctantly.<sup>136</sup>

## B. Handicapped Discrimination

"Had that baby been normal," remarked a Baby Doe editorial, "his death by starvation would have been a public concern. But because he had been inadvertently robbed of perfection, he was deliberately robbed of life. His flaws somehow cancelled out his rights."<sup>137</sup> Perhaps due to the perceived failure of neglect statutes,<sup>138</sup> or to the inapplicability and ineffectiveness of other sanctions,<sup>139</sup> *Baby Doe* and subsequent nontreatment cases are being attacked as a form of discrimination against the handicapped.<sup>140</sup>

An early case declared: "A person of 'unsound mind'—an idiot,

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*thanasia and the Defective Newborn*, 22 ST. LOUIS U.L.J. 501, 504 (1979); Robertson, *supra* note 6, at 243; Comment, *supra* note 69, at 710.

134. One commentator has observed:

Indeed, no sensitive person can fail to sympathize with the plight of the parents, or blithely pass judgment on the choice they make. After months of expectancy, they are informed that the newborn infant has serious mental and physical defects and will never know a normal existence. 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 potentially devastating effects on their marriage, family, and personal aspirations. If asked to approve a medical or surgical procedure necessary to keep the child alive, it is perhaps understandable that the parents view a life capable only of minimal interaction and development as the greater evil and refuse to provide consent.

Robertson, *supra* note 6, at 215. See also PRESIDENT'S COMM'N REP., *supra* note 4, at 210-211.

135. See *infra* note 187. See also PRESIDENT'S COMM'N REP. *supra* note 4, at 212, nn.62-63. Some authorities wish to treat parental autonomy as a fundamental constitutional right to be infringed only upon a showing of compelling state interest (the "strict scrutiny" test). See Note, *supra* note 27, at 1387. Parental autonomy has been viewed by the courts in past years as both a "sacred" natural right, see *In re Hudson*, 13 Wash. 673, 126 P.2d 765 (1942), and as a property interest, the subject of which "transcends property." *Denton v. James*, 107 Kan. 729, 735, 193 P. 307, 310 (1920).

136. It has been suggested that neglect laws really don't operate to help the child, but exist primarily to punish the parent. Wald, *supra* note 124, at 1037. In a Baby Doe situation, however, punishing the parents is probably undesirable.

137. N.Y. Times, Apr. 27, 1982, at A22, col. 1.

138. See *supra* notes 103-22 and accompanying text.

139. See *infra* notes 177-86 and accompanying text.

140. Wallis, *supra* note 131, at 58; The Wash. Post, May 19, 1982, at A21, cols. 4-6.

for example, is to all intellectual purposes, dead . . . ."<sup>141</sup> Although society has become more enlightened about mental retardation since then,<sup>142</sup> the mentally retarded person is still unable in many cases to make his or her own treatment decisions. The mentally handicapped individual is no longer considered intellectually dead, but nonetheless may require someone else to make a judgment about his medical care. The doctrine of "substituted judgment," which first appeared in a case involving the administration of the estate of an incompetent,<sup>143</sup> originally called for a court to "don the mental mantle of the incompetent."<sup>144</sup> While not couched specifically in terms of handicapped discrimination, several cases deal with the handicapped, specifically the mentally retarded, and substituted judgment with respect to medical treatment decisions.<sup>145</sup> Admittedly, there is a distinction between physically disabled adults who are capable of making their own decisions, and mentally disabled adults who are deemed incompetent to judge for themselves, and require a surrogate. This distinction brings the case of an incompetent adult, regardless of the type or degree of disability, very close to that of the defective infant: both must surrender what may be a life or death decision to someone else.<sup>146</sup>

Judicial handling of an incompetent's medical decision, regardless of the analysis purportedly followed, can be unpredictable, since it is often not clear which standard a court adopts and how that court applies the immediate facts to the standard. Uniform, widely-embraced guidelines for the courts could reduce the incidence of strained and inconsistent results in all but the most difficult cases. The post-*Baby Doe* demand for recognition of the rights

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141. *Jenkins v. Jenkins' Heirs*, 32 Ky. (2 Dana) 102, 104 (1834).

142. See R. BURGDORF, *THE LEGAL RIGHTS OF HANDICAPPED PERSONS* 46-52 (1980).

143. See *ex parte* Whitbread *in re* Hinde, a lunatic, 35 Eng. Rep. 878 (1816).

144. See, e.g., *In re* Carson, 39 Misc. 2d 544, 545, 241 N.Y.S.2d 288, 289 (Sup. Ct. 1962). Cf. *Strange v. Powers*, 358 Mass. 126, 136, 260 N.E.2d 704, 711 (1970).

145. See *infra* notes 259-80 and accompanying text.

146. For the handicapped person, the situation need not, of course be life or death, but may involve surrendering certain important rights to the decisionmaker. See, e.g., *Buck v. Bell*, 274 U.S. 200 (1927) (upholding the constitutionality of a statute that permitted an involuntary sterilization of mentally handicapped persons); *In re* Cavitt, 182 Neb. 712, 157 N.W.2d 171, *reh. denied*, 183 Neb. 243, 159 N.W.2d 566 (1968), *prob. juris. noted sub nom.* *Cavitt v. Nebraska*, 393 U.S. 1978, *vacated as moot*, 396 U.S. 996 (1969). *Cavitt* was the only decision to rely on *Buck* in upholding an involuntary sterilization of incompetents statute, and only on a three-judge majority. *Cavitt* made sterilization mandatory for the release of a mentally retarded woman from a state institution, seeing the "option" as hers. It was in *Buck* that Justice Holmes declared: "It is better for all the world, if instead of waiting . . . to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." *Buck v. Bell*, 274 U.S. 200, 207 (1927).

of defective newborns under already existing federal law may be a welcome step in that direction.

# 1. *The Attempt at Formal Federal Regulation*

## a. *Section 504*

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination, by any program or activity directly receiving federal funds, against any "otherwise qualified handicapped individual" excluded, discriminated against, or denied benefits "solely by reason of his handicap."<sup>147</sup> Whether physically disabled, mentally retarded, or suffering both physical and mental disabilities, it is clear that defective newborn infants fall under the statutory definition of "handicapped,"<sup>148</sup> and under most commonly accepted definitions, as well.<sup>149</sup> Undoubtedly, Baby Doe should have been protected by section 504: "solely by reason of his handicap" (Down's Syndrome), he was excluded from and denied the benefits of medical care that certainly would have been provided a non-retarded child. Starving a baby of normal intelligence simply because of esophageal fistula would never be tolerated:

[T]he standard . . . for letting die must be the same for the normal child as for the defective child. If an operation . . . is indicated to save the life of a normal infant, it is also the indicated treatment of a mongoloid infant. The latter is certainly not dying because of Down's Syndrome. Like any other child with [an] obstruction in its intestinal tract, it will starve to death unless an operation is performed . . . to permit normal feeding.<sup>150</sup>

If, indeed, the standard is the same in our society for providing care to the defective infant as it is for the normal infant, then the standard was completely ignored in *Baby Doe*, was very nearly circumvented in *Houle*, and may soon be defeated again.<sup>151</sup>

147. 29 U.S.C. § 794 (1982).

148. 29 U.S.C. § 706(7)(B) (1982) defines a "handicapped individual" as one who "(i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such an impairment."

149. The general definition of "handicap" is "a disadvantage that makes achievement unusually difficult." R. BURGDORF, *supra* note 142, at 3. The Burgdorf text provides an exhaustive survey of various definitions of "handicap," the etymological analysis of the word, and the impact connotations of the label "handicap" have had on those afflicted. *See also* State v. Turner, 3 Ohio App. 2d 5, 7, 209 N.E.2d 475, 477 (1965).

150. P. RAMSEY, *ETHICS AT THE EDGES OF LIFE* 192-93 (1978).

151. On October 11, 1983, Infant Jane Doe was born at Stony Brook Hospital, N.Y., with spina bifida and related complications. Her parents refused consent to surgery that would extend and improve her life, pursuant to a physician's nontreatment option. A. Lawrence Washburn, a Vermont attorney, petitioned a justice of the N.Y. Court of Appeals to order surgery. A guardian ad litem was appointed. *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 456 N.E.2d

b. *The 1984 "Baby Doe Regulations"*

A new federal regulation went into effect early this year, promulgated by the Department of Health and Human Services (DHHS), pursuant to section 504.<sup>152</sup> "Procedures relating to health care for the handicapped" is a thorough expansion of the section 504 philosophy specifically applied to handicapped newborns. The final regulation arrived after one false start, loud protest from the medical profession, and careful study of nearly 17,000 comments from doctors, nurses, hospital administrators, advocates for the disabled, and parents of the handicapped.<sup>153</sup> Its future and longevity are uncertain.<sup>154</sup>

The regulation requires that each "recipient health care provider" post an informational notice explaining the illegality of handicapped discrimination and providing telephone numbers of

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1186, 469 N.Y.S.2d 63 (N.Y. App. 1983), found that Washburn had failed to observe appropriate child protection procedures via the state's Family Court Act. *See supra* notes 104-21 and accompanying text. The court clearly chastised Washburn, finding his actions "unusual" and "offensive" attempts to "displace parental responsibility." *Id.* at 209, 456 N.E.2d at 1187, 469 N.Y.S.2d at 64.

The Infant Jane Doe decision, and its subsequent litigation, created new public furor over nontreatment decisions, and raised new questions about public policy in the area. Surprisingly, the same society that had condemned Baby Doe's parents only 18 months earlier seemed later to have had a change of heart. For the most part, the media portrayed the parents sympathetically, as harassed by a meddling stranger who was trying to usurp parental omniscience. The courts seemed to agree. The *Weber* court saw outside intervention as an attempt to intrude "into the very heart of the family circle, there to challenge the most private and precious responsibility vested in the parents . . . and at the very least force the parents to incur not inconsiderable expenses of litigation." *Id.* If the society wants to become involved, and wishes to issue periodic statements on the matter, it seems inconsistent that the society is so violently opposed to the efforts of Washburn, simply one of its members.

The government appealed *Weber* after becoming involved on behalf of the child, seeking to obtain medical records pursuant to federal regulation. *United States v. University Hosp. at Stony Brook*, 729 F.2d 144 (2d Cir. 1984). *See infra* notes 152-62 and accompanying text. The court held against the government, finding no statutory authority for intervention, and essentially finding the new regulations inapplicable. *See supra* note 19. *See generally* U.S. News & World Rep., Jan. 16, 1984, at 63; Henthoff, *A Case of Deformed Journalism at 60 Minutes*, Village Voice, Apr. 3, 1984, at 6; Henthoff, *Come Sweet Death and Judge Baby's Quality of Life*, Village Voice, Mar. 27, 1984, at 6; Henthoff, *Troublemaking Babies and Pious Liberals*, Village Voice, Jan. 3, 1984, at 8; Bird, *U.S. Role in 'Baby Doe' Case Defended by Surgeon General*, N.Y. Times, Nov. 7, 1983, at B4, col. 2.

152. 49 Fed. Reg. 1,622 (1984) (to be codified at 45 C.F.R. § 84.55).

153. *Id.*

154. *See supra* note 19.



reporting agencies.<sup>155</sup> The regulation also requires that federally funded state child protection agencies establish procedures using their "full authority pursuant to state law to prevent instances of unlawful medical neglect of handicapped infants." The procedures must include reporting requirements, methods for immediate review and on-site investigation, and provisions for obtaining court orders. Cooperation with any ethics committee involved is encouraged, and a model Infant Care Review Committee is outlined. Finally, the rule requires that child protective services report to DHHS each case of "suspected unlawful medical neglect involving the withholding, solely on the basis of present or anticipated physical or mental impairments, of treatment or nourishment from a handicapped infant who, in spite of such impairments, will medically benefit from the treatment or nourishment."<sup>156</sup>

Important, too, are the regulation's efforts to "narrow the gray area," by explaining section 504's definition of "handicapped" in the context of the newborn, and by specifying circumstances under which certain conditions will be treated in every instance. These clarifications will, it is hoped, sharply limit a doctor's discretion, and, if the courts pay close attention, will reduce the confusion the judiciary presently faces.

The DHHS reiterated its position that section 504 applies to handicapped infants as well as adults:

If the handicapped person is able to benefit medically from the treatment or service, in spite of the person's handicap, the individual is "otherwise qualified" to receive that treatment or service, and it may not be denied solely on the basis of the handicap.

Therefore, the analytical framework under the statute for applying section 504 in the context of health care for handicapped infants is that medically beneficial treatment and services not be withheld from a handicapped infant solely on the basis of the handicap.<sup>157</sup>

This position is clearly in line with the already recognized substantial benefit analysis in the common law.<sup>158</sup>

The DHHS sought to clarify this stand because some comments submitted on the proposed rule asserted that discrimination on the basis of handicap does not go to the heart of the treatment issue. Those comments argued that section 504 analysis is inapplicable in most nontreatment cases, because the handicap and the condition requiring treatment (upon which an allegation of discrimination rests) are one and the same.<sup>159</sup>

The Department responded with two illustrations. *Baby Doe* is

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155. 49 Fed. Reg. 1,651 (1984) (to be codified at 45 C.F.R. § 84-55).

156. *Id.*

157. *Id.*

158. See *supra* notes 48-56 and accompanying text.

159. 49 Fed. Reg. 1,636-37 (1984).

the "simple" case. There, the child has two distinct conditions, and the handicapping condition (Down's Syndrome) is separate from the surgically correctible difficulty. "[A]ssuming no other [contraindications]" the child with Down's Syndrome must be treated no differently than the child without.<sup>160</sup> The situation becomes more complicated when the handicapping condition is the problem that requires treatment: "In such a case the 'handicap' is the physical or mental impairment the infant has or will have . . . *after* completion of the treatment under consideration."<sup>161</sup> If "reasonable medical judgment" indicates that the infant is not able to benefit from the treatment, then it need not be extended.<sup>162</sup> However, if the treatment would be medically beneficial—likely to bring about the intended result of avoiding certain serious consequences to nontreatment—then failure to treat "because of anticipated impairments in future life" offends section 504, as the nontreatment "is *because* of the handicap and *in spite* of the infant's being qualified to receive surgery."<sup>163</sup>

Notably absent is any definition of what is "reasonable medical judgment" and what are "contraindications" to treatment.<sup>164</sup> Lest any physicians fear super-policing of a newborn's medical prognosis, "[t]he statutory framework does not provide for, nor will the Department engage in, second-guessing of reasonable medical judgments regarding medically beneficial care."<sup>165</sup> Asserting that constitutional protection for infants does not interfere with *bona fide* medical judgments,<sup>166</sup> the Department nonetheless acknowledges that "not every opinion expressed by a doctor automatically qualifies as a reasonable medical judgment."<sup>167</sup>

It is important to realize what the new regulation does *not* do. First, it does not require that the informational notice be posted for everyone to see, and this may affect opportunities to report nontreatment violations. Many comments expressed concern that hospital visitors who saw the notice would fear it meant that the particular institution practiced poor patient care.<sup>168</sup> Thus, a small notice need only be posted where medical professionals will see

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160. *Id.* at 1,637 (to be codified at 45 C.F.R. § 84.55).

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

162. *Id.*

163. *Id.* at 1,630 (emphasis in original).

164. Although it should be noted that the judgment is limited to what would be *medically* beneficial, as opposed to some other consideration.

165. 49 Fed. Reg. 1,622, 1,630 (1984).

166. *Id.* (citing *Youngberg v. Romeo*, 457 U.S. 307, 321 (1982)).

167. 49 Fed. Reg. 1,630 (1984). This comment specifically attacks the *Baby Doe* decision as unreasonable; DHHS asserts there are sufficient due process protections built into the regulations for doctors and hospitals fearing their judgments will be constantly scrutinized. *Id.* at 1,643.

168. *Id.* at 1,626.

it.<sup>169</sup>

Second—and more significant—section 504 applies only to programs receiving federal financial aid. It does not apply to decisions made by parents. Hospitals are not allowed to overrule even the most discriminatory parental decision: they are simply forbidden to effectuate it.<sup>170</sup> A recipient hospital “may not blindly implement improper and discriminatory” choices, but is now required to “resort to the *system provided by state law*” by notifying proper authorities, or seeking *judicial review*.<sup>171</sup> Given the troublesome possibilities, any weakness in these new regulations may be tried and tested on this very aspect.<sup>172</sup>

## 2. Local Analysis

Some state statutes expressly address abuse and neglect of the disabled,<sup>173</sup> and the new rules now insist that every recipient child protective services agency implement existing state law in their procedures. A state statute prohibiting handicapped discrimination may have more bite than section 504. The state may, for example, deem criminal any person's act of discrimination, and subject such a person to criminal sanctions. The teeth in section 504 simply provide for withholding or withdrawing funds from a federally funded entity.<sup>174</sup> However, a nontreatment decision will not necessarily trigger state sanctions. Finding discrimination is a prerequisite, and unless state law is narrowly and clearly drawn, a court may avoid that finding as easily as it may already avoid a neglect determination. A statute that defines handicapped abuse in terms of depriving a disabled person of “necessary food . . . or medical care”<sup>175</sup> is no stronger than a similar neglect statute.

Ultimately, then, the same interpretation and enforcement problems that beset child neglect law in nontreatment decisions will also plague disabled abuse law, and may render it somewhat ineffective in the nontreatment analysis.<sup>176</sup> The new and ambi-

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169. *Id.* at 1,625 (to be codified at 45 C.F.R. § 84.55).

170. 49 Fed. Reg. 1,631 (1984) (to be codified at 45 C.F.R. § 84.55).

171. *Id.* (emphasis added).

172. Frankly, the new regulations may never reach that stage. See *supra* notes 19 & 151 and accompanying text.

173. See, e.g., NEB. REV. STAT. § 28-708 (1979).

174. Thus, an entity is free to discriminate under federal law so long as it is willing to operate without federal funding.

175. NEB. REV. STAT. § 28-708 (Cum. Supp. 1982).

176. The Nebraska statute uses exactly the same language to protect the handicapped as it does to protect the neglected child: “A person commits abuse of an incompetent or disabled person if he . . . causes or permits an incompetent or disabled person to be: (a) Placed in a situation that endangers his life or health; or . . . (c) Deprived of necessary food, clothing, shelter, or

tious federal guidelines require state procedures for implementation. In response we must insist on thorough, clear, and controlled policy.

### C. Law On The Periphery

While neglect and discrimination theories are most pertinent to Baby Doe decisions, they do not complete a discussion of the controversy. The law is the voice of our society, attacking the evils we wish to be rid of, and protecting the values we hold dear. Society announces itself in the particular through a single statute or holding, but speaks in the larger sense through entire statutory schemes, or general judicial expressions of public order and morality. Thus any exploration of how we wish to deal with defective babies invites other questions: how do we respond to killings, or to the desires of children, or to life just before it is newborn?

#### 1. *Killing and Planning to Kill: Homicide and Conspiracy*

It has been argued that those responsible for nontreatment decisions may be charged with homicide.<sup>177</sup> Homicide by omission, that is, the death of another because of a failure to act,<sup>178</sup> suggests prosecution of those responsible for withholding medical care who have an affirmative duty to provide it. Clearly, a parent is charged with the duty to provide his or her minor child with necessary medical care, and where a parent fails to obtain needed professional assistance, the child's resulting death will be homicide. The attending physician may also be liable for homicide once he assumes the legal obligation to treat the infant when the failure to treat means death to the child,<sup>179</sup> even though treatment is foregone in accord with the parents' wishes.<sup>180</sup> Some rather elaborate theories assert parents' and doctors' affirmative duties to the de-

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care. . . ." NEB. REV. STAT. § 28-708 (Cum. Supp. 1982). Cf. NEB. REV. STAT. § 28-707 (1979) (protection with respect to minor children).

177. See Robertson, *supra* note 6, at 217-18 & 224-25.

178. W. LAFAVE & A. SCOTT, *supra* note 44, at 188-89. See also *State v. Williams*, 4 Wash. App. 908, 484 P.2d 1167 (1971), where the parents of a 14-month-old boy were guilty of manslaughter when the baby died of a toothache which had turned into a serious infection. The parents' love for the child, their ignorance, and their fear that the child would be taken from them by the public authorities was insufficient to reverse the manslaughter conviction. Compare *In re Green*, 12 CRIME & DELINQ. 377 (Milwaukee County Ct. Wis. 1966) (see *supra* notes 50-52 and accompanying text for a discussion of *Green*), and *In re Tuttendario*, 21 Pa. D. 561 (1912) (see *supra* note 55 and accompanying text for a discussion of *Tuttendario*).

179. Robertson, *supra* note 6, at 225.

180. *Id.*

fective newborn.<sup>181</sup> They remain, insofar as they could trigger liability for nontreatment, simply theories. To date, no court has imposed criminal sanctions on a parent for refusing treatment to a defective newborn,<sup>182</sup> and *Baby Doe* suggests that physicians may be easily relieved of liability so long as parents agree with the doctor's medically recommended course of nontreatment.

Likewise, criminal conspiracy law implies that parents and doctors acting in concert may be guilty of more than just murder or manslaughter. Conspiracy involves an agreement to achieve an unlawful objective, in this case, the death of a child, and often an affirmative, overt act to evidence the intent to achieve that objective.<sup>183</sup> If conspiracy law were successfully applied to those making nontreatment decisions, it would probably encompass all nontreatment attempts—regardless of whether the child's death resulted. Prosecution for conspiracy to withhold treatment from a defective newborn has probably never been attempted.<sup>184</sup> Perhaps, as with neglect law, courts are simply reluctant to hold culpable either parents who have made an anguished decision, or doctors who have exercised their best medical judgment in a medically frustrating situation. This surely explains any lack of prosecution in cases where the court intervenes and orders treatment over a nontreatment decision.

*Baby Doe*, however, suggests that there can be no prosecution for homicide or conspiracy even where a court does not order treatment. The *Baby Doe* court approved of, even encouraged, the nontreatment decision, so long as both parties to the decision—the doctor and the parent—agreed.<sup>185</sup> *Baby Doe* thus implies that regardless of our response to criminal killing, the essential factors in homicide or conspiracy are not met in nontreatment decisions. There is no unlawful act, or attempt to achieve an unlawful act, upon which to base a conviction.<sup>186</sup> This result may be inconsistent with our general philosophy regarding death from criminal omission. But this inconsistency is not terribly troubling, if consistency demands we severely punish a mother and father who have suffered too much already.

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181. See *supra* note 179.

182. Comment, *supra* note 69, at 710.

183. W. LAFAYE & A. SCOTT, *supra* note 44, at 453.

184. See Robertson, *supra* note 6, at 234-35.

185. *In re Infant Doe*, No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982). But see 45 C.F.R. § 84.55 (1984), encouraging a "presumption . . . in favor of treatment." 49 Fed. Reg. 1,652 (1984).

186. See also Note, *supra* note 63, at 613-15.

## 2. *The Child's Best Interests: Borrowing the Custody Standard*

In choosing which parent should have custody of a child after divorce, and in examining foster care and child neglect situations, the law most commonly invokes the "child's best interests" test.<sup>187</sup> This standard looks relatively simple on its face: it means that the child's welfare is given priority over every other interest involved. The child's-best-interests guide is surely consistent with the recognized social aim of protecting the young and helpless, and it has been adopted by courts to decide what degree of medical care children should receive.<sup>188</sup> It is logical, therefore, to extend the standard to those children born disabled:

At the point when a child is born, the focus has got to be only on the child and its interests. And if the child is born with a handicapping condition, but can live a life notwithstanding that condition, then its interests go in only one direction—and that is living.<sup>189</sup>

Pure as the child's-best-interests test may seem, it is an unreliable standard when applied to defective newborns' treatment decisions. It is "in many ways a fiction, because the child's [best] interests depend on who is defining them. . . ."<sup>190</sup> An infant's welfare, much like the quality of his life, may be extremely vulnerable to subjective, varying definition.

In applying this standard to a nontreatment controversy, courts will generally assume one of two things: either an infant's interest is always in life,<sup>191</sup> or, absent that first assumption (but perhaps not inconsistent with it), the parents are the ones who will most successfully and accurately determine what the child's best interests are.<sup>192</sup> To the extent that those two assumptions do not ulti-

187. *Id.* at 606. See *Finlay v. Finlay*, 240 N.Y. 429, 148 N.E. 624 (1925) (first articulated the "child's best interests" standard); Foster, *Adoption and Child Custody: Best Interests of the Child*, 22 BUFFALO L. REV. 1, 3 (1972); Note, *In the Child's Best Interests: Rights of the Natural Parents In Child Placement Proceedings*, 51 N.Y.U. L. REV. 446, 448-49 (1976).

188. The "Jehovah's Witness blood transfusion cases" provide excellent examples. See *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1962); *Hoener v. Bertinato*, 67 N.J. Super. 517, 171 A.2d 140 (1961).

189. Herbert Hinkle, Director of the N. J. Div. of Advocacy for the Developmentally Disabled, *quoted in* interface, Vol. 8, Nos. 4-5 (1983) (Newsletter of N.J. Dev. Disabilities Council).

190. Note, *supra* note 63, at 606. See *supra* notes 82-84 & *infra* notes 220-30 and accompanying text.

191. See, e.g., *Gleitman v. Cosgrove*, 49 N.J. 22, 30, 337 A.2d 689, 693 (1967). ("It is basic to the human condition to seek life and hold onto it however heavily burdened").

192. Parental autonomy enjoys some powerful constitutional support. *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (right to choose child's religious upbringing); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (right to choose child's education); *Meyer v. Nebraska*, 262 U.S. 390 (1923) (right to raise a child). There is

mately lead to the same conclusion, *Baby Doe* may signify a growing departure away from the first,<sup>193</sup> and an increasing reaffirmation of the second.<sup>194</sup>

The child's-best-interests standard resembles the concept of informed consent through substituted judgment regarding the treatment decision.<sup>195</sup> Each of these decision methods is unavoidably subjective to some degree. The academic distinction between the two is that the child's best interests analysis seeks to determine what is best for the defective newborn from a societal, medical, judicial, or parental standpoint, and the substituted judgment doctrine attempts to place the decisionmaker in the position of the handicapped newborn. Ultimately, however, any distinction is simply conceptual, and becomes blurred with practical application: "beyond their enforceable rights to medical treatment, infants also may have interests in merely staying alive, or in leading as full, rich, and rewarding lives as possible. Invariably, the extent of these interests in any particular infant varies with the perspective of whoever is attempting to evaluate them."<sup>196</sup>

The test is unworkable because the decisionmaker's perspective changes what a child's best interests are from case to case. Moreover, this perspective is clouded by competing interests—

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something of a limitation, of course: "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children. . . ." *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944). It has been suggested that parental autonomy be treated as a fundamental right. See generally Note, *supra* note 27, at 1388.

193. At the base of every analysis of defective newborn nontreatment is the assumption that, at some point, the child's interest in life gives way to an interest in death. See Clarke, *supra* note 75, at 823; Comment, *supra* note 62, at 795. See also *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976). *Quinlan* is often cited as the "right to die" case. See *supra* notes 72-76 and accompanying text. *Baby Doe's* presiding judge assumes this. There is reason to believe that *Baby Doe's* parents in good faith felt that their child had a right to die and that the exercise of this right was in his best interests (he was given last rites and baptized). The court may have agreed, since petitions to adopt the child were not heard. *In re Baby Doe*, No. JV8204-038A (Ind. Juv. Ct. Monroe County Apr. 13, 1982). Judge Baker stated: "It is a harsh view that no life is preferable to life," Judge Baker Letter, *supra* note 24, at 2, but that is precisely the conclusion drawn. Compare the wrongful life decisions. See Shaw, *supra* note 119, at 338.

194. *Baby Doe* is clearly an example of the emphasis on parental autonomy, for it was the right to privacy in nontreatment decisionmaking that the court endorsed. See *supra* notes 27 & 92. As Judge Baker noted: "To say that parents are neglectful implies that the State or society knows what is best for the child. In the 'Infant Doe' case, it could not be said that the parents were not acting in the best interests of the child, even though other parents might have acted differently." Judge Baker Letter, *supra* note 24, at 2.

195. See *infra* notes 259-67 and accompanying text.

196. Longino, *supra* note 2, at 386.

usually those of the parents—in avoiding the marital stress, the difficulties with siblings, the immense financial burdens, and the continuous grief that a defective child can bring to a family.<sup>197</sup> These competing interests may weigh heavily against a parent's duty to care for the child. The *Baby Doe* case did not speak directly to these issues, but one judge asserted "it could not be said that the parents were not acting in the best interests of the child, even though other parents might have acted differently."<sup>198</sup> It is difficult to imagine a decision which would permit any child's life to depend merely upon the financial, familial or emotional burdens of the persons legally charged with the duty to protect that life.<sup>199</sup> However, the fact that competing interests are given any recognition at all suggests that courts extend them some consideration and validity when parents urge nontreatment.<sup>200</sup>

### 3. *Protecting the Nearly-Born: Postviability Abortion Regulation*

A parental decision to withhold treatment from a disabled child closely resembles a mother's decision to abort a viable unborn child. Both controversies attempt to resolve privacy rights of choice, respecting personal or parental autonomy, with society's interest in protecting human life. Arguably, there is but a very fine line between the life interest of a nearly-born and a newborn. The decisionmaker's autonomy interests are similar, too: they include the right to beget children or to avoid the burdens of parenthood,

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197. See *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 403 (D.D.C. 1983). Competing interests are increasingly meriting serious consideration. It is suggested that the impact a defective child would have on the family unit, the marriage, sibling coping, and economic hardship, all deserve consideration. See Longino, *supra* note 6, at 386. Perhaps this is consistent with a state interest in preserving the family unit. The responses vary. *Id.* Economic considerations are troublesome, especially since the "healthier" a handicapped person may be, the longer he is likely to survive, even in his defective state, and therefore the more expensive his maintenance may be. On the other hand, the more seriously defective life may only last an extremely short period of time, and cost much less to care for (even if on a machine). From a purely financial standpoint, it is in the best interests of the one paying the bills to protect the seriously defective infant over the less sick, less defective one.

The more weight afforded competing interests, perhaps the nearer we reach risking other, broader nontreatment decisions with less sensitivity and concern for the individual who stands to be most directly and drastically affected.

198. Judge Baker Letter, *supra* note 24, at 2.

199. This is particularly true when the parents may relinquish custody. While not always possible, in *Baby Doe* there were couples willing to adopt the child. N.Y. Times, Apr. 17, 1982, at A6, col. 1.

200. See *supra* notes 197 & 221-25 and accompanying text.



and to decide when and how to raise a family.<sup>201</sup> Finally, some of the same concerns that permit a postviability abortion choice also disturb a clear and unprejudiced treatment choice: emotional or family strain, financial devastation, and mental well-being of the decisionmaker.<sup>202</sup>

The landmark abortion case, *Roe v. Wade*,<sup>203</sup> established that a prospective mother has a fundamental right to make her own decision, with proper medical advice, on whether to have an abortion.<sup>204</sup> The state acquires a compelling interest in the "potentiality of human life" only during that period of pregnancy "subsequent to viability."<sup>205</sup> Nearly half of the states presently regulate postviability abortions, and most of these regulations prohibit the abortion unless it is to protect the mother's life or health.<sup>206</sup>

*Roe* defines a viable fetus as one "potentially able to live outside the mother's womb, albeit with artificial aid,"<sup>207</sup> and many states define viability in exactly those words.<sup>208</sup> If a "viable" fetus is worthy of the state's protection, it should not follow that a child born alive and in need of treatment—now considered a "person" worthy of the constitutional protection that "personhood" requires—may be denied the same consideration for artificial support. *Baby Doe* involved such a child, if corrective surgery may be considered "artificial aid."<sup>209</sup> Yet the "course of nontreatment" adopted runs contrary to postviability abortion policy.

Notably, both nontreatment and abortion decisions afford great weight to medical judgment. A state attempting to protect its interest in "potential" life<sup>210</sup> must account for Supreme Court rul-

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201. See *supra* note 27.

202. See *Doe v. Bolton*, 410 U.S. 179 (1973). A third trimester abortion may be performed to save the life or health of the mother. The Court defined "health" broadly to include psychological as well as physical well-being, in light of all the circumstances. *Id.* at 191-92.

203. 410 U.S. 113 (1973).

204. *Id.* at 153.

205. *Id.* at 163.

206. For a survey of states which regulate postviability abortions, and their prohibitions, see Wood & Hawkins, *State Regulation of Late Abortions & the Physician's Duty of Care to the Viable Fetus*, 45 Mo. L. Rev. 394, 415, nn.139-41 (1980).

207. *Roe v. Wade*, 410 U.S. 113, 163 (1973).

208. See Wood & Hawkins, *supra* note 205, at 405. See also *Colautti v. Franklin*, 439 U.S. 379, 387 (1979) (viability determination requirement of § 5, Pa. Abortion Control Act, void for vagueness).

209. Compare the *Quinlan* situation, see *supra* notes 72-64 and accompanying text, with that in *Houle*, see *supra* notes 87-100.

210. "Potential" life is the Court's terminology. *Roe v. Wade*, 410 U.S. 113, 163 (1973). This should be compared with Professor Noonan's analysis in J. NOONAN, *A PRIVATE CHOICE* 147 (1979).

ings that the viability determination is a medical matter left to the judgment of the attending physician.<sup>211</sup> These cases emphasize the "seemingly absolute role of the physician" in determining viability.<sup>212</sup> This makes regulation of the doctor's decision virtually impossible; as a result the state cannot "vindicate its compelling interest in the life of the fetus after viability."<sup>213</sup> Perhaps, then, the doctor's subjective determination of viability offers only "scant" protection of a state interest.<sup>214</sup>

Most states that regulate postviability abortions usually protect the fetus delivered alive by declaring it to have the same rights as a live fetus intended to be born and not aborted.<sup>215</sup> Several of those states require that a physician planning to perform a third trimester<sup>216</sup> abortion consult one or two other doctors to certify that the operation is necessary to preserve the life and health of the mother.<sup>217</sup> Similar requirements imposed in nontreatment situations would better serve the compelling state interest in protecting life, and might help guard against extreme discretion on the part of the attending physician.<sup>218</sup> The *Baby Doe* court did not

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211. See Wood & Hawkins, *supra* note 206, at 405. See also *Colautti v. Franklin*, 439 U.S. 379 (1979).

212. See Wood & Hawkins, *supra* note 206, at 405. See also *Youngberg v. Romeo*, 457 U.S. 307, 321-22 (1982) (courts must show appropriate deference to professional determinations).

213. Wood & Hawkins, *supra* note 206, at 405.

214. *Id.*

215. *Id.* at 419. NEB. REV. STAT. § 28-331 (1979) directs that: "All reasonable steps, in accord with the sound medical judgment of the attending physician, shall be employed in the treatment of any child aborted alive with any chance of survival."

216. The Court has noted that: "Viability is usually at about seven months (28 weeks) but may occur earlier, even at 24 weeks." *Roe v. Wade*, 410 U.S. 113, 160 (1973).

217. See Wood & Hawkins, *supra* note 206, at 416. A federal court in Illinois struck down such a statute in *Wynn v. Scott*, 449 F. Supp. 1302 (N.D. Ill.), *appeal dismissed*, 439 U.S. 8 (1978), when it found no direct relationship between the state's interest in preserving maternal and fetal health, and the number of doctors participating in the decision. Still, it may be argued that the additional safeguard is desirable with a live birth.

218. Arguably, such a requirement may not have saved *Baby Doe*, since indications are that two doctors recommended corrective surgery, but one physician, "representing the concurring opinions of himself" and two other doctors, recommended nontreatment. See *In re Infant Doe*, No. GU8204-004A (Ind. Cir. Ct. Monroe County Apr. 10, 1982) (Declaratory Judgment). However, the *Baby Doe* court implies that it would have upheld the parents' decision so long as a "medically recommended treatment" mode was followed. *Id.* See *In re Green*, 12 CRIME & DELINQ. 377 (Milwaukee County Ct. Wis. 1966). In *Green*, the mother's decision to refuse her son blood transfusions was upheld partly "because of medical advice she has had from other physicians, and because doctors cannot assure her that it [treatment] will be effective in saving the life of the child or be of substantial benefit to him." *Id.* at

speak directly to the quantity of medical opinion necessary to determine withholding treatment. The court refused to intervene, however, partly because the Doe parents were following a medical recommendation. It may, therefore, be safe to assume that no more than one authoritative medical recommendation is needed for the nontreatment decision to be non-reviewable.<sup>219</sup>

If *Baby Doe* reflects good social policy, then the decision surely suggests inconsistency in our social conscience. We provide a medical safeguard where the life is only "potential," and in fact the intent is to successfully abort, yet the fetus is not entitled to full constitutional protection. Why then do we not require a similar medical safeguard, the "second opinion," to protect a live birth, established as human life, and conferred with personhood? Certainly, no postviability abortion statute allows a lower standard of care for the live-born fetus who also happens to be handicapped. And certainly, the mother's competing interest in her right to privacy in decisionmaking is at least as strong (if not stronger) with respect to an abortion decision as it is in a nontreatment decision.<sup>220</sup>

### III. DIRECTIONS THE LAW MAY SEEK

#### A. Chinks In The Doctor-Parent Armor

If there is no other rule to be gleaned from *Baby Doe*, the decision at least stands for the proposition that a court will not overturn a nontreatment decision as long as two requirements are met: first, the parents must be exercising a right to privacy, so that family autonomy vindicates the decision to withhold medical care; second, the decision must be based on a medical recommendation. While the decisions and judgments of both parties—doctor and parent—are probably *necessary* under most circumstances for the nontreatment conclusion, many question whether they are also *sufficient*.

In our society, parents are expected to be advocates for the child, substitute decisionmakers who grant consent and who are supposed to look out for the child's best interests. Surely the con-

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379-80. While it seems that many doctors are offended by an attempt to interfere with their decisionmaking and treatment, others might find a relief from such heavy decisionmaking responsibility welcome.

219. See *supra* notes 5 & 7 and accompanying text. See also 49 Fed. Reg. 1,630 (1984) (DHHS will not second guess reasonable medical judgments regarding medically beneficial care).

220. Some suggest that a defective newborn's potential for growth and development may be so limited that it cannot be considered a "person" for purposes of constitutional protection. Life alone, therefore, may not be a sufficient requisite for personhood. See Comment, *supra* note 62, at 788.

clusion to withhold or withdraw treatment is in most cases a painful and compassionate one to reach: "Parents are usually present, concerned, willing to become informed, and cognizant of the values of the culture in which the child will be raised. They can be expected to try to make decisions that advance the newborn's best interests."<sup>221</sup> However, not all parents faced with treatment options are going to make the best choice.<sup>222</sup> The interests of the parents and other family members compete with the child's, and make dispassionate judgment extremely difficult.<sup>223</sup>

It may be impossible for parents who waited anxiously for the birth of their child to accept the child's deformity without anxiety, guilt, or bitterness.<sup>224</sup> A decision to do everything possible to save the child, made in a moment of benevolence when a quick response to life or death demanded, may be later viewed as a mistake when the child must undergo yet another surgery in the course of ordinary treatment which may not appreciably improve the quality of life prognosis. Conversely, a decision to withhold treatment may haunt parents who might later wonder if they reacted immorally and too hastily. Finally, it may be much more difficult to make heartfelt parental decisions for a newborn than for an older child. The parent-child bond, established and strengthened over time and experience, through which the parent nurtures and defends the child, may be weakest at birth.<sup>225</sup>

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221. PRESIDENT'S COMM'N REP., *supra* note 4, at 209. One parent asserted:

I am very uncomfortable with the doctor assuming that if there are two equal things, he will decide and take the responsibility . . . [W]hen [I became] a parent . . . I had assumed there would be hard decisions to make, and some of them were harder than I anticipated. But nonetheless, I felt that was a responsibility I took for myself. And I don't want to turn it over to somebody who is going to spare me that.

*Id.* at 211. See 49 Fed. Reg. 1,631 (1984) (National Association of Children's Hospitals argued parents' determinations of their child's best interests "are theirs to make, a right and responsibility assigned to them universally by state statute."). *Id.* at 1,631.

222. See, e.g., *In re Phillip B.*, 92 Cal. App.3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980). *Phillip B.* involved a Down's Syndrome child whose parents institutionalized him at birth, and later refused consent to heart surgery that would extend his life beyond the projected twenty years. His condition without surgery would deteriorate from "mildly retarded" and able to perform certain tasks, to bedridden. Phillip's parents, however, felt that he would be better off dead than alive. See Longino, *supra* note 2, at 388 (citing trial transcript). Surgery was not deemed lifesaving. A foster couple successfully adopted him after a years-long court battle, and he now leads a full life.

223. See *supra* notes 192-94 and accompanying text.

224. See PRESIDENT'S COMM'N REP., *supra* note 4, at 210, 215-16.

225. The "parental bond" phenomenon has received some judicial recognition. See *Lehr v. Robertson*, 103 S. Ct. 2985 (1983) (examining the extent to which

Doctors, too, may be plagued with difficulty in advising the parents.<sup>226</sup> They feel that they must assume some of the burden of decisionmaking to alleviate the parents' suffering, especially since they are expected to move under the aegis of Hippocrates, and act as the child's advocate.<sup>227</sup> Undoubtedly, doctors are at least partially motivated by what experience has shown to be painful or futile or inhumane. Doctors are medical technicians able to announce what ticks and what does not; they are also ethical, careful, often religious, human beings.

But, as is the case with parents, not all doctors can be expected to offer the best evaluation all of the time. *Baby Doe* certainly demonstrates that doctors can and will disagree on what medical options are appropriately posed to the parents.<sup>228</sup> It has been asserted that even physicians remain quite ignorant about opportunities and prospects for the mentally retarded.<sup>229</sup> It has further been suggested that occasionally a doctor will not present parents with the entire range of choices available, either because the doctor thinks the parents incapable of fully understanding the gravity and complexity of the decision, or because the doctor fears liability if the parents later regret the professionally recommended option.<sup>230</sup>

## B. Alternatives To Doctor-Parent Exclusivity

A medical authority asserts that the decision whether to treat infants with birth defects should be borne exclusively by the doctor and parents, and that "much latitude in decisionmaking should be expected and tolerated. Otherwise, the rules of society or the policies most convenient for medical technologists may become the cruel masters of human beings instead of their servants."<sup>231</sup> Today, however, the rules of society, in their unrefined and con-

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the natural biological unwed father's relationship with his illegitimate child receives due process protection). See also Ellis, *supra* note 46, at 414 ("Parental-child bonding may not yet be complete, and the parental love assumed by society to exist in other contexts may not yet have developed. Thus, other considerations may prevail. A defective or deformed baby devastates parental expectations. A denial of treatment removes this unexpected and possibly unwanted infant.") Cf. 49 Fed. Reg. 1,622, 1,629 (1984) (testimonials from parents).

226. This discussion is synthesized largely from the PRESIDENT'S COMM'N REP., *supra* note 4, at 210.

227. See *id.*

228. See *supra* notes 5-7 and accompanying text.

229. The American Speech-Language-Hearing Association so reported to the DHHS. 49 Fed. Reg. 1,622, 1,650 (1984).

230. See PRESIDENT'S COMM'N REP., *supra* note 4, at 211.

231. Duff & Campbell, *supra* note 119, at 894.

fused form, are "cruel masters," not only of those chancing a bad decision, but of those human beings whose lives are at stake.

That being the case, so much decisionmaking latitude should not be tolerated. Though the parent and doctor each try to advance the child's best interests, the well-recognized interest in human life urges society itself to advocate for the child as well.<sup>232</sup> If our policy calls for new checks on the doctor-parent entity, we must answer fairly and responsibly. Incomplete goals and undefined guides do not ease the decisionmaker's burden. Federal regulation seems at this point to answer many of the issues. But in frustrated response to this difficult situation, some further suggestions have been put forth for social consideration.

### 1. *Ethics Committees*

One such alternative is an ethics committee, to advise and rule in the treatment process. *Quinlan* suggested this procedural tool for future nontreatment dilemma. That outline recommended that once the attending physicians conclude that there is "no reasonable possibility of . . . ever emerging from [the] present comatose condition to a cognitive, sapient state,"<sup>233</sup> and the guardian agrees with the doctor's nontreatment recommendation, a hospital ethics committee must concur before nontreatment is permissible.

Variations on the *Quinlan* framework carry the procedure several steps further. Those models recommend that if a defective newborn requires medical attention, and the parents refuse consent, treatment will not be administered if all of the treating physicians and the ethics committee concur. If, however, either the committee or any member of the medical staff favors treatment, a panel will hear the issue, with power to appoint guardians ad litem, commence judicial action, and expedite a decision.<sup>234</sup> Federal regulations recommend adherence to section 504 standards, and suggest a model committee.<sup>235</sup> Another guide for nontreatment is "clear and convincing evidence that such withholding of treatment is in the patient's best interest, considering the probability of recovery with the proposed treatment, the potential side effects of

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232. Public outcry over some nontreatment decisions may indicate a great willingness to involve society in the decisionmaking.

233. *In re Quinlan* 70 N.J. 10, 55, 355 A.2d 647, 671 (1976).

234. See Shapiro, *Medical Treatment of Defective Newborns: An Answer to the 'Baby Doe' Dilemma*, 20 HARV. J. ON LEGIS. 137, 151 (1983). See also 49 Fed. Reg. 1,651 (1984) (to be codified at 45 C.F.R. § 84.55).

235. The DHHS provides detailed guides for Infant Care Review Committees, recognizing them as potentially very valuable tools in the decision process. Due to the fact that the committees are "largely untried," they are "not demonstrably effective enough to justify requirement" for some 7,000 hospitals nationwide. 49 Fed. Reg. 1,622, 1,624 (1984).

the treatment, and the nature of the treatment."<sup>236</sup>

Though this and similar standards may be broad and vague,<sup>237</sup> the ethics committee concept need not be abandoned. Ethics committees or review panels have been endorsed by commentators<sup>238</sup> and medical professionals.<sup>239</sup> The best rationale for their involvement is that they provide an additional perspective, one that dramatically reduces the subjectivity of the treatment decision, and dilutes the considerations competing with the child's interests. The panel should be comprised of qualified, well-informed representatives of the community. It has been suggested, then, that physicians (besides the attending physician), hospital administrators, lawyers, advocates for the handicapped, and laypersons would provide a balanced review.<sup>240</sup>

Such reviewing bodies can be effective protections against rash decisions or questionable medical advice. However, if an ethics committee functions only as an advisory board, merely informing doctor and parent of options and liabilities, it is a voiceless and impotent representative—of both the child and the society that wants to save him.<sup>241</sup>

## 2. *Legislative Proposals*

It may be asserted that ethics committees and panels do not reflect the broad social consensus as well as the legislature might. Committee decisions, even if dispositive, may mirror only local community standards that will conceivably vary from place to place. The legislature might be expected to articulate public policy more completely, and thus the solution to the nontreatment dilemma—if, indeed, any solution is to be found—may call for legislative guidelines.

Currently, few states have any legislative initiative affecting the treatment of infants.<sup>242</sup> "Because of the paucity of legislation on

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236. Shapiro, *supra* note 234, at 151.

237. See *supra* notes 103-22 and accompanying text.

238. See, e.g., Shapiro, *supra* note 234, at 148-52.

239. The American Academy of Pediatrics' official policy was developed by their Committee on Bioethics, assisted by the Committee on Fetus and Newborn, Hospital Care, and Children with Handicaps. The AAP President asserts that "a better remedy [than federal intervention] . . . is the establishment in each hospital of an internal review procedure whenever the decision to forego life-sustaining therapy is being considered." Letter from James E. Strain, MD, Pres., AAP, published in *Treatment of Critically Ill Newborns*, 72 *PEDIATRICS* 565 (1983).

240. See Shapiro, *supra* note 234, at 151-52.

241. Professor Smith favors ethics committees, but only as advisors leaving the decision to the parents. See Smith, *supra* note 47, at 718.

242. See B. SALES, D. POWELL & R. VANDRUZIND, *DISABLED PERSONS AND THE LAW* 90 (1982).

this topic and because of the clear inadequacies" in some of those laws, a model statute for emergency medical care and treatment for infants was developed.<sup>243</sup> The Emergency Care statute "adopts the philosophy that life-preserving care and treatment should be provided on a nondiscriminatory basis to all infants regardless of present or potential disability, and explicitly rejects the quality of life and economic hardship rationales that have been advanced in favor of non-treatment."<sup>244</sup> The Department of Health and Human Services also recently proposed a model Child Protection Act,<sup>245</sup> which addresses a wide range of possible harms. The Act "seeks to establish an effective state and local system for child protection by providing those procedures necessary to safeguard the well-being and development of endangered children. . . ."<sup>246</sup>

It is noteworthy that each proposal recognizes the child's family. The Child Protection Act generally expresses an intent to "preserve and stabilize family life, whenever appropriate."<sup>247</sup> The Emergency Care statute further develops that goal, providing financial assistance and family counseling (mandatory only after other means have failed). This statute attempts to maintain the integrity of the family unit, rather than to usurp the traditional parental position. Only in one instance—when failure to provide treatment will endanger the child's life—may treatment be provided without parental approval, and then "only to the extent necessary to assure that the infant's life is preserved."<sup>248</sup>

The real test of these model statutes lies in their effectiveness when applied to the nontreatment case. The Child Protection proposal is broader in scope, and only generally prohibits the failure to provide "food, clothing or shelter necessary for the child's health or safety" and "any medical or nonmedical remedial health care permitted or authorized under state law."<sup>249</sup> Unfortunately, the Act may not provide any more definite guidelines than present neglect and abuse law, and may thus prove to be equally inadequate in light of existing interpretation and enforcement difficulties.<sup>250</sup>

In contrast, the Infant Emergency Care statute deals carefully with defective newborn treatment. Not only does this model make a strong and specific commitment to ease family burdens, it also identifies which children are definitely within its protective

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243. *Id.*

244. *Id.* at 91.

245. See PRESIDENT'S COMM'N REP., *supra* note 4, at 478.

246. *Id.*

247. *Id.*

248. B. SALES, D. POWELL & R. VANDRUZIND, *supra* note 242, at 91.

249. See PRESIDENT'S COMM'N REP., *supra* note 4, at 479.

250. See *supra* notes 103-22 and accompanying text.



realm.<sup>251</sup> Like the new federal regulations,<sup>252</sup> the statute addresses only the infant care problem, and thoroughly defines its goals in the statutory language and supplemental comments. Finally, the statute provides that "[a]ny physician who knowingly fails to provide necessary medical care and treatment to an infant" (as defined in the statute) may have his license revoked and be subject to criminal liability.<sup>253</sup> Parents who fail to comply with a court order for treatment issued pursuant to the statute will be held in contempt of court.<sup>254</sup>

### C. The Role of the Court

While the debate continues with respect to what sorts of medical, ethical or legislative solutions are appropriate, the courts are, at least for the time being, forced to play an active role in the non-treatment controversy. Sometimes, the role is played reluctantly, indeed:

[C]are by societal standards is the responsibility of the physician. The morality and conscience of our society places this responsibility in the hands of the physician. What justification is there to remove it from the control of the medical profession and place it in the hands of the court?<sup>255</sup>

The justification, of course, is that our society may be unwilling to surrender completely its "morality and conscience" to the control of the medical profession. If the law articulates American conscience, it seems entirely appropriate to place a judicial check on certain individual judgments.

One court took a "dim view" of any shift in ultimate decision-making away from the judiciary, favoring court intervention over reliance on ethics committees and doctor-parent isolation.<sup>256</sup> The court was not a "gratuitous encroachment" on the medical field, but the body responsible for addressing the life or death question of nontreatment.<sup>257</sup> The court's duty was to "detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created."<sup>258</sup>

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251. The model statute protects the "developmentally disabled," which envisions covering "all conditions suggestive of later retardation" including Down's Syndrome, spina bifida, and brain disorders. See B. SALES, D. POWELL & R. VANDRUZIND, *supra* note 242 at 93.

252. See *supra* notes 152-72 and accompanying text.

253. B. SALES, D. POWELL & R. VANDRUZIND, *supra* note 242, at 97.

254. *Id.* at 98. For further consideration of the policy of legislative alternatives, see Ellis, *supra* note 46, at 417-23.

255. *In re Quinlan*, 70 N.J. 10, 44, 355 A.2d 647, 665 (1976) (quoting *In re Quinlan*, 137 N.J. Super. 227, 229, 348 A.2d 801, 818 (Ch. Div. 1975)).

256. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 758, 370 N.E.2d 417, 434 (1977).

257. *Id.* at 759, 370 N.E.2d at 435.

258. *Id.*

Admirable as this vision may be, experience teaches that unworkable standards and broad interpretations can lead to bad judgments as well as good ones. This is graphically illustrated by the doctrines, analyses, conclusions, and final result in two non-treatment cases involving practically the same facts.

*Superintendent of Belchertown State School v. Saikewicz*,<sup>259</sup> for example, determined the fate of a profoundly retarded, institutionalized man with leukemia. Due to the severity of retardation,<sup>260</sup> Saikewicz could not understand the nature of chemotherapy, including its painful side-effects. Despite the fact that most leukemia victims choose to withstand the side-effects and undergo chemotherapy, the court allowed treatment to be withheld under a substituted judgment analysis. Although the court found his privacy interest in refusing treatment<sup>261</sup> greater in this instance than the state's interest in preserving life, it attempted to personalize the manner in which it arrived at that decision.<sup>262</sup> The court expressly refused to take the prospective quality of life into consideration even though Saikewicz's life expectancy was little more than a year,<sup>263</sup> and focused instead on "the incompetent person's actual interests and preferences."<sup>264</sup>

Of course, Saikewicz's actual desires simply could not be determined, but the court maintained that the standard for substituted judgment should primarily be a subjective one.<sup>265</sup> The person charged with the responsibility of consent may be forced "to rely to a greater degree on objective criteria, such as the supposed inability of profoundly retarded persons to conceptualize or fear death."<sup>266</sup> Nevertheless, the court emphasized that "the effort to bring substituted judgment into step with the values and desires of the affected individual must not, and need not, be abandoned."<sup>267</sup>

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259. 373 Mass. 728, 370 N.E.2d 417 (1977).

260. The man had a mental age of two years, eight months. *Id.* at 731, 370 N.E.2d at 420.

261. Apparently, the court was following *Quinlan*. See *In re Quinlan*, 70 N.J. 10, 44, 355 A.2d 647, 663-64 (1976).

262. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 759, 370 N.E.2d 417, 431 (1977).

263. *Cf. In re Cicero*, 101 Misc. 2d 699, 41 N.Y.S.2d 965 (Sup. Ct. 1979).

264. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 759, 370 N.E.2d 417, 431 (1977).

265. This standard may be better than quality of life or child's best interests assessments, since it attempts to be as subjective as possible from the standpoint of the person for whom treatment is considered.

266. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 759, 370 N.E.2d 417, 430 (1977).

267. *Id.* at 759, 370 N.E.2d at 430-31. See *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969) (a kidney transplant from an incompetent to his brother would be in the incompetent's best interests, since he was psychologically dependent on his otherwise doomed brother).

While it may be impossible to confer any sense of value or desire on a newborn baby, *Saikewicz* may at least indicate attempts to adhere to as subjective a standard as possible and to avoid the outside considerations of family and finance that hamper defective newborn treatment decisions.<sup>268</sup>

*In re Storar*<sup>269</sup> involved much the same factual situation as *Saikewicz*, but eventually arrived at a different result.<sup>270</sup> *Storar* addressed the question of treatment of a profoundly retarded, institutionalized, older man whose mother wished to discontinue the necessary blood transfusions her son received as treatment for terminal cancer. The man's life expectancy was only a few months, he was losing a great deal of blood, and he required a sedative to receive the often painful and intrusive treatment, the purpose of which he could not comprehend.<sup>271</sup> The lower court, following a right of privacy argument,<sup>272</sup> approved withdrawing treatment, and *Storar* died of the cancer sometime thereafter. The appeals court reviewed the propriety of the decision, and reversed, clearly rejecting the substituted judgment doctrine as a workable standard in such cases.<sup>273</sup>

The *Storar* situation may be further contrasted with that in *Eichner v. Dillon*.<sup>274</sup> *Eichner* involved an elderly, comatose cancer victim near death who had (in the past and while competent) clearly expressed a desire not to have his life prolonged, should he be unable to make his own treatment decisions.<sup>275</sup> There was no proof that *Storar* had expressed such a desire. *Storar* had been mentally incompetent all of his life,<sup>276</sup> and thus completely incapable of making a reasoned judgment about medical treatment.

[I]t is unrealistic to attempt to determine whether he would want to continue potentially life-prolonging treatment if he were competent. . . .

[T]hat would be similar to asking whether 'if it snowed all summer would

268. The court may not have needed the substituted judgment doctrine to decide *Saikewicz*. Since the patient had a terminal illness and only a short time to live, the analysis might just as easily been one of balancing risk of harm against substantial benefit. See *supra* notes 48-56 and accompanying text.

269. 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981).

270. One may question whether the *Saikewicz* result (upholding nontreatment), so deliberately a substituted judgment conclusion, was preferable to the *Storar* decision (reversing nontreatment decision), which expressly rejected substituted judgment.

271. *In re Storar*, 52 N.Y.2d 363, 375, 420 N.E.2d 64, 69, 438 N.Y.S.2d 266, 271-72 (1981).

272. *In re Storar*, 106 Misc. 2d 880, 433 N.Y.S.2d 388 (Sup. Ct. 1980).

273. *In re Storar*, 52 N.Y.2d 363, 381-82, 420 N.E.2d 64, 73, 438 N.Y.S.2d 266, 275 (1981).

274. 73 A.D.2d 431, 467, 426 N.Y.S.2d 517, 544 (Sup. Ct. 1980).

275. *Id.* See also *Satz v. Perlmutter*, 362 So. 2d 160, 164 (Fla. App. 1978), *approved*, 379 So. 2d 359 (Fla. 1980) (dealing with the right of a competent adult to refuse treatment).

276. In fact, he had been institutionalized since age five. *In re Storar*, 52 N.Y.2d 363, 373, 420 N.E.2d 64, 68, 438 N.Y.S.2d 266, 270 (1981).

it then be winter?' Mentally John Storar was an infant and that is the only realistic way to assess his rights. . . .<sup>277</sup>

The *Storar* case suggests some clear parallels to *Baby Doe*:

[T]he transfusions were analogous to food—they would not cure the cancer, but they could eliminate the risk of death from another treatable cause. Of course, John Storar did not like them, as might be expected of one with an infant's mentality. But . . . the transfusions did not involve excessive pain and . . . without them his mental and physical abilities would not be maintained at the usual level. With the transfusions, . . . he was essentially the same as before. . . . A court should not in the circumstances of this case allow an incompetent patient to bleed to death because someone, even . . . a parent, . . . feels that this is best for one with an incurable disease.<sup>278</sup>

The *Storar* court relied on the "ordinariness" of blood transfusion treatment,<sup>279</sup> as contrasted with any extraordinary care of an heroic nature.<sup>280</sup> Clearly, a "Baby Doe" incompetent should not be allowed to starve to death for want of ordinary surgical treatment—treatment that certainly would have been provided to a non-retarded baby. It is simply immaterial that doctors could not predict the severity of Baby Doe's mental retardation. John Storar was profoundly retarded, and suffered the further complication of

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277. *Id.* at 380, 420 N.E.2d at 72-73, 438 N.Y.S.2d at 275.

278. *Id.* at 381-82, 420 N.E.2d at 73, 438 N.Y.S.2d at 275-76.

279. *Id.* at 381, 420 N.E.2d at 73, 438 N.Y.S.2d at 275.

280. There has been an attempt to "classify" nontreatment situations, according to the degree of medical treatment and attention the child requires. "Ordinary" care, it is argued, should be employed to save the defective newborn. But when the means necessary to sustain life become "extraordinary", that is, they involve substantial risk to the patient, or grave burdens to another, they are no longer required. As with many nontreatment labels, the "extraordinary" rubric is relative with respect to the benefit conveyed to the child, the severity of the disability, the quality of life prognosis, and finally, perhaps, with respect to the competing interests involved. See Longino, *supra* note 2, at 398. One author asserts that "[f]ew persons would argue that 'extraordinary' care must be provided a defective newborn, or indeed, to any person. The difficult question, however, is to distinguish 'ordinary' from 'extraordinary' care." Robertson, *supra* note 6, at 213 n.1. Certainly, the Catholic Church has taken the position that extraordinary care is never required. See Paris, *Terminating Treatment for Newborns: A Theological Perspective*, in LAW, MEDICINE & HEALTH CARE 120 (1982).

Another classification system attempts to determine which treatments are medically feasible and which are not, and thus, the focus is largely one of medical evaluation: "A treatment is 'infeasible' if it cannot benefit the infant—that is, if the treatment inevitably will prove futile once administered or will cause the infant's condition to deteriorate." Note, *supra* note 63 at 623. This standard may avoid certain elements such as quality of life, child's best interests, and substituted judgment—all of which are arguably too open to interpretation—in favor of a more rigid standard which allows much less discretion. It is suggested that a child's treatment is medically infeasible if death even with "the most advanced treatment" will occur within the first year of life, or if the cognitive brain function is absent. *Id.* at 624.

a painful terminal disease. Yet the court would not approve withholding him lifesaving treatment.<sup>281</sup>

Court involvement, as it is now, suggests not only problems in practice, but problems in practicality. Heavy reliance on judicial determinations may flood the courts with unnecessary litigation.<sup>282</sup> Even without this, the court system may simply be too cumbersome and slow-moving to handle nontreatment questions with efficacy.<sup>283</sup> Such practicalities aside, the fictions employed by the courts—those of substituted judgment, quality of life, and child's best interests—may ultimately be viewed as judicial nonsense:

The root of the problem lies in an underlying Orwellian assumption that a court using substituted judgment is positioned—like Big Brother—to know what is best for the dying patient. In my view such is practical, legal and moral nonsense. It is practical nonsense because Judges have no extraordinary insight enabling them to measure the "quality of life". . . . It is legal nonsense because in our "rights-oriented" modern jurisprudence, all rights begin with the human, qua human. To deprive a human of life, no matter how burdened it may be, is to deny that person of any and all rights. Such ultimate deprivation of rights makes a mockery of the lesser rights so zealously safeguarded. It is moral nonsense because to judicially order treatment terminated is antithetical to the moral precepts which underlie the common law. Courts should refrain from the temptation to be judicially active in this type of case involving such momentous moral issues.<sup>284</sup>

#### IV. CONCLUSION

Perhaps courts will never completely escape the pressure to adjudicate morality. For the nontreatment issue, they are ill-equipped to do so, since until quite recently the guidelines were thin and elastic. Further, the tools with which the court fashions a moral answer are logical ones. Precedents become premises, and logical derivations from judicial precedents do not always lead to moral conclusions. The right to privacy is a fundamental, morally based, constitutional derivative—and a good one. But when Baby Doe's life became subservient to his parents' right to privacy, that notion reached the limits of its logic, and went beyond the limits of its morality.

With the advent of ambitious federal regulation, the public's

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281. The notable absence of any medically recommended choice to withdraw the transfusion treatment may have affected the *Storar* decision.

282. Brant, *Last Rights: An Analysis of Refusal and Withholding of Treatment Cases*, 46 MO. L. REV. 337, 352 (1981).

283. It has been asserted that "when physicians want an answer, they want it in 10 minutes. When lawyers produce an answer, they congratulate themselves for producing it in 10 days." PRESIDENT'S COMM'N REP., *supra* note 4, at 225 n.94 (quoting testimony).

284. *In re Storar*, 78 A.D.2d 1013, 1013, 434 N.Y.S.2d 46, 47 (1980) (Cardamone, J., dissenting).

duty to complete the nontreatment inquiry has become compelling. Whether we choose to leave the parents to their privacy, or speak as one social child advocate, we must undertake the responsibility with understanding, and be clear about it. Should we decide to support private decisionmaking, we cannot later let it matter that one baby dies while his brothers are saved. Condemning that individual judgment is cruel hypocrisy once we have washed our hands of the larger issue.

Public concern and national debate suggest more thorough legislation is in order. Without stronger state law to protect weak life and to support suffering parents our society risks a little ethical self-destruction. For not only will our inaction affect the lives of handicapped citizens, it may impact upon healthy society, as well. We may spawn a newer, less tolerant, less willing society, neither tempered with the realness of pain nor brought up with the same capacity for compassion.<sup>285</sup> Despite all the medical advances, then, we may never fully realize our power to conquer sickness and disability if we simply refuse to tolerate it.

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285. And perhaps that is where a pure love motivation theory runs dry. See, e.g., Smith, *supra* note 47 at 734-35.