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## Withholding Treatment from Defective Infants: “Infant Doe” Postmortem

On April 9, 1982, a Down's syndrome infant, known only as “Infant Doe,” was born in a Bloomington, Indiana hospital.<sup>1</sup> The infant needed surgery to correct a blocked esophagus and thereby allow food to reach its stomach. The parents, as advised by attending physicians, decided to withhold the necessary surgery and also food and water, from the child.<sup>2</sup> Six days later the infant died.<sup>3</sup> National media attention touched off a storm of controversy over whether the parents' decision was justified.<sup>4</sup> The widespread public debate eventually caused the Department of Health and Human Services to issue regulations designed to prevent withholding treatment from defective infants.<sup>5</sup>

The recent public attention prompted by the “Infant Doe” case was preceded by a prolonged debate in both the legal<sup>6</sup> and medical<sup>7</sup>

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1 *In re Infant Doe*, No. 608204-004A at 1 (Monroe County Cir., Apr. 12, 1982) (declaratory judgment), *cert. denied*, 52 U.S.L.W. 3369 (U.S. Nov. 8, 1983) (No. 83-437).

2 *Id.* at 2-3.

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

4 See, e.g., Tift, *Debate on the Boundary of Life*, *TIME*, April 11, 1983 at 68, col. 1; Trafford, *Doctor's Dilemma: Treat or Let Die?*, *U.S. NEWS & WORLD REP.*, December 6, 1982 at 58, col. 1; *Infant Doe: Where to Draw the Line*, *Washington Post*, July 27, 1982, at A-15, col. 1; *Was Indiana Couple Entitled to Allow Their Baby to Die?*, *Chicago Tribune*, May 22, 1982, at 6, col. 1; *From Abortion to Infanticide*, *Chicago Tribune*, April 22, 1982, §1, at 24, col. 3; *The Killing Will Not Stop*, *Washington Post*, April 22, 1982, at A12, col. 2.

5 See notes 106-116 *infra* and accompanying text.

6 See, e.g., Clarke, *The Choice to Refuse or Withhold Medical Treatment: The Emerging Technological and Medical Ethical Consensus*, 13 *CREIGHTON L. REV.* 795 (1980); Ellis, *Letting Defective Babies Die, Who Decides?*, 7 *AM. J.L. & MED.* 393 (1982); Horan, *Euthanasia: Medical Treatment and the Mongoloid Child, Death or a Treatment of Choice?* 27 *BAYLOR L. REV.* 76 (1975); Kelsey, *Which Infants Should Live, Who Should Decide?*, 5 *HASTINGS CENTER REP.* 5 (Apr. 1975); Longino, *Withholding Treatment From Defective Newborns: Who Decides, and on What Criteria?*, 31 *U. KAN. L. REV.* 377 (1983); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 21 *STAN. L. REV.* 213 (1974); Shaw, *Genetically Defective Children: Emerging Legal Considerations*, 3 *AM. J.L. & MED.* 333 (1977); Note, *Birth Defective Infants: A Standard for Non-Treatment Decisions*, 30 *STAN. L. REV.* 599 (1975); Note, *Euthanasia: Criminal, Tort, Constitutional and Legislative Considerations*, 48 *NOTRE DAME LAW.* 1202 (1973) [hereinafter cited as Note, *Euthanasia*]; Comment, *Withholding Treatment From Defective Newborns: Substituted Judgment, Informed Comment and the Quinlan Decision*, 13 *GONZ. L. REV.* 781 (1978).

7 See, e.g., Black, *Selective Treatment of Infants with Myelomeningocele*, 5 *NEUROSURGERY* 334 (1979); Campbell & Duff, *Moral and Ethical Dilemma in the Special Care Nursery*, 289 *NEW ENG. J. MED.* 890 (1973) [hereinafter cited as Campbell & Duff, *Special Care Nursery*]; Campbell & Duff, *Moral and Ethical Dilemma: Seven Years into the Debate About Human Ambiguity*, 447 *ANNALS*

professions concerning withholding treatment from defective infants.<sup>8</sup> The debate has concerned two categories of infants. The first category includes infants with severe physical defects, such as spina bifida with myelomeningocele.<sup>9</sup> Even when treated, these infants will have a permanent physical handicap or paralysis, and sometimes mental retardation. The second category includes infants with a surgically correctable physical defect,<sup>10</sup> and an underlying permanent mental handicap such as Down's syndrome.<sup>11</sup> Although these infants' physical defects can be corrected, their mental handicaps cannot. The long term physical or mental handicaps of infants in both categories are seen by some individuals as a justification for withholding treatment, and even food and water, from the infants, thereby "allowing" them to die.

In 1973, two physicians revealed that during an eighteen month period at the Yale-New Haven Hospital special care nursery, 14% of the 299 infant deaths were related to withholding treatment.<sup>12</sup> In the

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19 (1980) [hereinafter cited as Campbell & Duff, *Seven Years*]; Diamond, *The Deformed Child's Right to Life*, in DEATH, DYING AND EUTHANASIA 127 (D. Horan & D. Mall eds. 1977); Johnson, *Selective Non-Treatment and Spina Bifida: A Case Study in Ethical Theory and Application*, 3 BIOETHICS Q. 91 (1981); Koop, *Ethical and Surgical Considerations in the Care of the Newborn with Congenital Abnormalities*, in INFANTICIDE AND THE HANDICAPPED NEWBORN (M. Delahoyd & D. Horan eds. 1982); Lorber, *Spina Bifida: To Treat or Not To Treat? Selection—The Best Policy Available*, 147 NURSING MIRROR 14 (1978); McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 339 J. A.M.A. 172 (1974); Shaw, *Dilemma of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 885 (1973); Silverman, *Mismatched Attitudes about Neonatal Death*, 11 HASTINGS CENTER REP. 12 (Dec. 1981).

8 Other professions have also joined the debate. See, e.g., Boyle, *Treating Defective Newborns; Who Decides? On What Basis?*, 63 HOSP. PROG. 34 (Aug. 1982) (philosopher); Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, 11 HASTINGS CENTER REP. 17 (Dec. 1981) (parents of defective infant); McCarthy, *Treating Defective Newborns: Who Judges Extraordinary Means?*, 62 HOSP. PROG. 45 (Dec. 1981) (clergy).

9 Spina Bifida with myelomeningocele is an open defect in the spine and associated structures, and occurs in up to 4 infants per 1,000 births. W. NELSON, TEXTBOOK OF PEDIATRICS 1413 (R. McKay & V. Vaughan 10th ed. 1975). The condition causes various degrees of permanent paralysis and deformity. Mental retardation accompanies this condition in fifty percent of the cases and hydrocephalus (a gross enlargement of the cranium caused by accumulation of fluid in the brain) develops in ninety percent of the cases. *Id.*

10 One example of a surgically correctible defect is tracheo-esophageal fistula, a condition which blocks the passage from the mouth to the stomach and therefore prevents oral feeding. See note 71 *infra* and accompanying text.

11 Down's syndrome, also known as mongolism or trisomy 21 syndrome, occurs in approximately 1.5 infants per 1,000 births and is accompanied by varying degrees of retardation and personality disorders. NELSON, *supra* note 9, at 134-37. As a result of recent improvements in the education and training of people with Down's syndrome, many of those afflicted with the condition are now able to live fairly normal, productive lives. For a concise statement of other various defects, see Ellis, *Letting Defective Babies Die, Who Decides?*, 7 AM. J.L. & MED. 393, 394-98 (1982).

12 Campbell & Duff, *Special Care Nursery*, *supra* note 7, at 890.

following years, various commentators discussed the civil, criminal, and constitutional issues involved in a non-treatment decision. These discussions considered the questions of who should decide when a defective infant should die and on what criteria the decision should be based.<sup>13</sup> Crucial to these questions are the rights and interests of the parties involved: the infant, the parents, the physician, and society in general.<sup>14</sup> Various approaches to legislation have been suggested,<sup>15</sup> each focusing on how best to safeguard the often competing rights and interests of the parties involved. Unfortunately, the Health and Human Services Regulations prompted by the "Infant Doe" case were hastily considered and promulgated, and are ill-suited for dealing with such a complex problem.<sup>16</sup> Several states have also recently enacted legislation concerning withholding treatment from defective infants.<sup>17</sup> Although these statutes comprise a more considered, thoughtful treatment of the problem, their provisions fall short of an ideal solution.

This note begins in Part I by briefly reviewing the rights and interests involved in withholding treatment from defective infants, and illustrates, through several recent cases, the judicial inconsistency in dealing with this issue. Next, Part II examines the Health and Human Services regulations, the public and medical community's reaction to them, and the recent challenge of these regulations in court. Part III discusses the recent state statutes dealing with this issue and their shortcomings, and then proposes a suggested approach for future legislation.

### I. Competing Rights and Interests: Whose Interests Prevail?

In the past, because the practice of withholding treatment from defective infants occurred in the privacy of hospitals, it received little or no publicity.<sup>18</sup> Due to recent increased public attention, however, more of these cases are now reaching the courts. When confronted with a case in which treatment has been withheld, the courts must balance the often competing rights and interests involved. The decisions in these cases have been inconsistent, with some courts granting priority to parental rights of privacy and some granting priority to the defective infant's right to life.

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13 See notes 6 and 7 *supra*.

14 See notes 19-38 *infra* and accompanying text.

15 See notes 141-164 *infra* and accompanying text.

16 See notes 106-116 *infra* and accompanying text.

17 See notes 161-194 *infra* and accompanying text.

18 Robertson, *supra* note 6, at 241-42.

The rights and interests of a defective infant are difficult to evaluate. All individuals have a basic right to life,<sup>19</sup> and defective newborn infants are no different. Infants also have an interest, however, in a life unhampered by physical defects, infirmities, and suffering.<sup>20</sup> Some commentators believe that courts must focus primarily on the infant's right to life and that other competing interests are inconsequential.<sup>21</sup> However, other commentators believe that a defective infant also has a right to die, analagous to that of a competent adult who decides to have life-sustaining treatment withheld.<sup>22</sup> In evaluating an incompetent adult's wish to die, however, the court must substitute for the incompetent's judgment that of a person qualified to evaluate his wishes, such as an immediate family member.<sup>23</sup> In the context of a newborn infant, the question of substituted judgment is even more complex. A defective infant's parents may not be able to fairly assess the infant's wishes due to their own competing interests.

Parents' rights and interests are intimately involved in a decision concerning the medical treatment of their infant. Traditionally, parents have been afforded broad authority to make decisions concerning the welfare of their children.<sup>24</sup> The parents' lives will be deeply affected by any decision concerning treatment of their defective infant. However, parental rights can be terminated when their actions become detrimental to the health or well-being of the child.<sup>25</sup> When confronted with a decision regarding their defective newborn, parents will probably consider factors other than the best interests of the defective infant.<sup>26</sup> For example, since the costs of caring for a defec-

19 The fifth, ninth, and fourteenth amendments guarantee a person's right to life. The fifth amendment states: "No person shall . . . be deprived of life . . . without due process of law . . . ." U.S. CONST. amend. V. The fourteenth amendment requires the same guarantees to be provided by states. U.S. CONST. amend. XIV, § 1. The right to life might otherwise be guaranteed by the ninth amendment: "The enumeration in the Constitution, of certain rights, shall not be construed to deny or disparage others retained by the people." U.S. CONST. amend. IX.

20 Longino, *supra* note 6, at 383. State child neglect laws generally protect infants' interests; they allow juvenile courts to intervene and take custody of a child who is in danger of physical abuse or injury. Paulsen, *The Legal Framework for Child Protection*, 66 COLUM. L. REV. 679, 693-97 (1956).

21 See generally, Diamond, *supra* note 7, at 136-137; Koop, *supra* note 7, at 55.

22 See, e.g., Garland, *Care of the Newborn: The Decision not to Treat*, 1 PERINATOLOGY/NEONATOLOGY 14, 16 (Sept.-Oct., 1977); Silverman, *supra* note 7, at 15-16.

23 See *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

24 The Supreme Court has recognized this right many times. See note 30 *infra*.

25 See, e.g., *In re Phillip B.*, 92 Cal. App. 3d 796, 801, 156 Cal. Rptr. 48, 51 (1979).

26 The considerations at such a time can be rather oppressive:

[I]f the child is treated and accepted at home, difficult and demanding adjustments must be made. Parents must learn how to care for a disabled child, confront

tive infant can be staggering, the family's financial situation could be a significant factor.<sup>27</sup> Also, the infant's presence may adversely affect the stability of the parents' marriage and the emotional well-being of siblings.<sup>28</sup> If such considerations persuade the parents of a defective infant to withhold treatment from the infant, the parents' right to make such a decision should then be balanced against the defective infant's rights. Since the constitution does not explicitly mention a parental right of privacy,<sup>29</sup> the constitutional bases and limitations of this right are rather unclear and provide no firm guidance for the courts.<sup>30</sup>

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financial and psychological uncertainty, meet the needs of other siblings, and work through their own conflicting feelings. Mothering demands are greater than with a normal child, particularly if medical care and hospitalization are frequently required. Counseling or professional support may be nonexistent or difficult to obtain. Younger siblings may react with hostility and guilt, or with shame and anger. Often the normal feedback of child growth that renders the turmoil of childbearing worthwhile develops more slowly or not at all. Family resources can be depleted (especially if medical care is needed), consumption patterns altered, or standards of living modified. Housing may have to be found closer to a hospital, and plans for further children changed. Finally, the anxieties, guilt, and grief present at birth may threaten to recur or become chronic.

Robertson, *supra* note 6, at 257-58. See also Fost, *Counseling Families Who Have a Child With a Severe Congenital Anomaly*, 67 PEDIAT. 321, 322-23 (1981); Gustafson, *Mongolism, Parental Desires, and the Right to Life*, in DEATH, DYING AND EUTHANASIA 254-59 (D. Horan & D. Mall eds. 1977).

27 For example, in one 1976 case, six months of treatment for a premature baby cost \$104,403.20. Stinson & Stinson, *On the Death of a Baby*, 7 J. MED. ETHICS 5, 10 (1981). See also Lorber, *supra* note 7, at 16 ("By the time a child with spina bifida has left school he will have cost some 100,000 [pounds sterling]—much more than the lifetime earnings of an average family—and yet the results are often disastrous.")

28 See, e.g., Robertson, note 26 *supra*; *How Two Couples Dealt With Doomed Children*, Chicago Tribune, Feb. 24, 1980, at 17, col. 3.

29 Roe v. Wade, 410 U.S. 113, 152 (1972).

30 The Supreme Court has gradually developed the "right" of parental autonomy and privacy in various situations. The earliest cases involved education; the Court first based a parent's right to direct their child's education upon the concept of liberty in the fourteenth amendment which denotes freedom to "establish a home and bring up children . . ." Mayer v. Nebraska, 262 U.S. 390, 399 (1922). The Court, in Pierce v. Society of Sisters, 268 U.S. 510, 534 (1924), reaffirmed the fourteenth amendment rights of "parents and guardians to direct the upbringing and education of children under their control."

A broader recognition of parental autonomy came in Prince v. Massachusetts, 321 U.S. 158 (1943), where despite a finding that the state could regulate children engaged in street preaching, the Court said:

It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder [citing *Pierce*] and it is in recognition of this that these decisions have respected the private realm of family life which the state cannot enter.

*Id.* at 166.

The right of parental privacy is also linked to the rights of marital privacy and some

Another concern of a defective infant's parents may be their possible criminal liability. Although no parents have ever been tried for withholding treatment or food and water from the infant, commentators generally agree that parents who do so would be subject to criminal charges of murder, attempted murder, or conspiracy to murder.<sup>31</sup>

The state also has several competing interests in defective infant cases. The state is first concerned with upholding the value of life, a basic, integral concept in society's moral structure.<sup>32</sup> The common law concept of *parens patriae*<sup>33</sup> vests the state with guardianship power

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aspects of procreation. In *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1941), the Court struck down a state law providing for the sterilization of criminals because the law interfered with the basic right of marriage and procreation. The Court further enunciated this concept in *Griswald v. Connecticut*, 381 U.S. 479 (1954), while holding that a Connecticut law forbidding the use of contraceptives violated the right of marital privacy. The Court found the right of marital privacy existed within the "penumbra" of the first amendment rights:

[S]pecific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance. Various guarantees create zones of privacy . . . .

. . . .  
We deal with a right of privacy older than the Bill of Rights—older than our political parties, older than our school system. Marriage is a coming together for better or for worse, hopefully enduring, and intimate to the degree of being sacred.

*Id.* at 484-86 (citation omitted). In *Eisenstadt v. Baird*, 405 U.S. 438 (1971), the Court, in striking down a Massachusetts statute forbidding the sale of contraceptives to unmarried people, seemed to somewhat diminish the marital privacy right established in *Griswald*. The Court said that marriage is basically an association of two individuals and that the right of privacy which protects personal decisions on procreation is an individual right. *Id.* at 453.

In *Wisconsin v. Yoder*, 406 U.S. 205, 213-15 (1972), the Court affirmed parents' rights to direct their children's religious training. Then in *Roe v. Wade*, 410 U.S. 113, 152-53 (1972), the Court reaffirmed that the concepts of personal privacy are founded upon various guarantees in the first, fourth, fifth, ninth, and fourteenth amendments and applied the right of privacy to family relationships (citing *Prince*), child rearing, and education (citing *Pierce*). Most recently, in *United States v. Orito*, 413 U.S. 139 (1972), the Court stated: "The Constitution extends special safeguards to the privacy of the home, just as it protects other special privacy rights such as those of marriage, procreation, motherhood, child rearing, and education." *Id.* at 142.

Since the constitutional foundation of parental privacy is so vague, its limitations are correspondingly indistinct. However, such an ill-defined right should probably yield to a defective infant's fundamental right to life.

31 See Fost & Robertson, *Passive Euthanasia of Defective Newborn Infants: Legal Considerations*, 88 J. PEDIAT. 883, 884 (1976); Robertson, *supra* note 6, at 217-18.

32 The value of life is such a fundamental concept in our society that "the common law regards life as sacred and inalienable, and the criminal law reflects this basic philosophy." Note, *Euthanasia*, *supra* note 6, at 1203-04 (citing *State v. Moore*, 25 Iowa 128, 135-136 (1868)).

33 *Parens patriae* is based upon English common law and was recognized in the United States as early as 1846 when the Indiana Supreme Court defined it as "the duty of looking after the welfare of those who, from tender age and imbecility of mind, are incapable of taking care of themselves, [and] contains a principle necessary to the well being of any state,

over disabled people and children, giving it the right to intervene to preserve the physical or mental well-being of these individuals.<sup>34</sup> Child abuse laws also provide the state with the authority to intervene where a child's well-being is endangered.<sup>35</sup> Unfortunately, the state must also consider a practical problem—the allocation of scarce medical resources, which some commentators believe should not be squandered on hopeless cases.<sup>36</sup>

Physicians and hospitals, like the state, also have an interest in determining how medical resources are allocated. However, aside from concern for the patient's welfare, they must also consider the possibility that a decision to withhold treatment may subject them to civil or criminal liability.<sup>37</sup> Several commentators have concluded that a decision to withhold treatment would subject doctors, as well as the parents, to criminal charges.<sup>38</sup>

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whatever may be the form of its government." *McCord v. Ochiltree*, 8 Blackf. 15, 19-20 (Ind. 1846).

34 *Parham v. J.W.*, 442 U.S. 584, 603 (1978). The state's *parens patriae* power has frequently been invoked to limit parental authority over children. In *Prince v. Massachusetts*, 321 U.S. 158, 166 (1943), the Supreme Court stated:

Acting to guard the general interest in youth's well being, the state as *parens patriae* may restrict the parent's control by requiring school attendance, regulating or prohibiting the child's labor and in many other ways. . . . The right to practice religion freely does not include liberty to exploit . . . the child . . . to ill health or death. The catalogue need not be lengthened. . . . *The state has a wide range of power for limiting parental freedom and authority in things affecting the child's welfare.*

*Id.* at 166-67 (citation omitted) (emphasis added).

35 See Paulsen, *The Legal Framework For Child Protection*, 66 COLUM. L. REV. 679, 693-703 (1966). For further discussion of state intervention on behalf of neglected children, see Baskin, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV. 1383 (1974); Wald, *State Intervention on Behalf of Neglected Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975).

36 See, e.g., Longino, *supra* note 6, at 393; *Health-Care Rationing Consensus Backed*, Phoenix Gazette, June 4, 1983, at A3, col. 1.

37 Several commentators have discussed the possible liabilities of physicians and hospitals for withholding treatment from defective infants. See, e.g., Chabon, *You May Face a Nightmare in the Newborn Nursery*, 7 LEGAL ASP. MED. PRAC. 43, 45 (1979); Fost & Robertson, *supra* note 31, at 884-86; Robertson, *supra* note 6, at 224-44; Note, *Euthanasia*, *supra* note 6, at 1203-26 (1973).

38 See the sources cited in note 37 *supra*. In the United States, although physicians have had criminal charges brought against them, none have gone to trial. See notes 55-58 *infra* and accompanying text.

In England, however, at least one doctor has been tried for withholding treatment from a defective infant. In this case a jury found a doctor who had withheld treatment and food from a Down's syndrome infant not guilty of attempted murder, even though the child died within three days. Brahams, *Acquittal of Paediatrician Charged After Death of Infant With Down's Syndrome*, 2 LANCET 1101, 1101 (Nov. 14, 1981). However, one commentator pointed out that the physician's acquittal was merely based on the facts of the case and did not resolve the legal issues involved. *Dr. Leonard Arthur: His Trial and its Implications*, 283 BRIT. MED. J. 1340,



Courts have dealt differently with the various competing rights and interests involved in a decision not to treat a defective infant. In *Matter of Cicero*,<sup>39</sup> the parents of a newborn infant girl with spina bifida with myelomeningocele<sup>40</sup> refused to consent to surgery to repair the infant's condition.<sup>41</sup> Untreated, this condition will cause death or extensive paralysis and mental retardation; surgical treatment can in many cases lessen the degree of paralysis and even prevent mental retardation.<sup>42</sup> The New York court awarded custody to a guardian for consent for the treatment.<sup>43</sup> The court found that in this case, where the infant had a "reasonable opportunity to live, to grow and to surmount [her] handicaps," her interests superseded parental rights to withhold treatment.<sup>44</sup> The court stated: "Parental rights . . . are not absolute. Children are not property whose disposition is left to parental discretion without hindrance."<sup>45</sup> The court also rejected any philosophy that would allow newborn infants to die without an effort to save their lives.<sup>46</sup> The court relied on its *parens patriae* power and the New York child neglect statutes as authority to order treatment.<sup>47</sup> There is no record of criminal charges against the parents or physicians involved in this case.

An Illinois case, *In re Jeff and Scott Mueller*,<sup>48</sup> involved Siamese twins born joined at the waist.<sup>49</sup> The parents and attending physicians decided not to surgically separate the children, and further, not

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1340 (1981). Of particular significance was a defense expert's testimony that his autopsy of the infant revealed physical defects undiscovered by the prosecution's expert. Brahams, *supra*, at 1101. This evidence suggested that the child may have possibly died from these other defects, not dehydration or starvation. *Id.*

39 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Bronx County Sup. Ct. 1979).

40 For an explanation of this condition, see note 9 *supra*.

41 101 Misc. 2d at 700, 421 N.Y.S.2d at 966.

42 Lorber, *supra* note 7, at 16.

43 101 Misc. 2d at 702-03, 421 N.Y.S.2d at 968.

44 *Id.* at 701, 421 N.Y.S.2d at 968.

45 *Id.* at 702, 421 N.Y.S.2d at 968.

46 The court stated:

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. . . . [T]here is a strident cry in America to terminate the lives of other people—deemed physically and mentally defective. This court was not constituted to hear that cry. Rather . . . it is our function to secure each his opportunity for "life, liberty, and the pursuit of happiness."

*Id.* at 702, 421 N.Y.S.2d at 968 (quoting *Matter of Weberlist*, 79 Misc. 2d 753, 757, 360 N.Y.S.2d 783, 787 (N.Y. County Sup. Ct. 1972)).

47 101 Misc. 2d at 701, 421 N.Y.S.2d at 967.

48 Nos. 81J300 & 81J301 (Ill. 5th Cir., May 15, 1981) (order granting custody).

49 Robertson, *Dilemma in Danville*, 11 HASTINGS CENTER REP. 5, 5 (Oct. 1981).

to feed the children.<sup>50</sup> When informed of the situation, the Illinois Department of Children and Family Services (IDCFS) filed a neglect petition with the Illinois Family Court to gain custody of the twins. The court subsequently awarded custody to IDCFS for the purpose of authorizing surgery and medical treatment for the twins.<sup>51</sup> While the *Cicero* court did not specifically mention the right to life, the *Mueller* court found the twins' "inalienable right to life," granted by the Illinois State Constitution, could not be disregarded by any "individual, professional group, legal, medical, or otherwise . . . ."<sup>52</sup> In its decision, the court did not discuss how the twins' right to life balanced against competing parental privacy rights.

The *Mueller* court, like the *Cicero* court, also relied on child neglect laws for its authority to order treatment for the twins. The court found that, under the Illinois child neglect laws, the twins were entitled to both an expert examination and an attempt to correct their problem, neither of which had been done.<sup>53</sup> The court held that the failure to provide such examination and treatment constituted neglect, but declined to fix blame upon the parents or the attending physicians, implying that the neglect was unintentional.<sup>54</sup>

On June 11, 1981, in an unprecedented move, the Illinois State's Attorney in Danville filed charges of attempted murder against the Mueller twin's parents and the attending physician.<sup>55</sup> At the preliminary hearing, however, nurses did not link the parents or physician with the order to withhold food, and the charges were dismissed.<sup>56</sup> The State's Attorney subsequently asked a grand jury to indict the twin's parents on charges of attempted murder, conspiracy to murder, and solicitation to murder. He also attempted to indict the attending physician on conspiracy to murder.<sup>57</sup> The grand jury did not indict.<sup>58</sup>

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50 "Do not feed in accordance with parent's wishes" was written on the medical chart. *Id.*

51 *Mueller*, order at 3-4.

52 *Id.* at 1. The Illinois Constitution states in part: "All men . . . have certain inalienable rights among which are life, liberty and the pursuit of happiness." ILL. CONST. art. I, §1.

53 *In re Jeff and Scott Mueller*, No. 81J300 & 81J301 at 1 (Ill. 5th Cir., May 15, 1981) (findings of fact accompanying order).

54 *Id.* at 1. Since the court found that "all parties involved thought they were doing the right thing," it simply found "the minors were not given proper and necessary treatment . . . [and] they were substantially denied food" and made no finding in regard to parental neglect. *Id.* at 3. See also, *The Moral Dilemma of Siamese Twins*, NEWSWEEK, June 22, 1981, at 40, col. 1.

55 Robertson, *supra* note 49, at 5.

56 *Id.*

57 *State Drops Siamese Twins Case*, N.Y. Times, Apr. 17, 1983, at 6, col. 2.

58 *Id.*

*In Re Phillip B.*,<sup>59</sup> a California case, did not involve withholding treatment from a defective *infant*, but the issues involved in the case were quite similar to those in defective infant cases. Phillip, a twelve year-old Down's syndrome child, suffered from a congenital heart defect which, if untreated, would cause a gradual deterioration of the lungs and eventual death.<sup>60</sup> When Phillip's parents refused to consent to the surgery necessary to repair the defect, the California juvenile probation department filed a petition in juvenile court requesting that Phillip be declared a ward of the court for the purpose of permitting the surgery.<sup>61</sup> The juvenile court dismissed the petition because the juvenile probation department had failed to show by clear and convincing evidence that the child had not been provided the "necessities of life."<sup>62</sup>

On appeal, the California Court of Appeals for the First District upheld the juvenile court's ruling.<sup>63</sup> The court reviewed the constitutional foundation and development of parental privacy as an outgrowth of fourteenth amendment privacy rights.<sup>64</sup> The court stated that parental rights are not absolute, and that "[o]ne of the most basic values protected by the state is the sanctity of human life."<sup>65</sup> The court commented that when parents deny their children adequate medical care, the state has a right and a duty to intervene under the *parens patriae* doctrine, to protect the children.<sup>66</sup> The court warned, however, that the state must overcome a "serious burden of justification" before abridging the parental autonomy presumption.<sup>67</sup> It concluded that the trial court had faithfully balanced the risks and benefits involved in the operation and that it could not say that "as a matter of law" there was no substantial evidence to support the trial court's decision.<sup>68</sup>

59 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980).

60 The defect—a ventricular septal defect—causes elevated pulmonary blood pressure, and increases the rate at which the heart must pump blood. *Id.* at 800, 156 Cal. Rptr. at 50.

61 At the hearing doctors testified that the surgery involved a five to ten percent mortality rate for normal patients, but posed higher risk to patients with Down's syndrome. This higher mortality rate is due to greater risk of post-operative complications in Down's syndrome children. *Id.*, 156 Cal. Rptr. at 50-51. The doctors also testified that surgical correction of the defect would significantly lengthen Phillip's then expected twenty-year life span. *Id.*, 156 Cal. Rptr. at 50-51.

62 *Id.* at 802, 156 Cal. Rptr. at 51-52.

63 *Id.* at 804, 156 Cal. Rptr. at 52.

64 *Id.* at 801, 156 Cal. Rptr. at 50-51.

65 *Id.*, 156 Cal. Rptr. at 51 (citing U.S. CONST. amend. XIV, §1).

66 *Id.*, 156 Cal. Rptr. at 51.

67 *Id.* at 802, 156 Cal. Rptr. at 51.

68 *Id.* at 803, 156 Cal. Rptr. at 51. In *In Re Becker*, 7 Fam. L. Rep. (BNA) 2647, 2648

Probably more than any other case, the "Infant Doe"<sup>69</sup> or "Bloomington Baby" case has roused the greatest public reaction. Infant Doe was born on April 9, 1982, in a Bloomington, Indiana hospital.<sup>70</sup> Shortly thereafter, the attending physician diagnosed the child as suffering from Down's syndrome and tracheo-esophageal fistula, a condition which blocks the esophageal passage from the mouth to the stomach, therefore preventing oral feeding.<sup>71</sup> After the parents decided to withhold treatment, food, and water from the infant, a hospital representative contacted a Monroe County Superior Court judge.<sup>72</sup>

After a short hearing at the hospital,<sup>73</sup> the court ordered the hospital to comply with the parent's non-treatment decision.<sup>74</sup> Three days later, on April 13, the Monroe County prosecutor filed a petition with the Monroe County Juvenile Court for an emergency detention order to have custody of the child taken from the parents.<sup>75</sup> The juvenile referee *referee pro tem* decided there was no probable cause to suspect parental neglect and denied the petition.<sup>76</sup> On April 14th,

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(Aug. 7, 1981) the California Superior Court for Santa Clara County awarded custody of Phillip to a couple and authorized "immediate catheterization to determine the feasibility of surgery for his ventral septal defect."

69 *In re Infant Doe*, No. GU8204-004A (Monroe County Cir., Apr. 12, 1982) (declaratory judgment), *cert. denied*, 52 U.S.L.W. 3369 (U.S. Nov. 8, 1983) (No. 83-437) [hereinafter cited as *Infant Doe*].

70 *Id.* at 1.

71 W. NELSON, TEXTBOOK OF PEDIATRICS 803-04 (R. McKay and V. Vaughan 10th ed. 1975). This condition can be corrected in most patients; 78% of patients without other anomalies survive corrective treatment. *Id.* at 805. The attending physician consulted several doctors who agreed with the diagnosis. *Infant Doe*, at 1.

72 Rebone, "Minimal Quality of Life": *Why Parents, Courts Chose Infant Doe's Death*, 63 HOSP. PROG. 10, 10 (June 1982).

73 On April 10, the court held a hearing at the hospital. *Infant Doe*, at 1. Infant Doe's father, the parents' attorney, various hospital officials, and six doctors attended the hearing. *Id.* The delivering obstetrician testified that the possibility that the infant would have a minimally adequate quality of life was non-existent due to his "severe and irreversible mental retardation." *Id.* at 2. He recommended treatment consisting of only sedation to keep the infant free of pain. *Id.* A consulting pediatrician recommended the infant be transferred to a hospital in Indianapolis for immediate surgery. Two other pediatricians agreed with this latter recommendation. *Id.*

The infant's father testified that he and his wife felt a minimally acceptable quality of life was never present for a Down's syndrome child. *Id.* at 3. He also testified that he and his wife had signed a statement directing that medical treatment, food, and water be withheld in accordance with the delivering obstetrician's recommendation. *Id.*

74 *Id.* The court also appointed the Monroe County Department of Public Welfare as infant Doe's guardian for purposes of appeal. *Id.* at 4.

75 Rebone, *supra* note 72, at 10.

76 The referee found that since the parents had made their decision after consulting physicians, and had chosen one of two medical options presented them, there was no probable cause for neglect. *Id.*

the Monroe County prosecutor unsuccessfully appealed both rulings to the Indiana Supreme Court.<sup>77</sup> On the afternoon of April 15th, the Monroe County Superior Court denied a married couple's petition to intervene to adopt the child.<sup>78</sup>

Infant Doe died on the evening of April 15, 1982, while a county prosecutor and an Indiana University law professor were en route to Washington for an emergency appeal to United States Supreme Court Justice John Paul Stevens.<sup>79</sup> The coroner's report listed multiple congenital abnormalities as the proximate cause of death and dehydration and lack of food as contributing factors.<sup>80</sup>

When the *Infant Doe* court's rationale is compared to the rationale of previous decisions, many inconsistencies appear. Unlike the New York court in *Cicero*,<sup>81</sup> the Monroe County court felt that the value of parental autonomy outweighed the infant's right to life where "a minimally adequate quality of life was non-existent."<sup>82</sup> And unlike the California Appeals Court in *Philip B.*,<sup>83</sup> the Monroe County court said the fourteenth amendment had been "often misquoted to stand for the right of life" but that its actual purpose is to safeguard the family's right to be free from undue governmental interference.<sup>84</sup> The Indiana Constitution, like the Illinois Constitution,<sup>85</sup> guarantees an "inalienable" right to life.<sup>86</sup> The *Infant Doe* court apparently did not consider this guarantee relevant in its decision to allow withholding treatment, food, and water from Infant Doe.<sup>87</sup> In contrast, the *Mueller* court found the Illinois guarantee

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77 The court denied the prosecutor's *mandamus* petitions. *Id.* at 11. *See also*, *Supreme Court Refuses to Order Care for Dying Baby*, *The Evansville Journal-Gazette*, Apr. 15, 1982. On April 15, the Monroe County Juvenile Court denied both an injunction to force Bloomington Hospital officials to keep the baby alive, and a temporary restraining order to require the infant's parents to provide nutrition and medical care. Rebone, *supra* note 72, at 13. The Monroe County Superior Court also denied an appeal for a restraining order. *Id.*

78 *Id.* at 14. Several other families also volunteered to adopt the infant. *Id.*

79 *Id.*

80 *Id.*

81 *See* notes 44-45 *supra* and accompanying text.

82 Letter from Judge John Baker of the Monroe County Superior Court to anonymous person at 2 (June 8, 1983) (discussing rationale of the *Infant Doe* decision)[hereinafter Letter]. All records other than Judge Baker's original order and his letter have been sealed. Telephone conversation with S. Deckard, Assistant Court Reporter, Monroe County Superior Court (Mar. 25, 1983).

83 *See* note 65 *supra* and accompanying text.

84 Letter, *supra* note 82, at 3.

85 *See* note 52 *supra*.

86 IND. CONST. art. I, § 1.

87 The court did not mention the guarantee in its order or letter to an anonymous person. *See* Letter, *supra* note 82.

highly relevant in its decision to order treatment of the Mueller twins.<sup>88</sup> Also, unlike the *Cicero* and *Mueller* courts, the *Infant Doe* court found that withholding treatment, food, and water from the infant did not constitute neglect under the state child neglect statutes since the court "could not [say] the parents were not acting in the best interests of the child. . . ."<sup>89</sup> The Monroe County prosecutor did not file criminal charges against either the infant's parents or the attending physician.<sup>90</sup>

Most recently, on October 28, 1983, the New York Court of Appeals affirmed the dismissal of a legal guardian's application for corrective surgery for a newborn defective infant.<sup>91</sup> The infant, identified only as "Baby Jane Doe," was born on October 11, 1983, in a Long Island, N.Y. hospital.<sup>92</sup> The infant's defects included spina bifida and accompanying hydrocephalus,<sup>93</sup> microcephaly,<sup>94</sup> and other neurological defects.<sup>95</sup> After consulting with doctors and counselors, the parents decided against surgery to correct the infant's defects and decided to follow a more "conservative" treatment.<sup>96</sup> Shortly thereafter, a Vermont resident unconnected with the family filed a petition in the Suffolk County Supreme Court which resulted in the court appointing a legal guardian for the infant.<sup>97</sup> The guardian petitioned the court to order surgery for the infant, and, after two

88 *Mueller*, order at 1.

89 Letter, *supra* note 82, at 3. The Indiana legislature recently revised their child neglect laws to include in their definition of a neglected child:

[A] handicapped child who is deprived of nutrition that is necessary to sustain life, or who is deprived of medical or surgical intervention that is necessary to remedy or ameliorate a life threatening medical condition, if the nutrition or medical or surgical intervention is generally provided to similarly situated handicapped or non-handicapped children.

Act of Apr. 19, 1983, Pub. L. No. 288-1983, 1983 Ind. Acts 1783 (to be codified at IND. CODE § 31-6-4-3).

90 *Charges Weighed for Parents Who Let Baby Die Untreated*, N.Y. Times, Apr. 17, 1983, at 6, col. 1.

91 *Weber v. Stony Brook Hospital*, No. 83-672, slip op. at 5 (N.Y. Oct. 28, 1983) (per curiam). See also 52 U.S.L.W. 2267 (Nov. 15, 1983).

92 *Spinal Surgery for L.I. Baby Is Ordered and Then Stayed*, N.Y. Times, Oct. 21, 1983, at 10, col. 1.

93 For an explanation of these conditions, see note 9 *supra*.

94 Microcephaly is a defect in the growth of the head which causes progressive mental retardation. NELSON, *supra* note 9, at 1417.

95 One doctor testified in a lower court hearing that these defects left the infant immobile and incapable of controlling her body wastes. N.Y. Times, Oct. 21, 1983, at 10, col. 2.

96 *Weber*, slip op. at 1-2. The conservative treatment apparently involved little more than anti-biotics to prevent infection in the infant's spinal column defect. *Difficult Issues Abound in Baby Jane Litigation*, Nat'l. L.J., Nov. 7, 1983, at 6, col. 3.

97 *Weber*, slip op. at 2.

days of hearings, the court did so.<sup>98</sup> Within hours, an Appellate Division Court stayed the order,<sup>99</sup> and later dismissed the action, saying the infant's parents had elected a treatment "well within accepted medical standards."<sup>100</sup>

On appeal, the New York Court of Appeals affirmed the dismissal, and like the *Phillip B.* court, based their decision on a procedural issue.<sup>101</sup> The court noted that in Section 1032 of the New York Family Court Act,<sup>102</sup> the legislature had assigned primary responsibility for initiating child neglect actions in family court to child protective agencies or persons acting at a family court's direction.<sup>103</sup> The court found that in this case, the petitioners had not observed this statutory scheme.<sup>104</sup> To allow any person to thus bypass the statutory requirements, the court reasoned, would "catapult him into the very heart of a family circle" to challenge the parents' responsibility to care for their children.<sup>105</sup> The court observed that although there might be appropriate occasions for court action without advice of a child protective agency, the court found such circumstances were not present and that the proceeding was therefore unjustified.<sup>106</sup>

## II. Administrative Regulation

The "Infant Doe" case prompted the Department of Health and Human Services (HHS) to take two administrative actions. On May 18, 1982, the HHS director of the Office for Civil Rights issued a "Notice to Health Care Providers."<sup>107</sup> This notice "reminded" hospitals receiving federal financial aid that Section 504 of the Rehabili-

98 N.Y. Times, Oct. 21, 1983, at 10, col. 2. At the hearing, doctors testified that without surgery, the child would die within six weeks, but that with successful surgery, the infant could live to the age of twenty but would be retarded, epileptic, and bed ridden. *Id.*

99 *Id.*

100 Nat'l. L.J., Nov. 7, 1983 at 6, col. 4.

101 *Weber*, slip op. at 1.

102 N.Y. JUD. LAW § 1032 (McKinney Supp. 1976-1982).

103 *Weber*, slip op. at 3.

104 The court stated that neither the petitioner nor the Supreme Court had notified or consulted with the state Department of Social Services before the hearing. *Id.* at 4.

105 *Id.*

106 *Id.* at 4-5. Shortly after the Court of Appeals decision in *Weber*, the Justice Department sued in Federal District Court to compel Stony Brook Hospital to produce the infant's medical file. *U.S. Suing for L.I. Records of Baby in Surgery Dispute*, N.Y. Times, Nov. 3, 1983, at 19, col. 1. The Department wanted to determine whether the infant had been discriminated against because of her handicaps. *Id.*

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

tation Act of 1973<sup>108</sup> applied to defective infants.<sup>109</sup> The notice stated in part:

[I]t is unlawful . . . to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life threatening condition if:

- (1) the withholding is based on the fact that the infant is handicapped; and
- (2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.<sup>110</sup>

Although some commentators praised the notice,<sup>111</sup> and physicians criticized it,<sup>112</sup> the notice apparently had little effect on health care providers.<sup>113</sup>

On March 7, 1983, the HHS Secretary issued an "interim final rule" to become effective on March 22, 1983.<sup>114</sup> The rule informed hospitals that HHS intended to enforce the Section 504 requirements<sup>115</sup> with regard to handicapped infants.<sup>116</sup> The rule required hospitals to post a notice in pediatric facilities stating that federal law prohibited the failure to feed or care for handicapped infants.<sup>117</sup> The notice also provided a toll-free hotline number for use by "any per-

108 29 U.S.C. § 794 (1976). Section 504 states in part:

No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . ."

*Id.*

109 Notice, *supra* note 107.

110 *Id.*

111 One commentator said the notice agreed with "accepted moral norms" and would only serve to help handicapped infants "who should be the last to be treated unfairly or neglected." Connery, *An Analysis of the HHS Notice On Treating the Handicapped*, 63 HOSP. PROG. 18, 20 (July 1982).

112 One doctor criticized the notice as "vague and misdirected" and an undesirable attempt to legislate morality. Fost, *Putting Hospitals on Notice*, 12 HASTINGS CENTER REP. 5, 8 (1982).

113 One hospital administrator referred to the notice as "a non-binding opinion." *Hospital Warned About Loss of Funds in Withholding Treatment*, Associated Press (May 19, 1982) (available on NEXIS library).

114 Office of the Secretary, Department of Health and Human Services, *Nondiscrimination on the Basis of Handicap*, 48 FED. REG. 9630 (1983) (interim final rule modifying 45 C.F.R. § 84.61).

115 *See* note 108 *supra* and accompanying text.

116 48 Fed. Reg. 9630 (1983).

117 The notice read in its entirety:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW.

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from par-



son having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care."<sup>118</sup>

The medical profession immediately criticized the rule.<sup>119</sup> On March 18, 1983, the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and Children's Hospital National Medical Center, filed suit against the HHS Secretary, asking the court to declare the interim final rule invalid and enjoin its enforcement.<sup>120</sup>

On April 14, 1983, a District of Columbia federal district court declared that the interim final rule was "arbitrary and capricious and promulgated in violation of the Administrative Procedure Act (A.P.A.)."<sup>121</sup> The court ordered the Secretary to declare the rule invalid.<sup>122</sup> The court concluded that HHS had promulgated the rule without notice or opportunity for comment by persons affected by it,

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icipation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

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

Handicapped Infant Hotline

U.S. Department of Health and Human Services

Washington, D.C. 20201

Phone 800 - \_\_\_\_\_

(Available 24 hours a day)

*or*

Your State Child Protection Agency

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

Identity of callers will be held confidential.

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

*Id.* 9630-31 (1983).

118 *Id.* at 9031.

119 *See Physicians Criticize Rules on Newborns*, N.Y. Times, April 7, 1983, at C3, col. 1.

120 Complaint at 17-18, *American Academy of Pediatrics v. Heckler*, No. 83-0774 (D.D.C. filed Mar. 18, 1983). The complaint alleged, *inter alia*, that the rule did not comply with the 30 day notice requirement of the Administrative Procedure Act, *see* note 123 *infra*, failed to establish minimum procedures for appropriate investigation of and/or intervention in medical decisions concerning defective new infants, failed to provide adequate or even minimal procedures to protect the confidentiality of medical reports, jeopardized medical care of defective infants, and ignored the findings of the recently released report by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (*see* note 126 *infra*). Complaint at 8-17, *Heckler*.

121 *American Academy of Pediatrics v. Heckler*, No. 83-0774 at 1 (D.D.C. Apr. 14, 1983) (order and declaration). The Administrative Procedure Act, 5 U.S.C. §§ 551-576 (1977), is designed to check overzealous administrators who might otherwise exceed their office's authority, and to prevent "arbitrary official encroachment on private rights." *United States v. Morton Salt Co.*, 338 U.S. 632, 644 (1950).

122 *Heckler*, order and declaration at 1.

as the A.P.A. required.<sup>123</sup>

Although the court invalidated the rule primarily on procedural grounds, it did discuss the underlying issue— withholding treatment from defective infants. The court noted that traditionally, the decision to treat or not to treat a defective newborn had been made within the privacy of the physician/parent relationship.<sup>124</sup> The court said these parties usually weighed several factors in making their decisions. For example, the risks of treatment, the infant's quality of life, the prognosis of a certain death, and the impact a defective infant would have on the family and its financial resources are all factors parents considered in deciding whether to withhold treatment.<sup>125</sup> The court found that the rule did not adequately consider these factors.<sup>126</sup>

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123 American Academy of Pediatrics v. Heckler, No. 83-0884 (D.D.C. Apr. 14, 1983) (memorandum accompanying order). The Act requires, *inter alia*, that notice, a comment period, and publication of the rule be given 30 days prior to its effective date. 5 U.S.C. § 553(b)-(d) (1977). However, these requirements can be waived if "the agency for good cause finds . . . that notice and public procedure thereon are impractical, unnecessary, or contrary to the public interest." *Id.* at § 553(b)(B).

124 *Heckler*, memorandum accompanying order at 1.

125 *Id.* at 2-3. One commentator criticized the court's suggestion that a decision to withhold treatment should be based on the quality of life of others (the infant's family): "[T]his would be a monumental and unjustified change in the law, and runs contrary to child abuse and neglect statutes." Annas, *Disconnecting the Baby Doe Hotline*, 13 HASTINGS CENTER REP. 14, 15-16 (June 1983).

126 The court found the Secretary had also not considered "many highly relevant factors central to . . . medical care of newborn infants" before promulgating the rule. *Heckler*, memorandum accompanying order at 10. Among these factors were the disruptive effect a 24-hour hotline for reporting non-treatment might have on ongoing treatment, parental and family interests involved in such decisions, and funding and medical resource allocation problems. *Id.* at 10-12. The court found that the various legal and constitutional interests involved had not been adequately considered, and that a "customary medical care" standard for handicapped infants had not been established. *Id.* at 12-13. The court also found it disturbing that the Secretary failed to consider the eminent release of the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research ("President's Commission"), which suggested different approaches to the issue. *Id.* at 12. See also notes 149-153 *infra* and accompanying text.

The President's Commission convened in January 1980 with a congressional mandate to report on "the matter of defining death" and "any other appropriate matter." 42 U.S.C. § 300v-1(a) (Supp. 1981). The Commission consisted of eleven prominent members of the medical, legal, clerical, and related professions. On March 21, 1983, the Commission published their report on decisions to withhold treatment. In this report, the Commission criticized the HHS notice and interim rule as ineffective and "adding further uncertainty to an already complex situation." The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life Sustaining Treatment: A Report on Ethical, Medical and Legal Issues in Treatment Decisions* 226-227 (Comm. Print March 21, 1983). The Commission recommended that the government encourage hospitals to improve their in-house supervision of such decisions and not become directly involved in

The HHS Secretary had argued that the A.P.A.'s thirty-day notice requirement should be waived because the rule was necessary to immediately "protect life from imminent harm."<sup>127</sup> The court found this argument without merit,<sup>128</sup> and stated that Section 504 had probably not been intended to "reach so far into such a sensitive area of moral and ethical concerns . . . ."<sup>129</sup> Finally, the court noted that the rule's application might infringe on parental privacy rights in some instances. However, the court did not directly address the privacy issue since it was not squarely presented in the case.<sup>130</sup>

Two months after the *Heckler* decision, on July 5, 1983, the HHS Secretary published a new "proposed rule" on the care of handicapped infants<sup>131</sup> which essentially repromulgated the preliminary rule. In the proposed rule, the Secretary once again emphasized that Section 504 of the Rehabilitation Act of 1973 prohibits denying medical treatment from defective infants on the basis of his handicap.<sup>132</sup> The Secretary explained, however, that "medical decisions" by parents and doctors to withhold treatment were outside Section 504's scope.<sup>133</sup> Rather, Section 504 only applied when "non-medical" quality of life considerations, such as a handicap, persuaded parents and doctors to withhold treatment.<sup>134</sup>

The proposed rule would also require hospitals to post in infant care areas a notice practically identical to that which the previous

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them. *Id.* at 227. The report also criticized the financial sanction approach of the HHS actions as having the potential to "unjustly penalize other patients and professionals." *Id.*

127 *Heckler*, memorandum accompanying order at 13-14.

128 *Id.* at 14 (citing *Guardian Fed. Sav. and Loan Ass'n. v. FSLIC*, 589 F.2d 658, 664 (D.C. Cir. 1978)). The court said the Secretary had failed to meet the good cause exception to the A.P.A. notice requirement, *see* note 123 *supra*, since the exception should be narrowly construed. Further, arguing that the rule was necessary to save lives "could as easily be used to justify immediate implementation of any sort of health or safety regulation . . . ." *Id.* at 14-15 (citing *New Jersey v. EPA*, 626 F.2d 1038, 1045 (D.C. Cir. 1980)).

129 *Id.* at 17. The court said that after extensive research, it found: "[N]o congressional committee or member of the House or Senate ever even suggested that Section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life." *Id.* at 15.

130 *Id.* at 19.

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

132 *Id.* at 30846. The Secretary did not address the *Heckler* court's finding that no legislative history indicated § 504 should apply to treatment of defective newborn infants. *See* note 129 *infra*.

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

134 *Id.*

preliminary rule required.<sup>135</sup> Additionally, the proposed rule mandates that state child protection agencies receiving federal funds establish procedures to ensure that the full authority of state law is used "to prevent medical neglect of handicapped infants."<sup>136</sup> In observance of the A.P.A. notice and comment requirement,<sup>137</sup> the proposed rule also allowed a two month comment period,<sup>138</sup> and would not become effective until after HHS personnel evaluated comments received during this period.<sup>139</sup>

In retrospect, the preliminary rule's "hotline" strategy, which the proposed rule would continue, proved ineffective. Of 600 calls received on the hotline from March 17th to April 14th, 1983, only five warranted further action.<sup>140</sup> But more significantly, administrative action on the issue of withholding treatment from defective infants by HHS is manifestly inappropriate. Regardless of any moral position on the issue, regulating a problem with such enormous moral and ethical implications should not be attempted without thoroughly discussing and considering all factors involved. This process should be left to the legislature, not to administrative action. Only a legislative setting can provide the appropriate forum for discussion that the issue of withholding treatment from defective infants requires.

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135 See note 117 *supra*.

136 Proposed Rule, *supra* note 131, at 30851. The proposed rule says these procedures shall include:

- (1) A requirement that health care providers report immediately to the State agency suspected cases of medical neglect of handicapped infants;
- (2) A method by which the agency can receive reports of suspected medical neglect of handicapped infants from health care providers, other individuals, and the Department on a timely basis;
- (3) Immediate review of reports of suspected medical neglect of handicapped infants and, where appropriate, onsite investigation of such reports;
- (4) Provision of child protective services to medically neglected handicapped infants, including, where appropriate, seeking a timely court order to compel the provision of necessary nourishment and medical treatment; and
- (5) Immediate notification to the Department's Office for Civil Rights of each report of suspected medical neglect of a handicapped infant, the steps taken by the agency to investigate such report, and the agency's final disposition of such report.

*Id.* at 30851.

137 See note 123 *supra*.

138 Proposed Rule, *supra* note 131, at 30846. When the September 6, 1983, deadline for comments had arrived, HHS had received over 16,000 comments on the proposed rule. Telephone conversation with S. Shalhoub, Office of Civil Rights, Department of Health and Human Services (Sept. 29, 1983).

139 HHS personnel estimated the rule would not become effective until December 1983 or January 1984. *Id.* Court challenges could further delay the effective date.

140 Annas, *supra* note 125, at 16.

### III. Legislation

#### A. *Past Proposals*

Since 1973 when the debate on the treatment of defective infants began, prominent figures in the legal, medical, and related professions have proposed several different approaches to legislative treatment. The medical profession itself does not agree that one approach is best. The majority believes that parent-physician autonomy should be left intact,<sup>141</sup> and that ideological criticism and threats of criminal prosecution make the decision to withhold treatment much more difficult.<sup>142</sup> These doctors reason that since families and their physicians are intimately aware of all the factors involved, and since families bear the burden of living with their decision, they should be allowed to decide whether or not to withhold treatment.<sup>143</sup> The majority of doctors therefore believe that parents and physicians should be allowed great latitude in making decisions affecting defective infants—as long as they remain within certain general guidelines.<sup>144</sup>

A minority of doctors believe, however, that the parent-physician autonomy approach is inappropriate because of the circumstances under which such decisions are usually made.<sup>145</sup> They argue that parents, emotionally shocked by their defective child and counseled by unfamiliar professionals in an unfamiliar hospital environment, are in no position to make a life or death decision for their child.<sup>146</sup> The United States Surgeon General, Doctor C. Everett Koop, rejects every argument for withholding treatment, calling this practice “infanticide.”<sup>147</sup> Koop believes that continued reliance on

141 See, e.g., Campbell & Duff, *Special Care Nursery*, *supra* note 7, at 893; Garland, *Care of the Newborn: The Decision Not to Treat*, 1 PERINATOLOGY/NEONATOLOGY 14, 15 (Sept.-Oct. 1977); Garland, Jonsen, Phibbs & Tooley, *Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIAT. 756, 761, 763-64 (1974); Havard, *Legislation is Likely to Create More Difficulties than it Resolves*, 9 J. MED. ETHICS 18, 20 (1983); Krane, Howell, Shannon & Todres, *Pediatrician's Attitudes Affecting Decision Making in Defective Newborns*, 60 PEDIAT. 197, 199 (1977).

142 Campbell & Duff, *Seven Years*, *supra* note 7, at 28.

143 Campbell & Duff, *Special Care Nursery*, *supra* note 7, at 893-94.

144 *Id.*

145 See, e.g., Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 PEDIAT. 321, 322-23 (1981); Diamond, *Treatment Versus Non-Treatment for the Handicapped Newborn*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 55, 62 (D. Horan & N. Delahoyd eds. 1982); Sherlock, *Selective Non-Treatment of Newborns*, 5 J. MED. ETHICS 139, 139 (1979); Waldman, *Medical Ethics and the Hopelessly Ill Child*, 88 J. PEDIAT. 890, 890-91 (1976); Editorial, *Severely Handicapped Infants*, 7 J. MED. ETHICS 115, 116 (1981).

146 Diamond, *supra* note 145, at 62-63.

147 Koop, *Ethical and Surgical Considerations in the Care of the Newborn with Congenital Abnormal-*

parental-physician autonomy in the treatment decision is intolerable.<sup>148</sup>

In its recent report, *Deciding to Forego Life-Sustaining Treatment*, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research ("President's Commission") criticized governmental intrusion into the parent-physician decision process and endorsed an informal approach.<sup>149</sup> The Commission recommended that hospitals be required to institute a review process for cases when parents and attending physicians decide to withhold treatment from a defective infant. The Commission suggested that this process include an ethics committee review of the most difficult cases.<sup>150</sup> The Commission stated that such a process would guarantee an objective discussion of the relevant issues while avoiding the public exposure that a court proceeding involves.<sup>151</sup> The Commission also recommended that courts should involve themselves only when the "rapidly deteriorating medical status" of a defective infant required parents and physicians to act without the review.<sup>152</sup> Courts would then conduct a "retrospective review . . . [to] ensure a high standard of decision making practices . . . ."<sup>153</sup>

Most legal commentators agree with the minority of doctors that the decision of whether or not to treat a defective infant should not be left to parents and physicians.<sup>154</sup> However, legal commentators have suggested approaches for formulating decision-making mechanisms different from those suggested by the medical profession. Professor John G. Robertson<sup>155</sup> suggested that a decision-making

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*ities*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 89 (D. Horan & N. Delahoyd eds. 1982).

148 *Id.* at 103. Interestingly, in an article written by the parents of a defective infant, the parents also argued that, because of the problems inherent in the situation, parents and hospitals should not be left without guidance in deciding whether or not to treat. Bridge & Bridge, *supra* note 8, at 19 ("Since the pediatric profession does not approach these infants with any degree of consistency, and has its own conflicts of interest, we regard any decision making by concerned physician and parents behind closed doors of the pediatric unit as a haphazard approach."). See also Stinson & Stinson, *supra* note 27, at 8-10.

149 President's Commission, *supra* note 126, at 227.

150 *Id.* The report stated these reviews would include those cases in which life-sustaining therapy has been withheld because of a physical or mental handicap. *Id.*

151 *Id.*

152 *Id.* at 228.

153 *Id.* at 228 n.99.

154 See, e.g., Robertson, *supra* note 6, at 414 ("By any standard, this is not the optimum time for parents to make life and death decisions with respect to this newborn.").

155 Professor Robertson, who has written extensively on the issue of withholding treatment from defective infants, teaches in the law school and in the Program in Medical Ethics at the University of Wisconsin.

body operating under legislative guidelines should decide whether treatment should be withheld. He felt such guidelines would represent a collective social judgment rather than the "idiosyncratic choices of parents or committees."<sup>156</sup> Professor Robertson admitted that articulating acceptable criteria for when treatment should be withheld would be difficult, but insists that it is nonetheless necessary.<sup>157</sup> He also recommended that, to ensure consistency, parents should follow mandatory procedures after a defective infant's birth.<sup>158</sup> These steps would include instituting a mandatory seven day waiting period during which no treatment could be withheld, providing counseling sessions for the parents with social workers, and providing parents with access to all information on agencies available to assist them should their child live.<sup>159</sup>

Another legal commentator suggested judicial review of parental decisions, but only if that decision is to withhold treatment.<sup>160</sup> This judicial review would be limited to consideration of only two issues: the infeasibility of treatment<sup>161</sup> and the decision-making process.<sup>162</sup>

Several commentators have stated that courts, acting under legislative guidance, are the appropriate decision-making bodies.<sup>163</sup> One author, T.S. Ellis, III, suggested the novel approach of creating a decisional matrix to guide courts' decisions.<sup>164</sup> Within this matrix, the court would consider the infant's particular defective condition, the treatment necessary to correct that condition, current medical capabilities, and the economic, psychological, and moral impact on the family and society.<sup>165</sup> Ellis concluded that legislative guidance

<sup>156</sup> Robertson, *supra* note 6, at 266.

<sup>157</sup> *Id.* at 267. He compared the problem of drafting criteria for withholding treatment with the problem of drafting the definition of brain death. *Id.* at 269. Robertson's view is realistic. The task of articulating such criteria should not be avoided because of its difficulty.

<sup>158</sup> *Id.* at 267.

<sup>159</sup> The Arizona legislature included informational requirements similar to those Robertson suggested in their legislation concerning withholding treatment from defective infants. *See* note 182 *infra* and accompanying text.

<sup>160</sup> Note, *Birth Defective Infants: A Standard for Non-Treatment Decisions*, 30 STAN. L. REV. 599, 629-31 (1975).

<sup>161</sup> Treatment is infeasible, according to the commentator, in situations of imminent death and irreversible unconsciousness. *Id.* at 631.

<sup>162</sup> The proper decisional process, according to the commentator, is: 1) a prognosis of infeasibility by the physician; 2) parental understanding of all options; and, 3) a final parental decision to withhold treatment. *Id.* at 628, 632.

<sup>163</sup> *See, e.g.*, Ellis, *supra* note 6, at 415-18; Longino, *supra* note 6, at 403-05 ("Courts and the judicial process might serve as a more appropriate decision making forum.")

<sup>164</sup> Ellis, *supra* note 6, at 418-21.

<sup>165</sup> *Id.*

was imperative: "It is simply society's duty, through the legislative process, to decide and communicate the decision clearly for guidance to all."<sup>166</sup>

### B. *State Legislation*

Despite the medical community's suggestion that the decision to withhold treatment be left to parents and physicians, several state legislatures have passed legislation that restricts parent-physician autonomy. These statutes all have positive aspects, but unfortunately, most do not provide the guidance needed in those exceptional situations where life-sustaining treatment, by all ethical standards, should be withheld from a defective infant.

The Pennsylvania legislature integrated legislation on withholding treatment from defective infants with their abortion regulation laws.<sup>167</sup> The statute classifies all human beings born alive as "persons" under the Pennsylvania Constitution.<sup>168</sup> Some commentators have suggested criteria for "personhood" that would exclude defective infants, thereby denying them constitutional protection.<sup>169</sup> The Pennsylvania statute, however, safeguards severely defective newborn infants' constitutional protections by clearly including them in its definition of "person."

The statute further provides:

All physicians . . . attending a child who is born alive . . . shall provide such child that type and degree of care and treatment which, in the good faith judgment of the physician, is commonly and customarily provided to any other person under similar conditions and circumstances.<sup>170</sup>

The phrase "commonly and customarily provided to any other person under similar conditions and circumstances" in this statute is ambiguous. In the case of a child born with spina bifida with myelomeningocele, as in *Matter of Cicero*,<sup>171</sup> a "person under similar conditions and circumstances" would be another infant born with these defects. The treatment of such infants is currently a topic of

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166 *Id.* at 423.

167 PA. STAT. ANN. tit. 18, § 3212 (Purdon Supp. 1974-1982).

168 *Id.* § 3212(a).

169 *See, e.g.,* Fletcher, *Four Indicators of Humanhood—The Inquiry Matures*, 4 HASTINGS CENTER REP. 4, 5-6 (Dec. 1974). Fletcher suggested four criteria for personhood: neocortical function, self-consciousness, relational ability, and happiness. *Id.*

170 PA. STAT. ANN. tit. 18, § 3212(b) (Purdon Supp. 1974-1982).

171 *See* notes 39-47 *supra* and accompanying text.



debate in the medical profession;<sup>172</sup> thus, “commonly and customarily” has no meaning in this instance and its application fails to guide a court facing the decision. As the *Heckler* court noted, “there is no customary standard of care for the treatment of severely defective infants.”<sup>173</sup>

The Pennsylvania statute has several other deficiencies. The statute does not grant immunity to physicians for treating a newborn without parental consent. Such immunity is necessary to insulate a doctor from civil liability for treating a critically ill defective infant if the parents refuse consent for the treatment. The statute also establishes no reporting requirements. Because decisions to withhold treatment were seldom reported in the past, such reporting requirements are essential to make such legislation effective. The Pennsylvania statute also has no provisions to assist the parents of a defective infant. Such provisions should: (1) require that information be provided to the parents of a defective newborn on the various public agencies that are available to assist them; and (2) establish a mechanism for parents who do not wish to care for their infant to relinquish custody of the child.

The Arizona legislature recently enacted legislation concerning withholding treatment from defective newborn infants which does not have many of the deficiencies of the Pennsylvania statute.<sup>174</sup> The Arizona statute forbids the denial of food, water, nutrients, or oxygen from newborn infants.<sup>175</sup> Such a clause is necessary to prevent cases such as *Mueller*<sup>176</sup> and *Infant Doe*<sup>177</sup> from recurring. The suggestion by some doctors that active euthanasia be employed to hasten the death of defective infants<sup>178</sup> provides further justification for the clause. The statute also forbids the denial of “necessary life-saving

172 See, e.g., Lorber, note 7 *supra*; Zachary, *Give Every Baby a Chance*, 147 NURSING MIRROR 17 (1978).

173 *Heckler*, memorandum accompanying order at 13.

174 Act of Apr. 27, 1983, 1983 Ariz. Legis. Serv. 1112 (West)(to be codified at A.R.S. §§ 13-3620 and 36-2281) (effective July 1, 1984)[hereinafter cited as Act].

175 *Id.* § 36-2281(A).

176 See notes 48-58 *supra* and accompanying text.

177 See notes 69-90 *supra* and accompanying text.

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

medical treatment or surgical care" from newborns.<sup>179</sup> Thus, this statute would effectively prevent the *Infant Doe* situation, where parents and their physician denied an infant the surgery necessary to correct a tracheo-esophageal fistula.

Unlike the Pennsylvania statute, the Arizona statute contains several enforcement provisions. The statute establishes reporting requirements for health care personnel and provides absolute immunity from civil or criminal liability to those making these reports.<sup>180</sup> It also requires health care institutions to inform their personnel of these reporting requirements.<sup>181</sup>

The Arizona statute also has an informational requirement. Health care institutions must provide parents of handicapped newborns with information concerning agencies available to assist them.<sup>182</sup> This requirement ensures that parents of a defective infant can make an informed decision about their newborn, knowing what assistance they can expect from these agencies.

The Arizona statute's weakness is that it allows parents and their physician, while exercising competent medical judgment, to withhold treatment not necessary to sustain life, or treatment where the "potential risk to the child's life or health outweighs the potential benefits."<sup>183</sup> This language presents two problems. First, the terms "potential risk" and "potential benefit" are ambiguous. The statute does not define them and they are therefore subject to broad interpretation. Applying this statute to the *Mueller* situation,<sup>184</sup> the parents would have been able to prevent the surgery that separated the twins since a great risk is involved in such surgery, and the operation was not necessary to save the twins' lives. Second, the statute allows parents and physicians to make the decision to withhold treatment under these circumstances without review. But, continued parent-physician autonomy is inherently unfair to the infants involved. Because of the emotional, confused, and vulnerable state parents are in following the birth of a defective infant, they are very dependent upon their physician's advice. However, given the current diversity in medical opinion on this issue, the advice of these physicians can

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179 Act, *supra* note 174, § 36-2281(B).

180 *Id.* § 13-3620(A). The statute also provides immunity from civil liability and disciplinary action for these reports. *Id.* §§ 13-3620(D), 36-2282(B).

181 *Id.* § 36-2282(A).

182 *Id.* § 36-2283.

183 *Id.* § 36-2281(C).

184 *See* notes 48-58 *supra* and accompanying text.

vary immensely.<sup>185</sup> Thus, whether an infant receives life-saving treatment and survives, or is denied this treatment and “allowed” to die, depends primarily on the fortuity of the attending physician’s personal views. Unfortunately, the Arizona statute allows this situation to continue within guidelines so ambiguous that they provide no guidance at all.

The Louisiana statute on withholding treatment from defective infants<sup>186</sup> is similar to the Arizona statute. It provides that:

No infant born alive shall be denied food, nutrients, water, oxygen . . . [or] medical or surgical care necessary to attempt to save the life of the child . . . despite the opinion of the . . . parents . . . physicians, or others that the quality of the child’s life would be deficient . . . .<sup>187</sup>

Also like the Arizona statute, the Louisiana statute establishes several reporting requirements.<sup>188</sup>

The Louisiana statute, however, includes several useful provisions not included in the Arizona legislation. The statute allows “any agency, institution, or person interested in the child’s welfare” to institute enforcement proceedings in juvenile court and provides that the court shall appoint an attorney to represent the infant.<sup>189</sup> This provision strengthens the statute’s enforcement provisions by granting anyone standing to protect an infant’s well-being. The Louisiana statute also allows doctors to proceed with treatment of a defective infant when parents refuse to consent to such treatment.<sup>190</sup> The statute also provides that parents of a defective infant may at any time surrender the child to an adoption agency, at which time the agency will immediately provide the infant with necessary treatment.<sup>191</sup> This provision allows parents who do not want the responsibility of raising their defective infant an alternative other than ordering their

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185 This problem has even been pointed out in medical literature. *See, e.g.*, Waldman, *supra* note 129, at 891 (“I find the ethics and morality of the neonatal intensive care unit a total enigma. In some places the neonatal intensive care unit is committed to the role of salvaging every infant. . . . And in . . . other intensive care units, neonatologists admit that they allowed infants to die . . . by administratively withholding treatment . . . .”); Editorial, *The Right to Live and the Right to Die*, 283 BRIT. MED. J. 569, 569 (1982) (“[G]uidance given to parents varies among doctors—it is likely to be pragmatic and personal . . . .”).

186 LA. REV. STAT. ANN. § 1299.36.1-36.3 (West Supp. 1983).

187 *Id.* § 1299.36.1(A)-1(B).

188 *Id.* § 1299.36.2(B).

189 *Id.* § 1299.36.3(A).

190 *Id.* § 1299.36.2(C).

191 *Id.* § 1299.36.2(A).

doctor to withhold treatment.<sup>192</sup>

The Louisiana statute allows parents and physicians, exercising competent medical judgment, to withhold treatment from a defective infant in two situations: (1) when the potential risks to the child's life or health outweigh the potential benefits of survival, and (2) when a child is in a "continual profound comatose state" with "no reasonable chance of recovery. . . ."<sup>193</sup> The first clause suffers from the same vagueness problem as the Arizona statute. The second clause, however, is a more effective attempt to provide guidance for when treatment may be withheld. However, a legislative commission<sup>194</sup> should further define what constitutes a "continual profound comatose state" to prevent misinterpretation of the clause. Unfortunately, even though the Louisiana statute's guidance may be somewhat better than the Arizona statute's, it still leaves the decision of when to withhold treatment from a defective infant to the parents and their physician. Any future legislation should instead allow only courts to make this decision.

### C. Recommended Legislation

The Pennsylvania, Arizona, and Louisiana statutes have a basically similar approach to the problem of withholding treatment from defective infants. These statutes presume that *all* defective infants should be treated, and allow treatment to be withheld from these infants only in *exceptional* circumstances. This approach is consistent with both the value our society places on human life and with fourteenth amendment guarantees. Each statute has its strengths and weaknesses. Combining the best aspects of each statute would result (with the addition of item eight) in a statute containing the following:

- (1) A statement defining "persons" to include any infant born alive, regardless of his condition at birth;
- (2) A clause which absolutely forbids withholding food, nourishment, water, or oxygen from a newborn infant;
- (3) A clause which forbids withholding medical or surgical care when such care is necessary to save the infant's life;
- (4) A section which requires medical personnel to report all cases where treatment is withheld from a defective infant. This sec-

192 *Id.* It also gives the infant an opportunity for a home with adoptive parents who care for it rather than biological parents who do not want the infant.

193 *Id.* §§ 1299.36.2C, 1299.36.2D.

194 Such a commission should be composed of physicians, lawyers, clergy, and other qualified professionals.

tion should also require health care institutions to inform their employees of these requirements and to instruct them in how to make such reports;

(5) A method whereby the parents of a defective infant can quickly and voluntarily surrender custody of their child for treatment and eventual adoption, should they so desire;

(6) A requirement that health care institutions provide the infant's parents with information on agencies which are available to assist and counsel them should they desire to proceed with treatment *and* retain custody of the child;

(7) Civil and criminal immunity for medical personnel who comply with the statutory reporting requirement and for doctors who proceed with treatment without parental consent; and,

(8) A clause permitting a court to order treatment to be withheld from a defective infant under specifically defined circumstances.

Even the most outspoken advocates of treatment for defective infants admit situations exist where treatment would be futile.<sup>195</sup> Rather than allowing unquestioned parent-physician discretion in these cases, item eight requires that decisions to withhold treatment be made by courts acting within legislative guidelines. In the past, courts acting *without* legislative guidance have acted inconsistently. The court in *Infant Doe*<sup>196</sup> permitted parents to withhold food from a Down's syndrome infant who had a relatively minor physical defect, while the court in *Matter of Cicero*<sup>197</sup> ordered treatment of an infant with a more serious physical defect. Item eight would allow courts to order treatment withheld from a defective infant under "specifically defined circumstances." However, these circumstances must be painstakingly defined by a legislative committee after thorough de-

195 For example, Dr. Koop has stated:

[M]edicine may *never* have all the solutions to all the problems that occur at birth. I personally foresee no medical solution to cephalodymus or an anencephalic child. The first is a one-headed twin; the second, a child with virtually no functioning brain at all. In these cases the prognosis is an early and merciful death by natural causes. There are no so-called "heroic measures" possible and intervention would merely prolong the patient's process of dying.

Some of nature's errors are extraordinary and frightening . . . but nature also has the kindness to take them away. For such infants, neither medicine nor law can be of any help. And neither medicine nor law should prolong these infants' process of dying.

*Handicapped Infants: Over-sight Hearing on the Treatment of Handicapped Infants Born with Other Defects Before the Subcomm. on Select Education of the House Comm. on Education and Labor, 97th Cong., 1st Sess. 5 (1982)* (statement of Dr. C. Everett Koop, U.S. Surgeon General, Department of Health and Human Services).

196 See notes 69-90 *supra* and accompanying text.

197 See notes 39-47 *supra* and accompanying text.

liberation. This committee, consisting of physicians, lawyers, and other qualified lay persons, could thus provide the concrete guidance courts need for consistent decisions. Even though requiring a court order to withhold treatment might be awkward, such a requirement accords with the presumption of treatment for all defective infants and provides a degree of consistency and fairness which these decisions require. Additionally, courts and legislatures could develop procedures to expedite judicial action and minimize the delay in obtaining an order.

Legislation to preserve the lives of all but the most defective infants carries with it the responsibility to provide assistance to the infants and their families. Legislatures must not overlook this responsibility, and must provide funds to support medical payment assistance, counseling, and special training and educational programs.<sup>198</sup>

#### IV. Conclusion

Those confronted with the decision of whether or not to treat a defective infant face an enormous ethical and moral dilemma. The many inconsistencies associated with past decisions illustrate the necessity for a legislative solution. To permit parents and physicians to make these decisions on an *ad hoc* basis is unfair to the infants involved. The distraught parents of a defective newborn infant are unduly influenced by the attending physician's advice and that advice can vary greatly from one physician to another. Whether a defective infant lives or dies should not depend upon the fortuity of the delivering physician's personal views.

Only courts, guided by legislation, can ensure that fair and consistent decisions are reached. Requiring a court order to withhold treatment from a defective infant may be cumbersome, but procedures to facilitate rapid judicial response could be developed. Our society provides an elaborate review mechanism to criminals sentenced to death. Society certainly owes innocent defective infants similar safeguards when the decision to withhold treatment from them is just as final as a death sentence.

*John M. Maciejczyk*

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198 *Accord*, President's Commission, *supra* note 110, at 228-29. The commission stated that the decision to provide life-sustaining treatment to newborns creates an obligation to provide the "continuing care that makes a reasonable range of life choices possible." *Id.*