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## Establishing Decisionmaking Standards for Medical Treatment to Protect the Civil Rights of Handicapped Newborns

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# ESTABLISHING DECISIONMAKING STANDARDS FOR MEDICAL TREATMENT TO PROTECT THE CIVIL RIGHTS OF HANDICAPPED NEWBORNS

## I. INTRODUCTION

The prospects for improving the civil rights of the nation's handicapped appeared good during the 1970's, especially in the areas of employment, education, transportation, and health care. This decade was marked by extensive federal legislation and litigation that mandated and funded progressive rehabilitation programs. These programs helped handicapped persons to maintain a steady integration into the social and economic mainstream of society.<sup>1</sup>

Ironically, during this same period, a discriminatory practice against handicapped newborn babies was being quietly advanced in the nation's hospital nurseries.<sup>2</sup> Some handicapped newborns were being denied lifesaving medical care, not because surgery or other medical intervention was useless

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1. *Lloyd v. Regional Transportation Authority*, 548 F.2d 1277 (7th Cir. 1977) (ruling that Section 504 of the Rehabilitation Act of 1973 establishes affirmative rights for qualified handicapped citizens in programs or activities receiving federal financial assistance and a private cause of action can be implied to vindicate those rights); *Michigan Association for Retarded Citizens v. Smith*, 475 F. Supp. 990 (E.D. Mich. 1979), *aff'd*, 657 F.2d 102 (6th Cir. 1981) (case seeking to remedy institutional abuses by providing effective family-scale residential services in the community); *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania*, 343 F. Supp. 279 (E.D. Pa. 1972) (first "right to education" case opening a free, appropriate public education to all disabled children); Education of All Handicapped Children Act of 1975, 20 U.S.C. § 1400 (1975); Rehabilitation Act of 1973, 29 U.S.C. § 701 (1973).

2. Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (1973) (two Yale-New Haven pediatricians reported that fourteen percent of the infant deaths in their hospital were caused by or related to withholding treatment. They called for a revision of the law to officially permit this practice); Jonsen, Phibbs, Tooley, & Garland, *Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIATRICS 756 (1975) (report of the Sonoma Valley Conference in California supporting in theory the concept of direct intervention to end the life of a disabled but self-sustaining baby) [hereinafter cited as Jonsen]; Todres, Krane, Howell, & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977) (survey of Massachusetts pediatricians' attitudes relating to medical management of handicapped infants showing that a majority of physicians modify their attitudes in accord with the parents' wishes); Shaw, Randolph, & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (1977) (nationwide survey measuring

or would only prolong dying, but because their parents and physicians believed that the life of a severely handicapped person was not a life worth living.<sup>3</sup>

Secrecy surrounded this practice, and most cases were not brought to the attention of the legal authorities. When they were, prosecutors were reluctant to bring the cases before juries likely to be sympathetic with the parents.<sup>4</sup> Almost overnight, however, the veil of secrecy disappeared, due to the nationwide media attention given to the judicially approved starvation death of a Down's Syndrome infant in Bloomington, Indiana, on April 15, 1982.<sup>5</sup> There, the parents not only refused necessary surgery to allow the child to eat normally, but they also told the hospital to stop intravenous injections of food and water.<sup>6</sup> When the hospital sought a judicial opinion on the legality of nontreatment, the court ruled that the hospital could legally withhold nourishment.<sup>7</sup> The child died six days later from starvation and dehydration.<sup>8</sup>

Reaction against the child's death was widespread, and during the last three years the controversy surrounding the Baby Doe case in Indiana, and an analogous case in New York state, has blossomed into a national debate over the denial of treatment to handicapped newborns.<sup>9</sup> Unfortunately, the two controlling federal cases have failed to adequately clarify the most important issues involved in this complex area of medicine and ethics—the

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the attitude of physicians toward ethical questions surrounding medical treatment for disabled and very sick children).

3. UNITED STATES COMMISSION ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES 35 (1983) (finding by the Commission that handicapped newborn babies were frequently denied life-saving medical care simply because of their handicaps). See Smith, *Triage: Endgame Realities*, 1 J. CONTEMP. HEALTH L. & POL. 143 (1985).

4. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213-44 (1975). For other works on the legal aspects of selective infanticide, see Horan, *Medical Treatment and the Mongoloid Child: Death as a Treatment of Choice*, 27 BAYLOR L. REV. 76 (1975); Comment, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEX. TECH L. REV. 569 (1983).

5. In re Infant Doe, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.*, State of Indiana on Relation of Infant Doe by Guardian by Order of Circuit Court, No. 482 § 139 (Ind. S. Ct. May 27, 1982), No. 482 § 140 (Ind. S. Ct. April 26), *cert. denied*, 464 U.S. 961 (1983).

6. *Id.* at 3.

7. *Id.*

8. Carroll & Andrusko, *Baby Doe's Legacy*, 1985 AMERICA 450, 451.

9. This is partly due to the fact that the media gave the issue so much attention. For an excellent critical review of the media coverage of the Baby Doe cases in Indiana and New York, see Hentoff, *Nat Hentoff on the Babies Doe*, 10 HUM. LIFE REV. 73 (1984); see also *Death in the Nursery*, WNEV-TV (Boston, Mass) (Feb.-Mar. 1983) (local news team explored infanticide in hospitals around the nation and discovered that withholding lifesaving medical care is widespread).

standard for decisionmaking and the identity of the decisionmaker. This comment will propose a method for analyzing the issues by suggesting an appropriate standard for decisionmaking and by identifying the proper decisionmaker.

## II. THE STANDARD OF DECISIONMAKING

Two standards used in determining whether to withhold treatment for handicapped newborns have surfaced in recent years. The courts must eventually decide whether to use the quality-of-life or the sanctity-of-life standard. Proponents of the quality-of-life standard view the less-than-perfect human life as valuable only in relation to other societal interests such as parental wishes or costs of care. Often, the underlying and highly subjective assumption is that a life with a severe handicap is not a life worth living.<sup>10</sup> According to some proponents of this view, a severely handicapped infant is not a legal person; therefore, the state does not have sufficient interest in preserving his life necessary to justify the social and economic burden on the family and society.<sup>11</sup>

Conversely, those who support the sanctity-of-life standard believe that every human life has an intrinsic and absolute value that outweighs all other values. Under this standard, medical care is required unless the patient is in the process of dying or cannot be helped by treatment. Even in this situation, nourishment, pain medication, and supportive care are required.<sup>12</sup>

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10. Gross, Cox, Tatyrek, Pollay, & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983).

11. Robertson, *supra* note 4, at 252-62; Jonsen, *supra* note 2. See generally Horan, *Euthanasia as a Form of Medical Management* in DEATH, DYING AND EUTHANASIA 196 (D. Horan, D. Mall ed. 1980) and Dyck, *Ethical Reflections on Infanticide* in INFANTICIDE AND THE HANDICAPPED NEWBORN 107 (D. Horan & M. Delahoyde ed. 1982) (in this essay on the ethical considerations of infanticide, the author discusses the legal implications of defining the handicapped newborn as a non-person). See generally Brooks, *Ethical Dilemmas in the Treatment of Critically Ill Newborns*, 1 J. CONTEMP. HEALTH L. & POL. 133 (1985).

12. *Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1983: Hearings on S. 1003 Before the Subcomm. on Family and Human Services of the Comm. on Labor and Human Resources*, 98th Cong., 1st Sess. 6-9 (1983) [hereinafter cited as *Child Abuse Act Hearings*] (statement of C. Everett Koop, M.D., Surgeon General of the United States) ("The moral issue here is that no one may judge the quality of life of another, and we must not tolerate the attempts of those who take it upon themselves to do so. Whether a handicapped person's life is worth living or not is not a medical question. The Government's position ought to be seen in the context of its support of the provision of—not the withholding of— treatment for disabled infants"). See also American Academy of Pediatrics *Joint Policy Statement: Principles of Treatment of Disabled Infants*, 73 PEDIATRICS 559 (1984) (signed by the American Academy of Pediatrics, Association for Retarded Citizens, The National Association of Children's Hospitals and Related Institutions, Inc., Spina Bifida Association of America, The Association for Persons with Severe Handicaps, American Association on Mental Deficiency, American Association of University Affiliated Programs for Persons with

This section will present the argument that the quality-of-life standard should be rejected by the courts because it is discriminatory, subjective, and ambiguous. Moreover, it has the potential to lead to active euthanasia. In contrast, the sanctity-of-life standard protects the handicapped newborn's right to life and right to equal medical care. Moreover, it provides clear guidelines allowing the decisionmaker to consider all relevant circumstances necessary to guard against a mechanical decisionmaking process.<sup>13</sup>

#### A. *Variety of Tests but Only Two Standards*

In the current debate over the treatment of handicapped newborns, the tests for decisionmaking can be categorized as being based on one of two standards: either the quality-of-life standard or the sanctity-of-life standard. Using this framework, this Comment will analyze the technical criteria, the cost-benefit, and the substituted judgment tests. This comment will analyze the technical criteria, the cost-benefit, and the best-interests tests. The technical and the cost-benefit tests rely heavily on the quality-of-life standard, while the best-interests test may stress either of the two standards, depending on the interpretation of "best interests."<sup>14</sup>

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Developmental Disabilities, American Coalition of Citizens with Disabilities, Inc., and the National Down's Syndrome Congress) [hereinafter cited as *Principles of Treatment*].

13. There is a difference between cases involving a newborn child with a malformation or some kind of congenital defect (handicapped newborn baby) and one who is of low birthweight and is simply underdeveloped (premature baby). Physicians in neonatology wards make daily, sometimes hourly, decisions whether to stop treatment on premature babies, based on whether, in their best medical judgment, the child is in the process of dying. In such cases, further medical treatments are futile. This is different from a decision to withhold treatment from a handicapped baby just because the child is handicapped and will remain handicapped after the medical treatment. Inevitably, there are times where the two distinctions overlap. For example, if a premature baby is denied treatment, not because treatment is futile, but because the child will survive with a handicap, then that decision is discriminatory. *Hearings on the Protection of Handicapped Newborns, United States Commission on Civil Rights, Original Transcript*, 9-10, 48 (June 12-14, 1985) [hereinafter cited as *Civil Rights Commission Hearings*].

Throughout this paper, "equal medical care" will mean that a handicapped child should receive the same level of care that would be given to a non-handicapped child. In essence, the handicapped child may not be denied care based on the fact that the child will still have the handicap after the treatment.

14. In the most comprehensive book written on the topic of nontreatment of handicapped newborns, author Robert Weir categorizes the different ethical standards of decisionmaking into five categories: 1) treat all non-dying neonates; 2) terminate the lives of selected non-persons; 3) withhold treatment according to parental discretion; 4) withhold treatment according to quality-of-life projections; and 5) withhold treatment judged not in the child's best interest. Although this is an accurate description of the differing views put forth by various ethicists, Weir's system of characterization confuses the issue of choosing the appropriate standard of decisionmaking with the issue of choosing the appropriate decisionmaker. Weir recognizes this problem in his analysis of the different views when he criticizes one ethicist for basing his standard on the principle that "there is no 'right' decision to be made but only

### 1. *Technical-Criteria Test*

In the early 1970's John Lorber, a pediatrician in Sheffield, England, developed a selection test that relies on ostensibly technical criteria to evaluate which spina bifida babies to treat.<sup>15</sup> Although at first glance the test seems to be based purely on medical factors, it is really a value-judgment test based on the quality-of-life standard. In determining the prognosis of severely afflicted newborn babies, Lorber's method initially considers all the medical information available to the doctor. However, the decision process inextricably includes an assessment of the quality of life that handicapped children would have if they received care and lived. Experience exposed the main difficulty associated with Lorber's test; some of the children chosen for nontreatment and death survived unexpectedly, and their handicaps were more severe because they had not received early aggressive medical treatment.<sup>16</sup>

Critics of Lorber's technical-criteria test have made several proposals to achieve a higher predictive value. Some said that the criteria could be modified and improved to insure that fewer severely handicapped children survive in the nontreatment group.<sup>17</sup> Others suggested that active euthanasia should be considered for those who are selected for nontreatment. Since these children are selected to die from nontreatment, the commentators effectively proposed to kill them and shorten their suffering.<sup>18</sup>

### 2. *Cost-Benefit Test*

A second test for deciding whether to treat handicapped newborn babies is

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'right' persons to make it." R. WEIR, *SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS* ch. 6 (1984).

15. Lorber, *Selective Treatment of Myelomeningocele: To Treat or Not to Treat?*, 53 *PEDIATRICS* at 307-08 (1974); Veatch, *The Technical Criteria Fallacy*, 7 *HASTINGS CENTER REP.*, Aug. 1977, at 15. See generally Smith, *Defective Newborns and Government Intermeddling*, 25 *MED. SCI. AND L.* 44 (1985).

16. Reid, *Spina Bifida: The Fate of the Untreated*, 7 *HASTINGS CENTER REP.*, Aug. 1977, at 16.

17. Veatch, *supra* note 15.

18. Reid, *supra* note 16, at 19 (Reid, as a rationale for his view, argues that just as the medical profession's attitude toward abortion has changed, so too "[i]t is perfectly conceivable that the profession's declared attitude to euthanasia will equally reverse itself." He contends that "[h]uman values are not immutable" and that they must change to keep pace with changing medical values). See also Gallo, *Spina Bifida: The State of the Art of Medical Management*, 14 *HASTINGS CENTER REP.*, Feb. 1984, at 10; but see *Child Abuse Act Hearings*, *supra* note 12, at 65 (David G. McLone, M.D., Ph.D., Associate Professor of Surgery, Northwestern University Medical School, and Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, argues that it is morally and ethically correct to treat all children born with myelomeningocele [spina bifida] and that no valid criteria exist for the selection of infants for nontreatment.)

the cost-benefit analysis.<sup>19</sup> This test assesses the negative and positive economic consequences of a specific medical-care policy by assigning specific numerical values both to the benefits likely to result from medical intervention and to its costs. A quantitative comparison between the predicted costs and the predicted outcomes allegedly indicates which health-care interventions make the most efficient use of available resources. The cost-benefit analysis essentially reduces all factors to a common monetary system of measurement, resulting in mechanical decisionmaking as to whether the handicapped newborn may live, or must die.

Commentators have noted several flaws in this method when it is applied to medical care for human beings. For example, Dr. Jerry Avorn, M.D., at the Harvard Medical School, pointed out that the method contains a hidden set of value assumptions that virtually guarantees discrimination or a bias in developing the supposedly objective data.<sup>20</sup> The fallacy of the method, he noted, was that it tried to evaluate human capital based on the principle that "[d]eath is a great way to cut down on expenses." He argued that people live in a society, not an economy, and there is no way to measure pain and suffering, compassion, individual rights, and equity quantitatively.<sup>21</sup> This quality-of-life test places most of its emphasis on the economic burden of health care and concerns of justice and equity are not considered.<sup>22</sup>

### 3. *The Best-interests Test*

The third test for deciding whether to treat handicapped newborn babies

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19. Avorn, *Benefit and Cost Analysis in Geriatric Care: Turning Age Discrimination into Health Policy*, 310 NEW ENG. J. MED. 1294 (1984).

20. *Id.* at 1295.

21. *Id.* at 1297.

22. *Id.* at 1298 (Avorn also states that the approach is "subject to another, unrelated criticism: it is often bad science.").

Another study criticized the use of the cost-benefit test to evaluate neonatal intensive care as flawed because it relied on projections of future costs and earnings that are to a certain extent speculative, such as the costs of long-term medical problems and special educational programs and services. The benefit measured in this study was the average lifetime earnings per survivor. Since it assumed that severely handicapped infants would be unemployable, there were no cost benefits to the care of handicapped infants. The authors admitted that one of the drawbacks of the study was that it failed to measure intangible benefits such as the joy of parents and relatives over the survival of their child. Walker, Feldman, Vohr, & Oh, *Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less than 1,000 Grams at Birth*, 74 PEDIATRICS 20, 24 (1984). See also Johnson, *Life, Death, and the Dollar Sign: Medical Ethics and Cost Containment*, 252 J.A.M.A. 223 (July 1984). (Johnson warns against the use of cost-benefit analysis and states, "What patient groups will be the first victims of this burden of cost containment? The same groups that are now most vulnerable— the handicapped, the retarded, the chronically ill, and the poor. The humanity of our profession is imperiled by the cost cutter's knife.").

is the "best-interests" test in cases that involve treatment decisions for incompetent patients.<sup>23</sup> The theory underlying this test is that since competent patients have the right to refuse treatment, this right should also extend to incompetent patients. However, since incompetent patients cannot formulate or present their views, the court appoints a guardian who makes the decision for the patient. This guardian is required to consider the best interests of the patient, who presumably would make the same decision if he were suddenly lucid.<sup>24</sup>

The best-interests test can be based on either the quality-of-life standard or the sanctity-of-life standard depending on the interpretation of the term "best interests."<sup>25</sup> Proponents who favor the use of a sanctity-of-life standard have argued that the patient is best served by starting or continuing medical treatment unless either no life-saving or life-prolonging treatment exists, or the treatment would only cause a brief and uncertain delay in the natural death process. Furthermore, those proposing this standard reject

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23. The best-interests test for decisionmaking for incapacitated patients is very similar to the substituted judgment test. Under the substituted judgment test, the decision made for the incompetent person should be the very same decision the person would make if he were competent to do so even if the decision is irrational. However, there are some limits to the decision that can be made by the surrogate that are imposed by law or public policy. Therefore, even if the incompetent is believed to favor certain types of human research, the surrogate may not enroll the patient in such research. Also, because there is a public policy against suicide, the surrogate could not choose such a course of action. In *Brophy v. New England Sinai Hosp.*, No. 85E0009-G1 (Mass. Probate & Family Ct., Norfolk Div., Oct. 21, 1985) the judge found that Brophy's (the incompetent's) substituted judgment would be to decline the provision of food and water, and thereby terminate his life. *Id.* at 30. However, since the state has a compelling interest in preserving human life, the court said it is "ethically inappropriate to cause the preventable death of Brophy by the deliberate denial of food and water, which can be provided to him in a noninvasive, nonintrusive manner which causes no pain and suffering, irrespective of the substituted judgment of the patient." *Id.* at 42.

The best-interests test differs from the substituted judgment test in that it requires the decisionmaker to decide from an objective standpoint what will promote a patient's good, irrespective of the incompetent's actual or supposed preferences. The best-interests test is based on a "reasonableness" standard that is inherently cautious. It is presumed that the incompetent will make a reasonable decision. For an excellent legal analysis of these two standards, see Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 *ISSUES IN L. & MED.* 131 (1985).

24. Horan & Grant, *Prolonging Life and Withdrawing Treatment: Legal Issues*, 50 *LINACRE Q.* 153, 155-56 (1983). *But see* Smith, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 *NEB. L. REV.* 709 (1984) (author suggests a construct for decisionmaking that balances the sanctity-of-life and quality-of-life standards and includes integration of both the cost-benefit and technical-criteria tests).

25. Shapiro, *Medical Treatment of Defective Newborns: An Answer to the 'Baby Doe' Dilemma*, 20 *HARV. J. ON LEGIS.* 137 (1983). (Shapiro proposes a model statute to guide decisionmaking in cases requiring substituted judgment and adopts a sanctity-of-life standard). *See generally* Kuzma, *The Legislative Response to Infant Doe*, 59 *IND. L.J.* 377 (1984) (analysis of federal regulations and state legislative responses to Indiana Baby Doe case and examination of alternative state legislative solutions).



consideration of social, economic, or familial factors for fear of opening the door to legalized euthanasia.<sup>26</sup> Indeed, several ethicists have observed that there is no moral difference between killing handicapped newborn babies by withholding proper medical treatment and killing them through direct action.<sup>27</sup>

Still others have argued for utilizing the quality-of-life standard as a basis for the best-interests test. Under circumstances when surgery would prolong the life of a severely retarded, epileptic, or paralyzed person, who would experience a life of pain and severe disability, commentators have asserted that treatment would not be in the patient's "best interest."<sup>28</sup> This standard operates under the assumption that a life with a severe handicap is a life not worth living. According to the disability rights groups, such as the Association for Retarded Citizens and the Spina Bifida Association, this assumption is a discriminatory myth. These organizations proffer that handicapped persons, even those with severe handicaps such as spina bifida, may live happy and productive lives. They further note that accurately determining a handicapped newborn baby's prognosis is very difficult and uncertain.<sup>29</sup>

This author suggests that the best-interests test, based on the sanctity-of-life standard, should be adopted as the sole basis of decisionmaking in this area. Only this standard gives primary value to the interests of the child, is based on *bona fide* medical considerations, and does not make discriminatory judgments about the quality of a handicapped person's life.

The other dominant tests for decisionmaking suffer from fatal flaws. First, the technical-criteria test is deficient because experience has demonstrated that current medical knowledge is insufficient to determine a realistic prognosis for a newborn baby. Also, this standard is based on speculative and subjective judgments about the quality of life handicapped children lead when they survive. Moreover, this standard promotes active euthanasia. Second, the cost-benefit test unsuccessfully tries to apply mathematical and economic theory mechanistically to a very human situation. Some factors cannot be quantified, such as human emotions and cultural values about the transcendent significance of human life. Finally, the best-interests test based on the quality-of-life ethic suffers from unhelpful ambiguity and dangerous subjectivity, in that it incorporates a broad array of irrelevant factors into

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26. Horan & Grant, *supra* note 24, at 157-59. See also Weir, *supra* note 14, at 176 (a philosopher maintains that voluntary euthanasia is acceptable when it is decided that for the infant's best interests death is preferable to life).

27. Weir, *supra* note 14, at 152.

28. Arras, *Toward an Ethic of Ambiguity*, 14 HASTINGS CENTER REP., Apr. 1984, at 25.

29. Memorandum of Amici at 4-5, *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983).

the medical decisionmaking process, such as concerns of society and family. It also relies on the myth that a life with a handicap is not worth living. Unfortunately, this last standard seems to be the one that the federal courts prefer.

### *B. Federal Courts Lean Toward Quality-of-Life Standard*

During the last three years, efforts to establish the sanctity-of-life standard by using already existing civil rights legislation have been thwarted by the federal courts. A review of the controlling cases demonstrates how the courts' misunderstanding of some critical issues has resulted in *dicta* expressing a preference for the quality-of-life standard.

#### *1. Background of the Controlling Cases*

The public uproar caused by the starvation death of Baby Doe in Indiana prompted President Ronald Reagan to instruct the Secretary of the Department of Health and Human Services (HHS) on April 30, 1982, to issue a notice to health care providers that Section 504 of the Rehabilitation Act of 1973 forbids recipients of federal funds from withholding from handicapped citizens any benefit or health care that would be provided to persons without handicaps.<sup>30</sup> Ten months after sending the notice to approximately 7,000 hospitals, HHS issued interim regulations on March 7, 1983, to explain the procedures and guidelines relating to the health care of handicapped newborn babies under Section 504.

These regulations were promptly challenged in federal court by a coalition of medical organizations in *American Academy of Pediatrics v. Heckler*.<sup>31</sup> On April 14, 1983, Judge Gesell for the federal District Court in the District of Columbia ruled in *American Academy of Pediatrics* that the regulations were invalid as arbitrary and capricious, and that they violated statutory procedural requirements.<sup>32</sup> Accordingly, in July, 1983, HHS issued revised regulations.

Pursuant to the new rules, the Justice Department intervened in a suspected case of nontreatment in New York on November 2, 1983.<sup>33</sup> In this

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30. 49 Fed. Reg. 1622-23 (1984) (to be codified at 45 C.F.R. § 84). Section 504 is the civil rights statute for handicapped citizens, and it provides that "No otherwise qualified handicapped individual in the United States, . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . ." Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (1973).

31. 561 F. Supp. 395 (D.D.C. 1983).

32. *Id.* at 403.

33. *United States v. University Hospital*, 557 F. Supp. 607 (E.D.N.Y. 1983).

case, a baby girl (Baby Jane Doe) born on October 11, 1983, suffered from several medical conditions. The most serious were spina bifida, microcephaly (an abnormally small head) and hydrocephalus (an accumulation of fluid on the brain). The first pediatric neurosurgeon to examine her recommended immediate surgery to close the spinal opening and implant a shunt to relieve fluid pressure in the cranial cavity. After consulting with other physicians, the parents decided against surgery and chose instead to provide only nutrition, antibiotics, and a dressing for the baby's exposed spinal sac.<sup>34</sup>

Suspicious that Baby Jane Doe was the victim of discriminatory nontreatment and acting under the authority of Section 504, the Justice Department requested the child's medical records.<sup>35</sup> The hospital repeatedly refused to turn them over, and the government brought suit against the hospital in *United States v. University Hospital* but lost the case in both federal district and appellate courts. The federal regulations were ruled invalid by the Second Circuit on the grounds that they were issued without statutory authority.<sup>36</sup> This decision is presently being reviewed by the United States Supreme Court.<sup>37</sup>

## 2. Analysis of the Courts' Rulings

The courts in *American Academy of Pediatrics* and *University Hospital* did not rule explicitly on the issue of the standard of decisionmaking in medical treatment for handicapped newborn babies; however, both courts revealed their leanings on this crucial matter toward the quality-of-life standard. In *American Academy of Pediatrics*, Judge Gesell criticized the HHS regulations for establishing a standard that looks only to the medical factors without considering parental wishes, home life, and cost.<sup>38</sup> Though he suggested that grounds may exist for promulgating regulatory guidelines for the treatment of handicapped newborn babies, he found no expressed congressional suggestion that Section 504 should be used to monitor the medical treatment of defective newborn infants.<sup>39</sup> Gesell did find the suggestion reasonable that Section 504 prohibits denial of the most basic services, "such as access to medical care, hospital facilities, or food, to a *mildly* handicapped child whose parents *want* him to benefit from those services."<sup>40</sup> Under this stan-

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34. *United States v. University Hospital*, 729 F.2d 144, 146 (2d Cir. 1984).

35. *Id.*

36. *Id.* at 161.

37. *Heckler v. American Hospital Association*, No. 84-1529 (2d Cir. Order, December 27, 1984), *cert. granted*, — U.S. —, 105 S. Ct. 3475 (1985).

38. 561 F. Supp. at 400.

39. *Id.* at 401.

40. *Id.* at 402 (emphasis added).

dard, even *mildly* handicapped infants would not qualify for treatment if the parents did not *want* their child to benefit from medical services. The problem with this standard is that it is based on the desires of the parents rather than the interests of the infant. Moreover, Gesell confused the issue of which standard should be used in decisionmaking with the issue of who should be the decisionmaker.

The majority in *University Hospital* relied heavily on the *American Academy of Pediatrics* decision and refused to acknowledge any distinction between a discriminatory decision and a medical decision.<sup>41</sup> The court stated that the government had too simplistic a view of the medical decisionmaking process. They found it too difficult to say definitively when the decision to withhold treatment could be discriminatory, especially when the handicap was either related to, or was the condition, to be treated.<sup>42</sup> The court rejected the government's argument that a discriminatory and a *bona fide* medical decision could be distinguished by looking at the motive for non-treatment. The government's position is that if the lifesaving treatment is withheld because the child would still be handicapped after the treatment, then it is irrelevant whether the treatment is for the handicapping condition, a related condition or an unrelated condition. The decision is discriminatory.<sup>43</sup>

In *University Hospital*, the court's logic would preclude any possible finding that a decision to withhold treatment is discriminatory since the court believed that it cannot distinguish between *bona fide* medical decisions and those based on handicap. This logic leaves little protection for the handicapped infant who needs life-saving surgery if the parents and physicians decide to withhold treatment based on the fact that the child will continue to be handicapped after treatment.

In opposition to the court's preference for the quality-of-life standard in these two cases, the dissent in *University Hospital* agreed with the government's argument that a decision to withhold treatment on the basis of handicap is discriminatory. Judge Winter found that the law can distinguish between a discriminatory decision and a medical decision, and that protec-

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41. It is possible to delineate between a medical and a discriminatory decision. A doctor makes a valid medical decision when based on his medical knowledge and skill, he determines that the treatment will (1) cure or substantially alleviate the medical problem, (2) prolong life for a reasonable length of time, or (3) relieve pain. On the other hand, a doctor makes a discriminatory decision when he utilizes factors outside the purview of his medical expertise. For example, the physician may think that life with a handicap is too burdensome on the patient, the patient's family or to society in general. Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma "Experiment,"* 1 ISSUES IN L. & MED. 20-25 (1985).

42. 729 F.2d. at 156-157.

43. 49 Fed. Reg. 1637 (1984) (to be codified at 45 C.F.R. § 84).

tion is warranted for a child denied medical care on the basis of his handicap.<sup>44</sup> The dissent also stated that while the majority seems to be unable to decide what a *bona fide* medical judgment is, the application of the analogy to race should make it clear:

A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment.<sup>45</sup>

### C. Congressional Support for the Sanctity-of-Life Standard

Both the *American Academy of Pediatrics* and *University Hospital* opinions based their analysis on their finding that congressional intent was not clear about whether Section 504 should include handicapped newborn babies.<sup>46</sup> Since then, Congress has expressed its intent to protect handicapped newborns from invalid nontreatment decisions by enacting amendments to the Child Abuse Prevention and Treatment Act. These amendments define the failure to provide a handicapped infant with medically indicated treatment as a form of child abuse that would be subject to state action.<sup>47</sup> The

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44. 729 F.2d. at 162-63 (Winter, J., dissenting).

45. *Id.* Judge Winter notes that "if that interpretation stands, the handicapped will be deprived of a fairly won political victory and exposed to the possibility of future decisions excluding other services from coverage by Section 504."

For an international comparison, see Smith, *The Plight of the Genetically Handicapped Newborn: A Comparative Analysis*, 9 *HOLDSWORTH L. REV.* 164 (1984); see also Smith, *Defective Newborns and Government Intermeddling*, 25 *MED. SCIENCE & L.* 44 (1985); Smith, *Handicapped Babies and The Law*, *INTERNATIONAL LEGAL PRACTITIONER*, Sept. 1984, at 86.

46. The American Academy of Pediatrics court found that the regulations were invalid on the grounds that they were arbitrary and capricious and violated requirements of the Administrative Procedure Act. The court said that it needed clarification from Congress before it could decide if Section 504 reached handicapped newborn babies. 561 F. Supp. at 403. In *University Hospital*, the court ruled that it was unclear whether Congress intended protection from Section 504 to extend to handicapped newborn babies. 729 F.2d at 161.

47. Child Abuse Prevention and Treatment Act, Pub. L. No. 98-457, tit. 1, § 121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C. § 5101-5103 (Supp. 1985)). [hereinafter cited as *Child Abuse Amendments of 1984*].

The Child Abuse Amendments do not provide civil rights protection to the handicapped newborn and do not provide a mechanism for the federal government to either investigate or take any enforcement action. Paulus, *Supreme Court Asked to Review Application of Rehabilitation Act to Medical Decisions*, 1 *ISSUES IN L. & MED.* 69, 75-76 (1985); *Civil Rights Commission Hearings*, *supra* note 13, at 466-67 (Testimony by Charles Cooper, Deputy Assistant Attorney General, Civil Rights Division, United States Department of Justice) ("I think it is important to keep in mind that the Child Abuse Act . . . does not in any way place any independent federal duty on hospitals or health care services programs . . . [W]ithout 504 there is no duty of nondiscrimination that emanates from federal law anyway on the hospital and health care providers themselves.")

Disability rights organizations want protection for handicapped newborn babies through

standard adopted under this new law is a sanctity-of-life standard, and is supported by all the major disability rights organizations, pro-life groups, and the American Academy of Pediatrics, which had challenged the 504 regulations earlier.<sup>48</sup>

Under the new law, withholding treatment would only be justified if, in the physician's reasonable medical judgment, one of three clearly defined situations existed. First, the infant was chronically and irreversibly comatose. Second, the treatment would only prolong dying, or third, the treatment would not be effective in ameliorating or correcting all of the infant's life-threatening conditions or would be futile in terms of the survival of the infant.<sup>49</sup>

Use of this standard offers the three benefits of clarity, reasonableness, and nondiscrimination. First, the standard is clear because it is based solely on *bona fide* medical criteria. It is reasonable because it allows physicians to consider information within their expertise but prevents them from considering non-medical issues. It is nondiscriminatory because it focuses only on the health interests of the patient and does not permit subjective value judgments to enter into the decisionmaking process.

During the legislative process for this bill, the American Medical Association (A.M.A.) wanted to add wording to the statute that would have allowed withholding of treatment in cases where treatment would be "inhumane and unconscionable" and would result in intense suffering. This wording was rejected by the disability rights organizations because of its vagueness, and Congress chose not to adopt the A.M.A.'s language.<sup>50</sup>

In summary, the courts should follow the lead of Congress, the Reagan administration, the disability rights organizations, and the right-to-life groups by adopting the sanctity-of-life standard, because it is clear, reasonable, and nondiscriminatory. Just as the courts have heeded the counsel of those who faced racial discrimination, they should listen to America's disabled citizens who have consistently sought to destroy the myth that the life of a severely handicapped person is not worth living. As one disabled adult observed at the United States Civil Rights Commission hearing in June, 1985, the main problem for handicapped children is not their disabilities, it

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both federal civil rights statutes and state abuse laws. Representatives of the organizations have testified that if the Supreme Court affirms the Second Circuit opinion, then they will lobby Congress to amend Section 504 to include infants explicitly under the provisions of federal law protecting handicapped individuals. Glasow, *Advocates, Medical Community Clash Over Federal Role in "Baby Doe" Cases*, Nat'l Right to Life News, July 25, 1985, at 5, col. 1.

48. Child Abuse Amendments of 1984, 98 Stat. at 1752 (codified at 42 U.S.C. § 5101-5103 (Supp. 1985)).

49. *Id.*

50. Editorial, *A. Med. News* 4 (Aug. 1984).

is "the prejudice and the discrimination to which they are going to be subjected by the remainder of society."<sup>51</sup>

### III. THE DECISIONMAKER

Once a standard for decisionmaking is established, debate naturally shifts to the issue of who should be the decisionmaker. For example, should the parents of the handicapped child be given the ultimate decisionmaking power? Should the physician, who is more knowledgeable medically, decide? Should a hospital ethics committee have a role? Should the government ever assume the role as the child's advocate?

Parents are supposed to be their child's best advocate, and the law assumes that they will make decisions in their child's best interest.<sup>52</sup> In reality, however, when parents discover that their long-expected infant is born with a handicap, they often experience a period of emotional trauma and become unable to make a dispassionate decision.<sup>53</sup>

During this period, when parents are confronted with the need to make life-and-death decisions regarding the medical care for their child, they naturally rely heavily on their physician's advice. Unfortunately, they often receive inaccurate or biased information.<sup>54</sup> In June, 1985, Dr. C. Everett Koop, Surgeon General of the United States and a world-renowned pediatric surgeon, testified before the United States Civil Rights Commission during hearings on handicapped newborn babies on this crucial issue. In his opinion, too often doctors influence parents to not treat the child because the health professional is either ignorant of the hopeful long-term prognosis for handicapped people or prejudiced against handicapped people.<sup>55</sup>

Later at the civil rights hearings, representatives of several medical organizations rebutted Koop's assertions. They contended that doctors were the best advocates of the handicapped newborn babies' rights.<sup>56</sup> However, personal experiences described by parents of handicapped children who appeared before the Commission undercut that assertion.<sup>57</sup> According to the parents, the physicians had given them inaccurately dim prognoses for both

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51. *Civil Rights Commission Hearings*, *supra* note 13, at 245.

52. PRESIDENT'S COMM. FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 212 (1983) [hereinafter cited as PRESIDENT'S COMMISSION].

53. Kuzma, *supra* note 25, at 382.

54. *Civil Rights Commission Hearings*, *supra* note 13, at 15 (testimony of David McLone, M.D., Chairman of the Division of Pediatric Neurosurgery at Children's Memorial Hospital, Chicago, Illinois).

55. *Id.* at 24.

56. *Id.* at 86-87.

57. *Id.* at 121, 128, 140-41.

their children's immediate chances for survival and long-term ability to attain a normal level of mental and physical existence if they did survive.<sup>58</sup> In fact, one parent was convinced that the children were "at the mercy of the doctors."<sup>59</sup>

The most dramatic recent example where the physicians allegedly gave parents biased and inaccurate information occurred in Oklahoma. As described in an article in the October, 1983, issue of *Pediatrics*, the official journal of the American Academy of Pediatricians, a team of doctors at the Oklahoma Children's Memorial Hospital conducted an experiment using a quality-of-life formula to decide whether or not to treat handicapped newborn children.<sup>60</sup> Over an extended period of time, they used a mathematical formula as the basis for decisions not to treat twenty-four infants with spina bifida.<sup>61</sup> The derivation of this formula is important to understanding how the treatment decisions were made.

In this formula, the "quality of life" [QL] which a child could achieve, equalled the "natural endowment of the child" [NE] multiplied by the sum of two factors, "contributions from home" [H] plus "contributions from society" [S],  $QL = NE \times (H + S)$ .<sup>62</sup> In the article in *Pediatrics*, the authors asserted that the prognosis for babies with identical medical indicators could be quite different depending on contributions from home and society.<sup>63</sup>

After the team of physicians applied the formula and reached a decision not to treat an infant, they met with the parents to present that recommendation. The doctors did not inform the parents about either the criteria or the formula they had used to reach that decision. The parents were only told that the recommendation reflected the doctor's best medical judgment.<sup>64</sup>

Those nontreatment decisions had dramatic and fatal consequences for the infants involved. All twenty-four babies whose parents agreed with the doctor's recommendation for nontreatment died.<sup>65</sup> In *Pediatrics*, the physicians assessed the outcome of this experiment in this manner:

The "untreated survivor" has not been a significant problem in our experience. All 24 babies who have not been treated at all have died at an average of 37 days [after birth]. These data indicate to us that we are able to select babies with a more positive outlook—

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58. *Id.*

59. *Id.* at 142-43.

60. Gross, *supra* note 10.

61. *Id.* at 456.

62. *Id.*

63. *Id.*

64. Gerry, *supra* note 41, at 35.

65. Gross, *supra* note 10, at 452-53.



the only nonsurvivor of 36 babies for whom vigorous treatment was recommended died as a result of a motor vehicle accident.<sup>66</sup>

Following the publication of the article, the Cable News Network (CNN) broadcasted an extensive program with interviews with the parents of the infants involved in the experiment.<sup>67</sup> Many stated that they had no knowledge of the use of the formula, and several expressed anger that the doctors had taken such authority on themselves. Some parents of children who had been treated expressed relief that their children had not been selected to die.<sup>68</sup>

The Oklahoma experiment vividly illustrated the failure of doctors to communicate vitally important information to parents. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research came to similar conclusions regarding the flaws in the communication process in a report released in March, 1983.<sup>69</sup> The Commission found that the medical providers have not done enough to provide parents with appropriate information, and that physicians and parents often base life-and-death decisions on invalid preconceptions they have about the quality of life of handicapped individuals.<sup>70</sup> The Commission recommended that "professional associations and health care institutions should help ensure that the best information is available and is used when decisions about life-sustaining treatment are made."<sup>71</sup> In this connection, a specialist in the care of children with spina bifida has noted that, in his extensive experience, fully informed parents have never refused treatment for their child.<sup>72</sup>

Lack of accurate information is not the only reason a parent may not always serve as the best decisionmaker. If the parent's choice of action is based on the quality-of-life standard, then the decision may violate the child's right to life and right to medical care, equivalent to that provided to non-handicapped children. At a time when the parents are emotionally distraught and exhausted, they may only see that the child will be both a financial and psychological burden on the family.<sup>73</sup> Thus, they may base their

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66. *Id.* at 455.

67. Sherwood, *Who Lives, Who Dies?* —Part 1, Cable News Network Documentary, Radio TV Monitoring Service Transcript (Feb. 21, 1984).

68. *Id.* On October 3, 1985, a class action suit was filed on behalf of infants with disabilities and their parents alleging that the Oklahoma infants had been discriminatorily denied beneficial medical treatment. *Johnson v. Sullivan*, No. Civ. 85-2434A (W.D. Okla.).

69. PRESIDENT'S COMMISSION, *supra* note 52, at 209-10.

70. *Id.*

71. *Id.* at 224.

72. *Civil Rights Commission Hearings*, *supra* note 13, at 40.

73. Kuzma, *supra* note 25, at 382.

decision not to treat on their own and their family's best interests rather than those of their infant.

Sometimes, when the parents decide against treatment, the doctor may disagree with them and seek a judicial order for treatment.<sup>74</sup> The law is clear that although parents have the right to control the treatment, upbringing, and welfare of their children, this right is not absolute.<sup>75</sup> When the child's welfare is at stake, the state may intervene.<sup>76</sup> State authority to intervene can derive from either state child-abuse or child-neglect legislation or the common law doctrine of *parens patriae*.<sup>77</sup> Under this doctrine, while it is presumed that the parents will provide their children with the necessities of life, their failure to do so allows the state to intervene.<sup>78</sup> The state's interest in protecting children is indeed compelling, for it has been found to prevail over claims of religious freedom when parents refuse to consent to blood transfusions for their children on the ground that the practice violates their religion.<sup>79</sup>

What happens, however, if both the doctor and the parents decide to withhold treatment using a decision process based on the quality-of-life standard? Obviously, the child is left without an advocate unless the state may intercede. One of the principal purposes of the section 504 regulations was to provide a mechanism for the federal government to investigate and provide protection in such a case.<sup>80</sup> According to the regulations, anyone could report a suspected case of discriminatory nontreatment to HHS *via* a telephone hotline. The Department then could seek medical records to determine whether the child was being denied equal and adequate medical care.<sup>81</sup> One of the major criticisms of the 504 regulations was that they allowed the government to intervene in the decisions that many felt should be left solely

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74. In Application of Cicero, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979).

75. United States v. Orito, 413 U.S. 139, 142 (1973); Roe v. Wade, 410 U.S. 113, 152-53 (1973); Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925); Meyer v. Nebraska, 262 U.S. 390, 399 (1923).

76. In re Phillip Becker, 92 Cal. App. 3d 796, 802, 156 Cal. Rptr. 48, 51 (1979).

77. *Id.* at 51.

78. *Id.*

79. Jehovah's Witnesses in Washington v. King County Hosp., 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968). See also Mercy Hosp., Inc. v. Jackson, 62 Md. App. —, 489 A. 2d 1130 (1985) (The court ruled that a competent, conscious, rational, and pregnant adult may refuse, for religious reasons, to submit to blood transfusions during a caesarean section if the surgery does not endanger the life of the child); Crouse Irving Memorial Hosp. Inc. v. Paddock, 127 Misc. 2d 101, 485 N.Y.S.2d 443 (N.Y. Sup. Ct. 1985) (New York Court ordered the hospital to give both mother and child blood transfusions during caesarean section even though it violated the parents' religious beliefs because the state has an overriding interest in the welfare of the child).

80. 49 Fed. Reg. 1622-23 (1984) (to be codified at 45 C.F.R. § 84).

81. *Id.* at 1623.

to the parents in consultation with their physician.<sup>82</sup> The primary right of parents to choose the medical care for their children was raised as a defense against any power of the government to intervene.<sup>83</sup>

As noted earlier, the federal courts invalidated these regulations on procedural grounds.<sup>84</sup> In *American Academy of Pediatrics*, while Judge Gesell would not rule on the constitutional aspects of parental rights, he did say that "to the extent the regulation is read to eliminate the role of the infant's parents in choosing an appropriate course of medical treatment, its application may in some cases infringe upon the interests outlined in cases such as *Carey v. Population Services International*."<sup>85</sup> The Second Circuit opinion in *University Hospital* also suggested that the authority of the governmental agency to gain access to the infant's medical records might implicate parental and privacy rights.<sup>86</sup> In spite of all of the *dicta*, no federal court has yet decided the issue of who the proper decisionmaker should be, possibly because no court has yet definitively settled on the proper standard of decisionmaking.

Congress however, in the Child Abuse Amendments of 1984, has made it clear that *no* decisionmaker may use the quality-of-life standard as the basis of a decision to withhold care.<sup>87</sup> As described in section two, the Act has adopted a sanctity-of-life standard that must be used by *any* decisionmaker.<sup>88</sup> The Act implicitly allows the parents to be the decisionmaker unless they make a discriminatory decision that violates the child's right to "medically indicated treatment."<sup>89</sup> If suspicion exists that the parents have made an invalid decision, then the Act has designated the state protective service agency as the proper governmental body to protect the infant.<sup>90</sup> Basically, the case will be treated like any other child abuse case; however, the Act also requires the agency to identify a contact person in the medical facility to initiate and pursue a suspected case. The agency must also insure that the state law authorizes it to go to court to intervene in a suspected case.<sup>91</sup>

Whether the state agency will prove to be the child's best advocate will

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82. Kuzma, *supra* note 25, at 398-400.

83. *Id.*

84. *Supra* note 46.

85. 561 F. Supp. at 403.

86. 729 F.2d at 150.

87. 50 Fed. Reg. 14,878, 14,888 (1985) (to be codified at 45 C.F.R. § 1340).

88. *Id.*

89. *Id.*

90. *Id.* at 14,878.

91. Murray, *The Final, Anticlimactic Rule on Baby Doe*, 15 HASTINGS CENTER REP., June 1985, at 6.

depend upon the strength of each state's respective child abuse law,<sup>92</sup> and how aggressively the agency complies with the federal mandate. The only sanction for noncompliance by the agency is the loss of federal funds.<sup>93</sup> This is a limited penalty because federal funding to start protective service agencies is minimal at present.<sup>94</sup>

Commentators have recommended that hospital ethics committees function either as the final decisionmaker or as an aid to help parents decide whether to treat their handicapped newborn children.<sup>95</sup> The better idea, however, is to have the committee operate as a body that both educates the parents and protects the child from discriminatory nontreatment. This policy choice is evident in the Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, published by HHS, which recommended that the hospitals establish Infant Care Review Committees (ICRC) to "assure that medical treatment decisions are informed, thoughtful, and consistent with proper medical standards."<sup>96</sup> The guidelines state that the review committees should apply the same sanctity-of-life standard of decisionmaking that appears in the Child Abuse Amendments of 1984 regulations.<sup>97</sup> Moreover, HHS explains that the aim of the basic policy is to "prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions."<sup>98</sup>

The guidelines recommend that the ICRCs include individuals from a variety of disciplines and perspectives, including medical professionals, social workers, a representative from a disability rights group, a lay community member, clergy, perhaps a lawyer, and "other individuals with knowledge and perspectives valuable to effective action on particular functions and activities of the ICRC."<sup>99</sup> If the committee operates properly under the guidelines, it can provide parents with vital emotional and informational support. The parents need to know both the status of the law and what resources are available in the community for the care of their child. Without the restraints in the HHS guidelines, however, the committee could easily become an advocate of a discriminatory decision, especially if the committee uses or permits the use of a quality-of-life standard of decisionmaking.<sup>100</sup>

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92. Kuzma, *supra* note 25.

93. Murray, *supra* note 91, at 6.

94. *Id.*

95. *Guidelines for Infant Bioethics Committees*, 74 PEDIATRICS 306 (1984); Kuzma, *supra* note 25, at 406.

96. 50 Fed. Reg. 14,893 (1985) (to be codified at 45 C.F.R. § 1340).

97. *Id.* at 14,894-95.

98. *Id.* at 14,894 (emphasis added).

99. *Id.*

100. Kuzma, *supra* note 25, at 408-09.

## IV. CONCLUSIONS

The courts should adopt the sanctity-of-life standard as the basis for deciding when to withhold treatment from a handicapped newborn baby because it is clear, reasonable, and nondiscriminatory. Only this standard gives primary value to the interests of the child, is based on *bona fide* medical considerations, and does not make discriminatory judgments about the quality of a handicapped person's life.

The quality-of-life standard, on the other hand, views less-than-perfect life as valuable only in relation to other societal interests, such as parental wishes, cost of care, or a subjective view that life with a severe handicap is not a life worth living.<sup>101</sup> This standard has been denounced by disability rights organizations, pro-life groups, Congress, and the Reagan administration as violative of the civil right of handicapped newborn babies to receive medical care equal to that given to nonhandicapped children.

Although the law should presume that the parents are the best decisionmakers for their child's medical care, if the parents make a discriminatory decision that care should be withheld, then the state should have the right to act as the child's advocate.<sup>102</sup> The physicians should make certain that the parents are fully informed as to all pertinent medical information. The doctors should not, however, venture outside of their expertise and base their prognoses for the child on social and economic factors. A hospital ethics committee has the important function of providing information, support, and counseling, but its primary duty should be to insure that the parents understand the ethical restraints on their decisions imposed by the Child Abuse Amendments of 1984.

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101. See generally Smith, *Long Days Journey into Night: The Tragedy of the Handicapped at Risk Infants*, in *MORAL ISSUES IN MENTAL RETARDATION* 129 (I. Laura & A. Ashman ed. 1985).

102. See Smith, *supra* note 24, at 731.