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Let Live and Let Die: Disabled Newborns and Contemporary Law

JEFFREY A. PARNES* and ROGER STEVENSON**

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I. INTRODUCTION

Every child which is born into this world shall be reared, baptized, and carried to the church except that . . . which is born so deformed that the mother cannot give strength to it It shall be carried to a beach and buried where neither men nor cattle go; that is the beach of the evil one.¹

Although this ancient Norse law seems barbaric in modern times, several thousand infants die in the United States each year as a result of parental² decisions to withdraw or withhold necessary medical treatment.³ Physicians implement these decisions in treat-

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1. Rickham, *The Ethics of Surgery in Newborn Infants*, 8 CLIN. PEDIATRICS 251, 253 (1969) (quoting J.W. BALLANTINE, *MANUAL OF ANTENATAL PATHOLOGY AND HYGIENE* (1904)).

2. The term "parental" includes guardians and those who are not the natural parents but are nonetheless responsible for the care of newborns.

3. MEDICAL ETHICS: THE RIGHT TO SURVIVAL, 1974: HEARINGS ON EXAMINATION OF THE MORAL AND ETHICAL PROBLEMS FACED WITH THE AGONIZING DECISION OF LIFE AND DEATH BEFORE THE SUBCOMMITTEE ON HEALTH OF THE SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE, 93d Cong., 2d Sess. 26 (1974) [hereinafter cited as 1974 HEARINGS] (statement of Dr. Robert E. Cooke). Dr. Cooke extrapolated the "several thousand" figure based on a report that between January 1, 1970 and June 30, 1972, 43 out of 299 (14%) infant deaths in the Yale-New Haven Hospital Intensive Care nursery were "associated with discontinuance or withdrawal of treatment." *Id.* at 26. Duff & Campbell, *Moral and Ethical Dilemmas in*

ing infants born with disabilities that impose severe limitations on mental and physical capacities but do not shorten the infant's potential life span.⁴ Regarding such infants, one commentator noted:

Until recent developments in surgery and pediatrics, these infants would have died of natural causes. Today with treatment many will survive for long periods, although some will be severely handicapped and limited in their potential for human satisfaction and interaction. Because in the case of some defective newborns, the chances are often slim that they will ever lead normal human lives, it is now common practice for parents to request, and for physicians to agree, not to treat such infants. Without treatment the infant usually dies.⁵

Although medical technology can now prevent the early deaths of these infants, the necessary medical treatment is often withdrawn or withheld.

the Special-Care Nursery, 289 NEW ENG. J. MED. 890, 891 (1973). See also Ellis, *Letting Defective Babies Die: Who Decides?*, 7 AM. J. L. & MED. 393 n.1 (1982). Other physicians and clergymen commenting on the ethics of withdrawing treatment from a newborn have used actual case histories rather than empirical studies. Their research suggests that hospitals make such decisions every day. Though difficult to document or even estimate, the frequency of withdrawing medical treatment is high enough that ethical questions must be raised. Shaw, *Dilemmas of "Informed Consent" in Children*, 289 NEW ENG. J. MED. 885 (1973) (presenting six case reports from Shaw's own practice of pediatric surgery); McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J. A.M.A. 172 (1974) (discussing the "Baby Boy Houle" case and the "Johns Hopkins" case). See also McLaughlin & Shurtleff, *Management of the Newborn with Myelodysplasia*, 18 CLIN. PEDIATRICS 463, 473-74 (1979) (recommending less than aggressive treatment of certain defective newborns); Lorber, *Results of Treatment of Myelomeningocele*, 13 DEV. MED. CHILD NEUROL. 279 (1971) (stating that doctors should not treat all children with myelomeningocele even though, absent treatment, 60-80% will die); cf. *Editor's Column: Is There a Right to Die—Quickly?*, 80 J. PEDIATRICS 904 (1972) (noting that some untreated patients do survive but their condition is poorer than if they had received early treatment).

The treatment that is withheld varies from simple surgery, such as correction of an intestinal blockage or closure of an open spinal cord, to more complex surgery such as positive-pressure ventilation (i.e., connection to a respirator). Infants with uncorrected intestinal blockages are left without food until they die. See, e.g., Duff & Campbell, *supra*, at 891. The untreated condition which leads to death is often unrelated to the defect that prompted the decision. For example, doctors could always correct an intestinal blockage in a child who was otherwise normal, but they may not be able to correct the blockage in a child having Down's syndrome (Mongolism). See McCormick, *supra*, at 172.

Relevant disabilities include ancephaly, hydrocephaly, Down's syndrome, spina bifida, central nervous system disorders, myelomeningocele, Tay-Sachs disease, Lesch-Nyhan syndrome, Trisomy 13, and Trisomy 18.

4. For concise descriptions of the manifestations and prognoses of these various conditions, see Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975), and Note, *Birth-Defective Infants: A Standard for Nontreatment Decisions*, 30 STAN. L. REV. 599 (1978).

5. Robertson, *supra* note 4, at 214.

The Vikings addressed the problem of deformed children by statute. Their law dictated that certain children would live, while others would die; the state, rather than the physician or parent, was the determining voice. Contemporary American policy, expressed in homicide, child abuse and child neglect statutes is contrary: American laws protect all forms of human life.⁶ Yet, such laws are not always followed in situations involving disabled newborns.⁷

Both the ancient Norse law and contemporary American policy view different treatment of disabled newborns to be appropriate. Once a society adopts this view, it must then develop rational categorizations of those who are to be subject to differing treatment. The Norse law attempted to provide a standard for distinguishing between those infants who were to live and those who were to die. The distinction was whether the infant was so "deformed" that the mother could not give it strength. In a sense, the mother had the decisionmaking authority, since it was her ability to give strength that was determinative.

Unlike the Norse law, contemporary American policy evinces no standards as to the infant's treatment. Although precise equality of treatment is neither workable nor warranted, the contemporary unbridled discretion in the treatment of disabled newborns raises serious constitutional and ethical questions. In recent years, our society has begun to address these questions.⁸ Advances in the degree of state protection afforded children and incompetents, and the emerging protections afforded by the federal constitutional right of privacy, necessitate further legal recognition of the rights and needs of disabled newborns.

II. THE UNSATISFACTORY STATE OF PREVAILING LAW

Advances in medical technology dramatically decreased the infant mortality rate in the United States between 1940 and 1970.⁹

6. Of course, some view abortion as an exception to the general statement. To others, marital rights regarding abortion are founded on the view that the fetus is not a form of human life. Even when the fetus is not deemed a form of human life, its potentiality for life can be protected. Parness & Pritchard, *To Be or Not to Be: Protecting the Unborn's Potentiality of Life*, 51 U. CIN. L. REV. 257 (1982).

7. Robertson, *supra* note 4, at 217-44. Professor Robertson concluded: "Although a clear basis for prosecution exists, no parent or physician has to date been criminally prosecuted for withholding ordinary medical care from a defective infant." *Id.* at 243.

8. See, e.g., Robertson, *supra* note 4; Note, *supra* note 4; Ellis, *supra* note 3; Brant & McNulty, *Treating Defective Newborns*, 10 HUMAN RIGHTS 35 (1982).

9. Duff & Campbell, *supra* note 3, at 890.

One of the results of a low mortality rate is that many infants emerge from neonatal intensive care units requiring continual medical treatment. These infants receive a dim prognosis for a normal life.¹⁰ Some newborns can only expect to survive within a closed environment of medical life support systems and professional care.

Current medical practice in treating these more severely handicapped newborns varies. Medical care often hinges upon whether the required treatment program is deemed "ordinary" or "extraordinary,"¹¹ whether the infant has the potential to enjoy human relationships,¹² whether the parents or guardians desire to pursue treatment in light of the family's socioeconomic and emotional state,¹³ whether the treatment decision requires withdrawing or withholding medical attention,¹⁴ and whether the treatment is life-prolonging or life-preserving.¹⁵ While certain medical practitioners undoubtedly seek to treat severely disabled newborns regardless of the nature of the treatment or the family members' desires, the nontreatment of such newborns is a common occurrence in hospitals and other health care facilities throughout the United States.¹⁶ Indeed, it has been argued that nontreatment may be "good medical practice."¹⁷ Although nontreatment is common, there appears to be little commonality in the treatment of disabled newborns. A prominent physician testifying before Congress stated, "It is disquieting to discover that infants apparently have an identical condition and may be treated differently, and some may survive and some not[,] . . . but that is the way it is."¹⁸ Al-

10. Ellis, *supra* note 3, at 420.

11. Distinctions between ordinary and extraordinary care suggest a prior decision to formulate a treatment plan. See Robertson, *supra* note 4, at 420.

12. McCormick, *supra* note 3, at 175.

13. Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645 (1977).

14. The traditional distinction between active and passive euthanasia is criticized in Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78 (1975).

15. In a well-known case, the court observed that physicians distinguished "between curing the ill and comforting and easing the dying; that they refuse to treat the curable as if they were dying or ought to die; and that they have sometimes refused to treat the hopeless and dying as if they were curable." *In re Quinlan*, 70 N.J. 10, 47, 355 A.2d 647, 667 (1976).

16. 1974 HEARINGS, *supra* note 3.

17. Robertson, *supra* note 4, at 214. But see Strong, *The Tiniest Newborns*, 13 HASTINGS CENTER REP. 14 (1983) (finding no convincing arguments for withholding aggressive treatment of very low birth-weight infants).

18. 1974 HEARINGS, *supra* note 3, at 17 (statement of Dr. Raymond S. Duff); see also Editor's Column, 80 J. PEDIATRICS 904-07 (1972) (two opinions regarding children born with meningomyeloceles); Ellis, *supra* note 3, at 401; Chabon, *You May Face a Nightmare in the*

though the law should not require health care professionals to provide only one type of treatment for each particular ailment, the widespread disparity of treatment may not be justifiable.

Some legal commentators have suggested that present practices are unlawful.¹⁹ They argue that abandoning medical treatment of newborns undermines statutes on homicide, child abuse, child neglect, and child abuse reporting.²⁰ One court noted:

Ultimately, we must face the fact that technological advances in medicine have generally outpaced the ability of the judicial system to deal comprehensively with them in a manner consistent with the fulfillment of social policy objectives.

. . . .

. . . Clearly, it would be desirable for the State Legislature to address itself to these issues which are so interwoven with fundamental questions of public policy. But the fact is that it has not done so.²¹

The delay in legislation is surprising and distressing. Existing statutes do not harmonize contemporary medical practice with contemporary social values. The failure to update statutory law in this area adds to the confusion among the decisionmakers in the neonatal unit. Furthermore, lawmakers have ignored recent decisions involving the right to privacy and the concept of substituted judgment.²² Lawmakers should consider these decisions along with social policy objectives when they finally update statutes concerning medical treatment for disabled newborns.

Newborn Nursery, 7 LEGAL ASPECTS OF MED. PRAC. 43, 45 (June 1979).

19. Robertson, *supra* note 4, at 217-44; Ellis, *supra* note 3, at 401-10.

20. See, e.g., CAL. HEALTH & SAFETY CODE §§ 275, 286(B) (West Supp. 1982) (promoting health care for critically ill newborns).

21. *Eichner v. Dillon*, 73 A.D.2d 431, 447, 452, 426 N.Y.S.2d 517, 531, 534 (1980), *modified sub nom. In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981); see also Parness, *The Duty to Prevent Handicaps: Laws Promoting Prevention of Handicaps to Newborns*, 5 W.N. ENG. L. REV. 431, 433 (1983) (lamenting the time lag between medical and scientific advances and laws promoting prevention of handicaps to newborns).

22. Note, *supra* note 4, at 608-09 (briefly exploring the possible applicability of the privacy right in *Quinlan* to incompetent infants); Ellis, *supra* note 3, at 405-07 (finding *Quinlan* inapplicable). Also relevant, but not discussed here, are the equal protection rights of disabled newborns. Because disabled newborns seemingly do not belong to any suspect class, due process requires greater freedom from state intrusion than does equal protection. Of course, statutes can mandate equal protection. See, e.g., Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (1974) (codified at 29 U.S.C. §§ 701-94 (1976 & Supp. V 1981)).

III. ADJUSTING LEGAL GUIDELINES FOR DETERMINATIONS OF MEDICAL TREATMENT OF DISABLED NEWBORNS

Decisions to withdraw or withhold medical treatment from disabled newborns implicate the interests of those within and without the decisionmaking process. Those within the process include the newborn, the parents and other family members, and the medical staff and health care facility involved in the treatment. The public remains outside the decisionmaking process. Presumably, the government represents their interests.

Undoubtedly, the interests of the newborn are paramount. The constitutionally protected right to privacy is often involved in the treatment decision; therefore, the newborn's interests cannot be undermined absent compelling reasons.²³ This constitutional right may also be involved in the private or nonpublic health care setting.²⁴ Where the federal constitutional right is not relevant, the state's strong interest in protecting the sanctity of human life still makes the newborn's interests paramount.²⁵ The newborn's primary interests are continued life as well as the contrary interest in the termination of life. Of course, only one of the two interests can prevail in the decision involving life-sustaining medical treatment.²⁶

While some commentators have suggested that the Constitution does not protect the interests of disabled newborns,²⁷ United

23. See, e.g., *Roe v. Wade*, 410 U.S. 113, 155 (1973).

24. Often the constitutional right arises because the state has established a mechanism, usually within the judiciary, by which one private party can seek to vindicate individual rights of another private party. Consider, for example, petitions seeking judicial orders authorizing termination of medical treatment of terminally ill incompetent adults. *Quinlan*, 70 N.J. at 18, 355 A.2d at 651; *Eichner*, 73 A.D.2d at 460, N.Y.S.2d at 540; see also *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).

25. *Quinlan*, 70 N.J. at 10, 40, 355 A.2d at 647, 663 (1976) (recognizing the New Jersey constitutional right to privacy); *In re Guardianship of Richard Roe, III*, 1981 Mass. Adv. Sh. 1189, 421 N.E.2d 40 (Mass. 1981) (relying on state common law in finding individual's right to decide about potentially dangerous medical treatment involving antipsychotic drugs). Of particular importance is Louisiana's recent enactment entitled *Preserving the Life of Children*, LA. REV. STAT. ANN. § 40:1299.36.1 (West 1977), said to be the first state law of its kind. *Louisiana Enacts Bill on Newborn Care*, HASTINGS CENTER REP. Dec. 1982 at 2; see also CAL. HEALTH & SAFETY CODE § 275 (West Supp. 1982) (legislative policy of protecting the health of critically ill newborn children).

26. Thus, when a constitutionally protected privacy right based on an individual's interest in termination of life is asserted, the individual's interest in continued life becomes part of the state's attempt to demonstrate contrary compelling interests.

27. See, e.g., *Ellis*, *supra* note 3, at 405-07; Note, *supra* note 4, at 609, 615-16 n.88. But see Robertson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, in *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, 213, 224 (1982).

States Supreme Court opinions clearly suggest the opposite. In *Roe v. Wade*,²⁸ for example, although the Court held that the fetus was not a "person" within the meaning of the fourteenth amendment, it went on to suggest that the term "personhood" included all postnatal forms of human life.²⁹ Arguments that distinctions should be made among postnatal forms of human life, suggesting that some postnatal lives are outside the parameters of personhood, are without credible precedent in American jurisprudence.³⁰

Notwithstanding the newborn's interests, the interests of others are, at times, sufficient to override the newborn's interests in the treatment decision. Some of these other interests also involve constitutional concerns, such as parental autonomy³¹ and family integrity.³² In any treatment decision, the relevant interests must be considered and balanced according to both constitutional principles and social policy objectives. Because the interests of competent persons within the decisionmaking process often conflict with the interests of the incompetent newborn and the public, the courts must be ready to provide the balance in certain instances.

A. *The Disabled Newborn's Right to Live*

No American legislature to date has stated that a newborn whose life might be saved should be allowed to die. On the con-

28. 410 U.S. 113 (1973).

29. *Id.* at 157-58.

30. *But see* Kluge, *The Euthanasia of Radically Defective Neonates: Some Statutory Considerations*, 6 DALHOUSIE L.J. 229, 252-53 (1980) (suggesting distinctions between human beings and persons under criminal law). And, of course, certain postnatal forms of human life demand differing constitutional treatment although the "personhood" criterion has been met. *See* Ginsburg v. New York, 390 U.S. 629 (1968) (upholding anti-obscenity statute designed to protect children).

31. In *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944), the Court noted: "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."

32. Note, *The Right to Family Integrity: A Substantive Due Process Approach to State Removal and Termination Proceedings*, 68 GEO. L.J. 213, 222-23 (1979) (finding that United States Supreme Court decisions implicitly establish "some notion of a more general fundamental right of the family as a unit to be free from illegitimate, overbroad, and arbitrary governmental intrusions"); Burt, *The Constitution of the Family*, 1979 SUP. CT. REV. 329.

For a review of cases involving children's, parents' and family rights, see Wingo & Freytag, *Decisions Within the Family: A Clash of Constitutional Rights*, 67 IOWA L. REV. 401 (1982); Keiter, *Privacy, Children and Their Parents: Reflections On and Beyond the Supreme Court's Approach*, 66 MINN. L. REV. 459 (1982).

trary, the participants in a decision to allow a newborn infant to die through lack of medical care are theoretically subject to both criminal and civil liability.³³ The state could prosecute parents for homicide, child neglect or child abuse. The parents could be liable in a civil action for breach of the duty to rescue a person whom they placed in peril or for the intentional or negligent failure to provide medical care.³⁴ Additionally, the state could prosecute a physician or other health professional for similar crimes or for violating child abuse reporting laws.³⁵ The physician could also be liable in a civil suit brought on behalf of the infant whose death followed withdrawal or withholding of medical treatment.³⁶

In the absence of sufficient state action to trigger federal constitutional privacy rights, state policies may be the source of a right to life that is comparable to that found within the federal Constitution. Notwithstanding this right to life, participants in treatment decisions are seldom prosecuted or sued when they allow a severely disabled newborn to die. In the rare instances when health professionals and parents cannot agree on the treatment, the courts may prevent a possible violation of the law by ordering life-sustaining treatment. But when the parents desire to withhold lifesaving treatment from their disabled newborn, health professionals will usually comply with the parents' instructions. Professor Robertson observed:

Although a clear basis for prosecution exists, no parent or physician has to date been criminally prosecuted for withholding ordinary medical care from a defective infant. . . .

One might . . . describe the situation as one in which prosecuting authorities . . . have informally delegated authority to parents and physicians to decide the fate of defective newborns. . . .

Another explanation of nonenforcement is the extremely low visibility of the practice. In many cases of nontreatment no one complains to a district attorney because the parties involved agree that the best course of action has been taken Without doctors, nurses, and hospital authorities complying with reporting statutes, a district attorney has little chance to learn of the practice. . . .

In addition, some prosecutors may know of the practice but decide for other reasons not to prosecute [sic]. They too may feel

33. Ellis, *supra* note 3, at 401-13.

34. Robertson, *supra* note 4, at 217-24; Ellis, *supra* note 3, at 411-13.

35. Robertson, *supra* note 4, at 224.

36. Robertson, *supra* note 4, at 224-43; Ellis, *supra* note 3, at 411-13.

that withholding treatment is the most desirable practice. Or prosecution may appear politically unpopular, or unfeasible because of lack of manpower.³⁷

One is left wondering why laws that protect the disabled newborn's right to life are not enforced and why public outrage is so much more severe when parents harm a healthy child than when a decisionmaker allows a handicapped infant to die. The power of the state to limit parental autonomy and professionals' judgments in educational,³⁸ medical,³⁹ and other contexts involving healthy children seems equally applicable to decisions involving disabled newborns. The exercise of state power to protect children would appear to be most appropriate when a private decision has been made against life-sustaining treatment.⁴⁰

Allowing disabled newborns to be treated differently than other groups may reflect the state's interest in ensuring habitation by persons who are healthy rather than by persons with mental and physical disabilities. Another possible explanation is that the state has unofficially taken the position that there is no justification "for coercive intrusion by the state in those life-or-death situations . . . in which . . . there is less than a high probability that the nonexperimental treatment will enable the child to pursue either a life worth living or a life of relatively normal healthy growth toward adulthood."⁴¹ This justification has been explained as follows:

Absent medical agreement about what treatment is indicated, or absent a societal consensus about the rightness of the predicted result of treatment, there would be no justification for disqualifying parents from (or for qualifying agents of the state for) making the difficult choice Put somewhat more starkly, how can parents in such situations give the wrong answer since there is no way of knowing the right answer?⁴²

37. Robertson, *supra* note 4, at 243-44.

38. *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (recognizing that the state can require all children of proper age to attend school).

39. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (noting that many states have required all children to be vaccinated for smallpox as a condition of their right to enter or remain in public schools).

40. Occasionally, such an exercise becomes controversial because of competing values, perhaps constitutionally protected, which run contrary to the private decision against life-sustaining treatment. *Jehovah's Witnesses v. King County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968) (overruling desires of parents who were Jehovah's Witnesses to deny blood transfusions to their children).

41. Goldstein, *supra* note 13, at 653.

42. *Id.* at 654-55.

But this is not a plausible explanation, considering current laws and the state's intervention in other settings to ensure that private decisionmakers do not infringe upon the rights of those for whom decisions are made.⁴³

The lack of state action on behalf of the disabled newborn ignores the guarantees of the right to life and equal protection. States may continue their inaction only upon a showing that state interests do not compel any action in the case of disabled newborns. Yet, explicit elaborations of such state interests do not exist. And, although the community may be willing to infringe upon the constitutional rights of some disabled newborns, there may be other newborns whom the community wishes to protect. Because parents and physicians have relatively unbridled discretion to decide between life and death for a disabled newborn, an infant could die even though the community would wish it to live. Some commentators fear that explicit declaration of a policy in which infants with certain disabilities are allowed to die would place the state on a tightrope where protection of life depends solely on social judgments of utility.⁴⁴ One commentator has argued that explication "involves unacceptable costs."⁴⁵ Yet, the disabled newborn today is himself walking a tightrope and may pay with his life because of governmental reluctance to appear totalitarian. The newborn's survival depends entirely upon fortuitous

43. In *Quinlan*, the Attorney General of New Jersey intervened to oppose the petition seeking an order discontinuing all extraordinary medical procedures. 70 N.J. at 19, 355 A.2d at 651-52. In *Eichner*, the local district attorney, but not the state attorney general, opposed the petition seeking an order discontinuing extraordinary and artificial life-sustaining treatment. 73 A.D.2d at 438, 446 n.8, 426 N.Y.S.2d at 525, 530 n.8.

After the "Baby Doe" case, President Reagan sent a memorandum to the Secretary of Health and Human Services (HHS) in which he cited that case and noted that discrimination against the handicapped is illegal. In response, HHS issued regulations that would terminate federal funds to health care providers who refuse to treat handicapped infants. 48 Fed. Reg. 9,630 (1983). However, one court recently nullified this action, finding that HHS regulations were promulgated in an arbitrary and capricious manner in violation of federal statutory law. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). Since this nullification, the government has indicated its continuing desire to take action pursuant to the regulations. 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983) (revision of HHS Regulations).

44. Robertson, *supra* note 4, at 256; see also Note, *The Refusal of Life-Saving Medical Treatment vs. the State's Interest in the Preservation of Life: A Clarification of the Interests at Stake*, 58 WASH. U.L.Q. 85, 106-07 (1980); 1974 HEARINGS, *supra* note 3, at 7.

45. Burt, *Authorizing Death for Anomalous Newborns*, in *GENETICS AND THE LAW* 435 (A. Milunsky & G. Annas ed. 1976). Burt noted, "[C]ertainty of application would require us either to press enforcement to end all purposeful withholding of treatment for newborns or to establish that someone in this society has clear authority to end some infants' lives [E]ither stark position involves unacceptable costs." *Id.* at 447.

circumstances—the policy of the hospital of birth; the parents' perception of their own emotional state and financial ability to care for their disabled child; the physician's particular stance on the value of life; and the availability of a medical facility and staff capable of implementing a decision to provide life-sustaining treatment.

It has been suggested that although express declarations of state policy would be appropriate, "the burdens of decisionmaking must be borne by families and their professional advisers [with society and the health professions providing] only general guidelines for decision making."⁴⁶ The right to life, however, cannot be protected by simply providing the active decisionmakers with "general guidelines" for life-and-death decisions. Decisionmakers ignore existing laws that choose life over death in all cases, and public sentiment and constitutional doctrine recognize that life is not always preferable. Generalized guidelines would not fare any better if they failed to divide the cases in which the public believes that life-sustaining treatment should be administered from the cases in which the public believes that treatment should be withheld. Unequal treatment and confusion, though perhaps reduced, would continue. Although it is impossible to draft guidelines that clearly distinguish the life-or-death decision, decisionmakers need more specific guidelines.

During the past decade, courts have wrestled with cases involving the right to life of incompetent persons who need medical treatment. From these decisions a consensus emerges—in certain cases, the right to life is so strong that contrary interests cannot overcome it. This right to life exists when medical treatment can preserve life rather than simply prolong it,⁴⁷ when such medical treatment neither produces pain and suffering nor constitutes a significant bodily intrusion,⁴⁸ and when there are no countervailing constitutional rights.⁴⁹ The decision to preserve a life is not depen-

46. Duff & Campbell, *supra* note 3, at 894. For suggested general guidelines, see Kluge, *supra* note 30, at 256-57.

47. Of course, the right to preserve one's life is not absolute. In the criminal punishment context, a death sentence is constitutionally permitted notwithstanding the right to life and the right to be free from cruel and unusual punishment. *Proffitt v. Florida*, 428 U.S. 242 (1976).

48. Bodily intrusion can be significant though no physical contact is involved in the application of medical treatment. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (chemotherapy).

49. The constitutional protection regarding religious freedom might override the otherwise unassailable right to life. *In re Osborne*, 294 A.2d 372 (D.C. Cir. 1972) (Jehovah's Witnesses who had provided for the future well-being of his family could refuse life-preserving

dent solely upon the consent of the individual whose life is to be preserved. Assuming the incompetent had unequivocally expressed a desire to die prior to incompetency, the state can compel treatment. Therefore, the state effectively has the right to the life of the incompetent who would not wish to exercise the individual right to life.⁵⁰

Courts have recognized this unassailable right to life among various categories of incompetent persons. For example, persons incompetent only by virtue of youth have been afforded life-preserving medical treatment notwithstanding parental objections,⁵¹ and so have mentally incompetent adults despite their inability to consent to treatment.⁵² The right to life of a severely disabled newborn cannot be unassailable if life-preserving medical treatment can be so easily denied at the request of others. Laws should be written to deter and punish assaults on what has already been deemed unassailable. Otherwise, some severely disabled newborns (and adults) will receive treatment while others will not, and there will be no rational justification for the difference.⁵³

B. *The Disabled Newborn's Right to Die*

The disabled newborn's interest in death also deserves protection. Yet, the legal parameters of this interest are not clear. Although there is lower court precedent recognizing that the federal constitutional right of privacy sometimes includes the right to refuse life-sustaining treatment, the United States Supreme Court has not yet tested such authority. State court cases offer substantially less support for the right to terminate life.⁵⁴ Given this lack of clarity, it is more difficult to recognize those circumstances in which an unassailable right to death exists. As with the right to

blood transfusion).

50. *State ex rel. White v. Narick*, 292 S.E.2d 54 (W. Va. 1982); *Von Holden v. Chapman*, 87 A.D.2d 66, 450 N.Y.S.2d 623 (1982) (hunger-striking prisoners can be forced). *But see Zant v. Prevatte*, 248 Ga. 832, 286 S.E.2d 715 (1982) (court refused to sanction forced feedings of sane and rational prisoner on a hunger strike, justifying its refusal by characterizing such feedings as intrusions on prisoner's person); Note, *Prisoner Hunger Strikes: Constitutional Protection for a Fundamental Right*, 20 AM. CRIM. L. REV. 569 (1983).

51. *Custody of a Minor*, 385 Mass. 697, 379 N.E.2d 1053 (1978); *See also In re Adam L.*, 9 FAM. L. REP. (BNA) 2121 (D.C. Super. Ct. Fam. Div. Nov. 22, 1982).

52. *See, e.g., John F. Kennedy Memorial Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971) (adult whose religious beliefs forbid blood transfusion may be compelled to submit to treatment despite incompetency to consent to transfusion).

53. Discriminatory treatment of disabled newborns is barred by federal law. *Supra* note 43.

54. *See id.*

continued life, however, a consensus does emerge.

The right to terminate life is apt to be recognized when medical treatment can only prolong life rather than preserve it, especially when the life to be prolonged will only be of brief duration and will be accompanied by significant pain and suffering.⁵⁵ Even where these elements are present, there is no assurance that the right to die will prevail over the primary social value of preserving life. Both mentally incompetent and competent persons have been deemed to possess this right.⁵⁶ Before sanctioning the exercise of this right, the state requires proof that the patient voluntarily elected to refuse the available life-sustaining treatment. Mechanisms designed to assist courts facing mentally incompetent persons usually employ the concept of substituted judgment⁵⁷ to determine whether the incompetent person would choose to die, and in close cases, courts commit errors "on the side of life."⁵⁸

It is interesting that the state courts have recently recognized that the federal right of privacy encompasses a right to refuse life-sustaining medical treatment. In so doing, the state courts have relied heavily on earlier decisions of the United States Supreme Court delineating the federal right of privacy. The Court's decision in *Roe v. Wade*⁵⁹ contains the clearest statement of that right:

The Constitution does not explicitly mention any right of privacy. In a line of decisions, however, going back perhaps as far as *Union Pacific R. Co. v. Botsford* (1891), the Court has recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution. In varying contexts, the Court or individual Justices have, indeed, found at least the roots of that right in the First Amendment, in the Fourth and Fifth Amendments, in the penumbras of the Bill of Rights, in the Ninth Amendment, or in the concept of liberty

55. *Quinlan*, 70 N.J. at 23-29, 355 A.2d at 655-57; *Saikewicz*, 373 Mass. at 737-40, 370 N.E.2d at 423-24; *Eichner*, 73 A.D.2d at 468-69, 426 N.Y.S.2d at 545; cf. *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982) (involving an infant). Of course, there is no need to determine the right to refuse life-sustaining medical treatment when the state recognizes the concept of brain death. See *Lovato v. District Court*, 198 Colo. 419, 601 P.2d 1072 (1979) (en banc).

56. *Quinlan*, 70 N.J. at 42, 355 A.2d at 664; *Saikewicz*, 373 Mass. at 745-47, 370 N.E.2d at 427-28; *Eichner*, 73 A.D.2d at 464-65, 426 N.Y.S.2d at 542-43 (1980).

57. *Saikewicz*, 373 Mass. at 752-55, 370 N.E.2d at 431-32; *Eichner*, 73 A.D.2d at 472-73, 426 N.Y.S.2d at 548; *Custody of a Minor*, 385 Mass. 697, 712, 434 N.E.2d 601, 609. Whether substituted judgment is a constitutionally mandated test remains an open question. See *Mills v. Rogers*, 102 S.Ct. 2442, 2447 n.10 (1982).

58. Application of the President and Directors of Georgetown College, Inc., 331 F.2d 1000, 1010 (D.C. Cir.), cert. denied, 377 U.S. 978 (1964).

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

guaranteed by the first section of the Fourteenth Amendment. These decisions make it clear that only personal rights that can be deemed "fundamental" or "implicit in the concept of ordered liberty," are included in this guarantee of personal privacy. They also make it clear that the right has some extension to activities relating to marriage, procreation, contraception, family relationships, and childrearing and education.⁶⁰

The Court went on to find that the right of privacy, whether based on the ninth or fourteenth amendment, "is broad enough to encompass a woman's decision whether or not to terminate her pregnancy."⁶¹ But, it also found that the "right is not unqualified and must be considered against important state interests in regulation."⁶²

Less than six months after the decision in *Roe v. Wade*, a Pennsylvania trial court refused to appoint a guardian for an allegedly incompetent woman for the purpose of giving "consent to the performance of diagnostic and corrective surgery" involving a breast biopsy.⁶³ The court relied on the constitutional right of privacy:

In our opinion, the constitutional right of privacy includes the right of a mature competent adult to refuse to accept medical recommendations that may prolong one's life and which, to a third person at least, appear to be in his best interests; in short, that the right to privacy includes a right to die with which the State should not interfere where there are no minor or unborn children and no clear and present danger to public health, welfare or morals. If the person was competent while being presented with the decision and in making the decision which she did, the court should not interfere even though her decision might be considered unwise, foolish or ridiculous.⁶⁴

More recently, a New York court resolved a controversy concerning the discontinuance of life support machines by stating:

Roe acknowledges that pregnancy—and its termination—so fundamentally affect the integrity of a woman's body that the constitutional right to privacy necessarily extended to her "decision whether or not to terminate her pregnancy" subject only to

60. *Id.* at 152-53 (citations omitted).

61. *Id.* at 153.

62. *Id.* at 154. Recently, the court only "assumed" a liberty interest in avoiding the unwanted administration of antipsychotic drugs. *Mills*, 102 S. Ct. at 2448.

63. *In re Maida Yetter*, 62 Pa. D. & C. 619, 620-21 (1973).

64. *Id.* at 623 (footnote omitted).

countervailing compelling state interests. . . . By parity of reasoning, the constitutional right to privacy, we believe, encompasses the freedom of the terminally ill but competent individual to choose for himself whether or not to decline medical treatment where he reasonably believes that such treatment will only prolong his suffering needlessly. . . . The decision . . . is so manifestly a "fundamental" decision . . . that it is virtually inconceivable that the right of privacy would *not* apply to it.⁶⁵

In *In re Quinlan*,⁶⁶ the New Jersey Supreme Court held that the right to privacy recognized in *Roe v. Wade* was "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions."⁶⁷ Likewise, the Massachusetts Supreme Judicial Court relied on *Roe v. Wade* in deciding a case involving a mentally retarded adult in need of life-prolonging medical treatment. The court stated, "[a]s this constitutional guaranty [right to privacy] reaches out to protect the freedom of a woman to terminate pregnancy under certain conditions . . . so it encompasses the right of a patient to preserve his or her right to privacy against unwarranted infringements of bodily integrity in appropriate circumstances."⁶⁸

Widespread lower court recognition of both the competent and incompetent non-infant's right to refuse life-sustaining medical treatment⁶⁹ suggests that a similar right should be recognized for severely disabled newborns. Applying this suggestion, however, has its problems.

Consider, for example, an infant born with an intestinal blockage. Normally, this child would be given treatment without objection. If the parents attempted to withhold treatment, the hospital would probably seek a court order to protect the interests of the child.⁷⁰ Treatment for this child is clearly "lifesaving" as opposed

65. *Eichner*, 73 A.D.2d at 458-59, 426 N.Y.S.2d at 539 (citations omitted).

66. *Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

67. *Id.* at 40, 355 A.2d at 663.

68. *Saikewicz*, 373 Mass. at 729, 739, 370 N.E.2d at 419, 424.

69. See *Andrews v. Ballard*, 498 F. Supp. 1038, 1048-50 (S.D. Tex. 1980) (listing cases which found privacy rights implicated in medical treatment decisions, and criticizing two contrary cases).

70. *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979) (on request of hospital officials, court ordered treatment for child with meningomyelocele over parents' objection because treatment allowed reasonable opportunity to live a useful, fulfilled life, while nontreatment would likely have led to death within six months).

to "life-prolonging." But if this same infant also suffered from Down's syndrome,⁷¹ a disease that cannot be cured, treatment of the intestinal blockage is arguably "life-prolonging" and not "life-saving." The surgery may restore the child's abbreviated life expectancy, but that life will not be of "normal" duration or kind.

Compare the Down's syndrome/intestinal blockage case with one in which a court was asked to order surgery for a child born with meningocele.⁷² The court stated, "[t]his is not a case where [we are] asked to preserve an existence which cannot be a life."⁷³ In distinguishing between life-prolonging and life-preserving medical treatment the issue is the quality of life — whether the patient will live long enough and well enough so that the state's interests in his life outweigh the patient's privacy-based right to refuse treatment. Although courts might wish to avoid the notion that life-and-death decisions are based upon considerations of the quality of life,⁷⁴ that is the case with treatment decisions involving disabled newborns. Even without judicial oversight, private decisions take into consideration the quality of life.⁷⁵

When medical treatment is characterized as life-preserving, another question arises—when may the patient elect to refuse treatment?⁷⁶ The answer seems to depend upon the nature of the treatment. If treatment will constitute a severe bodily intrusion and yet offer little hope of recovery, then the patient should be free to refuse it. As stated in *Quinlan*, "[T]he State's interest . . . weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest."⁷⁷ In some instances where the chance of recovery was high, courts have allowed patients to refuse treatment based on the severity of the bodily intrusion. In one case involving a re-

71. Cases involving children with multiple ailments are not unknown. See Duff & Campbell, *supra* note 3, at 891-92; see also Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699 (1982) (the "Baby Doe" case, which prompted recent presidential action); Burt, *supra* note 45, at 438-39. For views on the problem, see R. VEATCH, DEATH, DYING, AND THE BIOLOGICAL REVOLUTION 124-25, 133-34 (1976); Gustafson, *Mongolism, Parental Desires, and the Right to Life*, 16 PERSP. BIO. & MED. 529 (1973).

72. *Supra* note 70.

73. *Id.* at 701, 421 N.Y.S.2d at 967.

74. *Saikewicz*, 373 Mass. at 742, 754, 370 N.E.2d at 425, 432.

75. See *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979).

76. *Holmes v. Silver Cross Hosp.*, 340 F. Supp. 125 (N.D. Ill. 1972); *In re Osborne*, 294 A.2d 372 (D.C. 1972); *In re Estate of Brooks*, 32 Ill. 2d 361, 205 N.E.2d 435 (1965); *Erickson v. Dilgard*, 44 Misc. 2d 27, 252 N.Y.S.2d 705 (N.Y. Sup. Ct. 1962).

77. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664.

quest for an order directing amputation of both legs, the court held that "the extensive bodily invasion involved . . . is sufficient to make the State's interest in the preservation of life give way to [the patient's] right of privacy to decide his own future regardless of the absence of a dim prognosis."⁷⁸ In another case, a hospital patient who would be "able to live an otherwise normal and healthy life if he continued to undergo dialysis [and who would be] a good candidate for a kidney transplant, [which] could restore him to complete health,"⁷⁹ refused to continue dialysis. The court conceded that the state's interest in preserving the patient's life was "quite strong,"⁸⁰ but it held that such an interest did not outweigh the patient's "interest in avoiding significant, nonconsensual invasions of his bodily integrity."⁸¹ It is important to note that in most cases where a court has permitted to refuse life-preserving treatment despite the state's objections, the patient himself has made the choice.

The disabled newborn is not competent to make his own decision and cannot assert a right of privacy to avoid significant bodily intrusions. In a severe case, the disability might necessitate permanent confinement in a state institution with no chance of ever seeing the outside world. That infant would probably be dependent on drugs and perhaps on medical machinery. Such treatment can lead to, or aggravate, physical handicaps and impair mental development.⁸² Lack of competence or ability to voice an objection to treatment should not preclude termination of a painful life in such severe cases. The severely disabled newborn should have the same privacy right as the severely disabled adult.

Because the infant is incompetent to make a decision or to assert a right to privacy, someone else must exercise the right to refuse treatment. Today the decisionmaker might be subject to criminal or civil liability. For this reason, judicial oversight pro-

78. *In re Quackenbush*, 156 N.J. Super. 282, 290, 383 A.2d 785, 789 (Morris County Ct. 1978).

79. *Commissioner of Correction v. Myers*, 379 Mass. 255, 259, 399 N.E.2d 452, 454 (1979).

80. *Id.* at 263, 399 N.E.2d at 456 (quoting *Custody of a Minor*, 375 Mass. 733, 755 n.12, 399 N.E.2d 1053, 1066 n.12 (1978)).

81. *Id.* at 263, 399 N.E.2d at 457. Nonetheless, the court did order treatment but only because the state's interest was bolstered by the fact that the patient was a prisoner and therefore treatment was deemed necessary to orderly prison administration. *Id.* at 266, 399 N.E.2d at 458.

82. See *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied sub nom. Botham v. Warren B.*, 445 U.S. 949 (1980); *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 96 (N.Y. Sup. Ct. 1979).

protects not only the newborn but also the decisionmaker. Court approval minimizes the guilt feelings of the decisionmaker, assures consideration of the State's interest in life, and promotes uniform treatment of disabled newborns.

C. *The Relevant Interests*

Although the interests of the disabled newborn are paramount, there are other relevant interests in the treatment decision. Other interested parties are the newborn's parents and family members, the medical profession, and the state. The newborn's interests must be balanced against these other interests. When a decisionmaker asserts the newborn's rights, there is usually a need to consider whether compelling reasons exist to override an attempt to exercise the rights.⁸³ The newborn's privacy right warrants federal protection. When there is an absence of the "state action" necessary to trigger consideration of a federal claim, state courts have balanced the competing interests in some cases.⁸⁴ Given the need for similar treatment of disabled newborns, state laws should also recognize the privacy rights of all newborns.

When courts rule on the medical treatment decision for a disabled newborn, the interests and privacy rights of the infant should initially be deemed paramount. But the courts must then balance these rights and interests against the rights and interests of others.

1. PARENTS AND FAMILY MEMBERS

Parents' constitutional rights to make decisions concerning their children are based in the fourteenth amendment liberty concept⁸⁵ and in the penumbral privacy right.⁸⁶ The state cannot deprive a parent of custody, even if it would be in the child's best

83. See *Saikewicz*, 373 Mass. at 742, 370 N.E.2d at 425-26.

84. But see *Eichner*, 73 A.D.2d at 461, 426 N.Y.S.2d at 540 (finding state action in the state's potential imposition of civil liability and criminal penalties, the state's licensing of physicians in private hospitals, and the state's *parens patriae* responsibilities to an incompetent). Cf. *Jennings v. Patterson*, 488 F.2d 436 (5th Cir. 1974) (failure of city to dismantle fence cutting off black landowner's access to public street constituted state action); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983) (finding state action in a *Quinlan*-type setting, because of possible criminal sanctions, physician licensure laws, guardianship laws, and the state's *parens patriae* responsibility regarding incompetents).

85. *Roe*, 410 U.S. at 153 (married women's right to procure abortion, absent spousal consent).

86. See *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

interest, without some showing of imminent harm⁸⁷ or of parental unfitness.⁸⁸ As the United States Supreme Court recently noted, "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."⁸⁹

In respect of parental autonomy, courts have refused to order: (1) surgery to prevent crippling by rickets;⁹⁰ (2) surgery to correct a harelip and cleft palate;⁹¹ (3) surgery to correct spinal curvature;⁹² (4) amputation of a grossly enlarged and useless arm;⁹³ (5) surgery for a retarded child's congenital heart defect;⁹⁴ and (6) radiation and chemotherapy for Hodgkins disease.⁹⁵ These cases do not suggest that a court could never overrule the parents' decision. As one court recently stated:

Parental autonomy, however, is not absolute. The state is the guardian of society's basic values. Under the doctrine of *parens patriae*, the state has a right, indeed a duty, to protect children. State officials may interfere in family matters to safeguard the child's health, educational development and emotional well-being.

One of the most basic values protected by the state is the sanctity of human life. Where parents fail to provide their children with adequate medical care, the state is justified to intervene. However, since the state should usually defer to the wishes of the parents, it has a serious burden of justification before abridging parental autonomy by substituting its judgment for that of the parents.⁹⁶

The state met its burden of justification to overcome the parents' decision in cases involving: (1) removal of a malignant eye;⁹⁷ (2) transfusion for severe burns;⁹⁸ (3) transfusion for corrective

87. *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (N.Y. Sup. Ct. 1979).

88. *Santosky v. Kramer*, 455 U.S. 745 (1982) (clear and convincing evidence of neglect required for termination of parental rights in natural child).

89. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

90. *In re Tuttendario*, 21 Pa. D. 561 (1912).

91. *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955).

92. *In re Green*, 220 Pa. Super. 191, 286 A.2d 861 (1971).

93. *In re Hudson*, 13 Wash. 2d 673, 126 P.2d 765 (1942).

94. *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979).

95. *In re Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

96. *In re Phillip B.*, 92 Cal. App. 3d at 801-02, 156 Cal. Rptr. at 51 (citations omitted); see also *Parham v. J.R.*, 442 U.S. 584, 604 (1979).

97. *In re Vasko*, 238 A.D. 128, 263 N.Y.S. 552 (1933).

98. *In re Brooklyn Hosp.*, 45 Misc. 2d 914, 258 N.Y.S.2d 621 (N.Y. Sup. Ct. 1965).

surgery of grotesque deformities caused by neurofibromatosis;⁹⁹ and (4) surgical repair of a newborn's meningomyelocele.¹⁰⁰ In determining whether parental autonomy should be abridged, courts consider such factors as the risks inherent in the proposed treatment,¹⁰¹ the seriousness of the condition needing treatment,¹⁰² the wishes of the minor, if such are known, and the benefits of the treatment.¹⁰³

The case law reveals that a court may override a parental decision to deny life-sustaining medical treatment to a disabled newborn, but the justification for doing so should be as strong as the justification in cases involving older children. Where the benefit to the child clearly outweighs the risk of treatment, courts usually infer that the child would choose treatment over non-treatment. Since parents would not always choose treatment¹⁰⁴ in such cases, the substituted judgment concept is necessary to protect the child who cannot speak for himself.

Although parental autonomy should be as strong with regard to newborns as it is with regard to older children, certain cases suggest that the courts view the parents' right to autonomy as dependent upon the significance of the relationship with the child. In *Quilloin v. Walcott*,¹⁰⁵ the United States Supreme Court held that the equal protection clause did not require that a natural father of an illegitimate child be given the same authority as a divorced father to block a child's adoption. The Court based its decision on the fact that the natural father had "never shouldered any significant responsibility with respect to the daily supervision, education, protection, or care of the child."¹⁰⁶ By analogy, the rights of a newborn's parents would not be as strong as the rights of an older child's parents if the daily supervision, education, protection, or care of the child determine the parents' rights. Therefore, the court could choose not to defer as much to the desires of the new-

99. *In re Sampson*, 65 Misc. 2d 658, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970), *aff'd*, 29 N.Y.2d 900, 278 N.E.2d 918 (1972).

100. Application of *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (1979). Other cases involving a clash between parental autonomy and children's rights are described in R. VEATCH, *supra* note 71, at 125-33.

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

102. See, e.g., *In re Brooklyn Hosp.*, 45 Misc. 2d 914, 258 N.Y.S.2d 621 (N.Y. Sup. Ct. 1965).

103. Cf. *In re Sampson*, 65 Misc. 2d at 670, 317 N.Y.S.2d at 654 (a court may order treatment when the health, safety, or welfare of the child requires it).

104. Ellis, *supra* note 3, at 414-15; Robertson, *supra* note 4, at 263.

105. 434 U.S. 246 (1978).

106. *Id.* at 256.

born's parents as it would to the desires of the older child's parents.¹⁰⁷

Another series of cases implicitly recognizes the right to be free of state interference in family decisions. Examples of this right are the right to marry,¹⁰⁸ the right to procreate,¹⁰⁹ the married couple's right to use contraceptives,¹¹⁰ the woman's right to decide whether to bear children,¹¹¹ and the right of an extended family to continue to live in one house.¹¹² In addressing these rights, one commentator noted:

Implicit in the Court's recognition of specific fundamental rights incident to establishing and maintaining a family . . . is some notion of a more general fundamental right of the family as a unit to be free from illegitimate, overbroad, and arbitrary governmental intrusions. Although this right to family integrity has not been explicitly considered by the Supreme Court, . . . recent lower federal court decisions . . . acknowledge directly the fundamental nature of such a right.¹¹³

If this is a meaningful right, the state must justify the abridgment of family integrity when substituting its judgment for that of the parents.¹¹⁴

For the state to meet its burden, it must demonstrate a serious and immediate threat to the welfare of the child.¹¹⁵ If it is questionable whether the welfare of the newborn would be enhanced by treatment, the state has not met its burden and the right to family integrity should prevail. If the correct course of action is not evident, the family decision should not be overridden.

Families know their values, priorities and resources better than anyone else. Presumably they, with the doctor, can make the

107. See *In re Phillip B.*, 92 Cal. App. 3d 796, 800, 156 Cal. Rptr. 48, 50 (1979) (where the court upheld parental autonomy by refusing to overrule the parents' decision not to consent to corrective heart surgery on their twelve-year-old son afflicted with Down's syndrome, even though "[a]t birth his parents decided he should live in a residential care facility" and even though they rarely visited him).

108. *Loving v. Virginia*, 388 U.S. 1, 12 (1967).

109. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

110. *Griswold*, 381 U.S. at 485.

111. *Roe*, 410 U.S. at 153.

112. *Moore v. City of East Cleveland*, 431 U.S. 494, 499 (1977).

113. Note, *supra* note 32, at 222-23.

114. See *supra* note 96 and accompanying text. Assuming a sufficient justification is found, the state may also shoulder the burden of assisting the newborn even though the family does not want state assistance. 1974 HEARINGS, *supra* note 3, at 13; Goldstein, *supra* note 13, at 657.

115. See, e.g., Goldstein, *supra* note 13, at 664.

better choices as a private affair. Certainly, they, more than anyone else, must live with the consequences. Most of these families know they cannot place that child for adoption because no one else wants the child. If they cannot cope adequately with the child and their other responsibilities and survive as a family, they may feel that the death option is a forced choice . . . But that is not necessarily bad, and who knows of a better way.¹¹⁶

Courts called upon to determine the course of treatment for a disabled newborn must give significant weight to the family's decision. Although the state has an obligation to protect the child, the family's decision deserves great deference. To preserve family integrity, courts must require a very strong showing before ruling contrary to the parents' wishes. The only justification for such a ruling is that the parents have made a decision that is clearly not in the child's best interests.

2. MEDICAL PROFESSION

Contemporary practice assigns a significant role to the physician attending a disabled newborn. His description of the infant's disability and its ramifications will undoubtedly influence the parents' and family members' decision as to treatment. If the parents decide in favor of treatment, the doctor will usually act in accordance with their decision, although he might have decided against treatment if it were his own child and he might believe that the decision undermines the newborn's right to refuse treatment. If the parents decide against treatment, the doctor may seek court authorization, refer the parents to a different physician, or accept the parents' decision against life-sustaining treatment.

When a court determines a disabled newborn's constitutional right to privacy, the physician's role changes. The attending physician may testify on matters such as the disability involved, the

116. *Id.* at 656, quoting Kelsey, *Shall These Children Live? A Conversation with Dr. Raymond S. Duff*, 72 REFLECTION, Jan. 1975 at 4, 7 (Yale Divinity School Magazine). But see Duff & Campbell, *supra* note 3, where Dr. Duff concedes the problems with allowing the family to be the final decisionmakers:

Families . . . may have mixed motives [in deciding whether their defective child is to live or die]. They may demand death to obtain relief from the high costs and tensions inherent in suffering, but their sense of guilt in this thought may produce the opposite demand, perhaps in violation of the sick person's rights.

Id. at 893. To ensure reasoned family decisionmaking, particularly when the life of a family member is at stake, the state should require assurance that the family members comprehend the information relevant to the decision. Comment, *Informed Consent: From Disclosure to Patient Participation in Medical Decisionmaking*, 76 NW. U.L. REV. 172 (1981).

medical experience of other persons having the same disability, and the usual prognosis. Although the medical profession may view judicial oversight as an infringement on its professional autonomy,¹¹⁷ the physician's testimony would aid the court in determining which privacy interest the newborn would choose to assert. Outside of this contribution, the medical profession has no role in the final decision. Of course, when a court does not become involved in the decisionmaking, the medical profession's role is far more significant.¹¹⁸

3. THE INTERESTS OF THE STATE

State interests in the treatment decision, discussed earlier,¹¹⁹ are mentioned again to emphasize that they are separate from those of the newborn, the parents and family members, and the medical profession. The Massachusetts Supreme Judicial Court has recognized at least four relevant state interests: (1) preservation of life; (2) protection of innocent third parties; (3) prevention of suicide; and (4) maintenance of the ethical integrity of the medical profession.¹²⁰

The first interest — preservation of life — decreases as the prognosis dims and the extent of bodily invasion increases. Thus, medical testimony is necessary in determining the strength of the state interest in life-sustaining treatment. Once the nature of this state interest is determined, the next question is whether it is strong enough to outweigh competing interests, particularly the newborn's interest in refusing treatment.

117. See Relman, *The Saikewicz Decision: Judges as Physicians*, 298 NEW ENG. J. MED. 508 (1979) (decision involving the medical treatment of a mentally incompetent adult was viewed as a "resounding vote of 'no confidence' in the ability of physicians and families to act in the best interests of the incapable patient suffering from a terminal illness").

118. *Quinlan*, 70 N.J. at 50-51, 355 A.2d at 669 (suggesting that decisions on the termination of life support systems often can be handled without court proceedings); *Parham v. J.R.*, 442 U.S. 584, 610 (1979) (courts need not decide whether parents' decision to commit a minor to a mental hospital is consistent with the child's interest).

119. *Supra* notes 54-82 and accompanying text.

120. *Saikewicz*, 373 Mass. at 741-44, 370 N.E.2d at 425-27. The list is not exclusive as the same court subsequently found another interest—upholding orderly prison administration. *Commissioner of Correction v. Myers*, 379 Mass. 255, 266, 399 N.E.2d 452, 458 (1979) (discussed *supra* note 81); see also *Eichner*, 73 A.D.2d at 455-56, 426 N.Y.S.2d at 536-37. The state's economic interests are also a consideration when it intercedes to mandate life-sustaining treatment. See *supra* note 114; Acton, *Measuring the Monetary Value of Life-saving Programs*, LAW & CONTEMP. PROBS., Autumn 1976 at 46; Blumstein, *Rationing Medical Resources: A Constitutional, Legal, and Policy Analysis*, 59 TEX. L. REV. 1345 (1981); Rosenblatt, *Rationing "Normal" Health Care: The Hidden Legal Issues*, 59 TEX. L. REV. 1401 (1981).

The second interest — protection of innocent third parties — is usually found to be a valid state interest in those cases where the person refusing treatment has dependents who would become a burden on society in the event of death.¹²¹ Of course, that interest does not exist in the case of a newborn.

The third interest — prevention of suicide — is often mentioned as a legitimate state interest;¹²² however, no cases can be found where this interest alone outweighed a patient's refusal of life-sustaining treatment. Courts usually find that suicide is not an issue when death will result from natural causes rather than from a death-producing agent set in motion by the patient.¹²³ This reasoning should also apply when it is inferred that a disabled newborn would choose not to be treated. To the extent that food, air and water are supplied in their normal form and fashion, death results from natural causes.

Courts do not view the fourth interest — maintenance of the ethical integrity of the medical profession — as a strong state interest.¹²⁴ This interest is relevant, however, when medical personnel seek to administer treatment and the patient or his representative will not consent. In those cases, the state intervenes so that the health professional will not be forced to allow a person to die who he felt duty-bound to save. This state interest, like the prevention of suicide interest, will not by itself support a treatment decision.

IV. SUGGESTIONS FOR DETERMINING MEDICAL TREATMENT OF DISABLED NEWBORNS

A disabled newborn's inability to communicate a personal choice regarding medical treatment raises difficulties with respect to privacy rights.¹²⁵ It is not possible to ascertain what the new-

121. Compare *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, cert. denied, 377 U.S. 985 (1964), with *In re Osborne*, 294 A.2d 372 (D.C. 1972) (the latter finding no state interest which justified overriding patient's desire to refuse life-sustaining treatment since provision had been made for future well-being of the patient's two children).

122. See, e.g., *Saikewicz*, 373 Mass. at 741-42, 370 N.E.2d at 425.

123. *Myers*, 379 Mass. at 262, 399 N.E.2d at 456; *Saikewicz*, 373 Mass. at 743 n.11, 370 N.E.2d at 426 n.11. For an earlier view, see *People v. Roberts*, 211 Mich. 187, 178 N.W. 690 (1920); *Blackburn v. Ohio*, 23 Ohio St. 146 (1872).

124. *Myers*, 379 Mass. at 265, 399 N.E.2d at 458.

125. For a discussion of the federal privacy right, see *supra* notes 27-30 and accompanying text & notes 60-68 and accompanying text; for a discussion of the non-federal privacy right, see *supra* note 25 and accompanying text.

born's choice would be if he were competent to make one. The substituted judgment concept partially alleviates these difficulties.¹²⁶ Employing that concept, courts can honor the privacy rights of newborns.¹²⁷ But when legitimate grounds exist to support both the choice to live and the choice to die, the utility of the substituted judgment concept is questionable. The general principles found in the cases involving the right to receive or to refuse treatment do not point to obvious solutions in difficult cases.

There are other possible approaches to these cases. A federal constitutional standard could be used to resolve the dilemma.¹²⁸ But what standard should be applied? Analogies to cases involving either conflicting constitutional rights,¹²⁹ such as fair trial and free press, or to cases involving conflicting constitutional interests,¹³⁰ such as federal commerce clause power and traditional areas of local or state regulation, are tempting, but these analogies are not helpful because they involve conflicting rights or interests protecting differing entities. In the case of the newborn, the only constitutional rights involved are those belonging to the newborn.

It is also tempting to draw inferences from the federal Constitution and to create a guiding principle to resolve the dilemma. For example, the preservation of human life (and the individual's right to continue living) might be inferred from the preamble, the due process clause, or the privileges and immunities clause. Under these guiding principles, life-sustaining medical treatment would be constitutionally mandated unless the specific (and inevitably narrow) privacy right to refuse life-prolonging treatment is found applicable.¹³¹

Another approach would be to use a state law standard in order to make a decision. But again, what standard should be applied? Perhaps the same state law standards that apply to other incompetents could also be applied to disabled newborns.¹³² State

126. *Supra* note 22 and accompanying text.

127. *Supra* notes 47-49 and accompanying text & note 55 and accompanying text.

128. *Supra* note 84 and accompanying text.

129. *Nebraska Press Ass'n v. Stuart*, 427 U.S. 539 (1976) (first amendment right to freedom of the press conflicting with sixth amendment right to fair trial).

130. *National League of Cities v. Usery*, 426 U.S. 833 (1976) (federal commerce clause power conflicting with areas of state sovereignty).

131. *Cf. supra* text accompanying notes 55-58 (the right to die).

132. For example, a resident of a state mental health facility has both an interest in childbearing and an interest in not bearing a child, and she may be susceptible to pregnancy and incapable of rationally deciding whether to bear children. *In re Grady*, 170 N.J. 98, 405 A.2d 851 (1979). Use of such analogies seems mandated by the federal guarantee of equal protection for all newborns, *supra* note 22, although recent federal regulatory action can be

law standards generally require extensive resort to the courts, which would result in significant and unfortunate delays in deciding the treatment of disabled newborns.

In our view, the best approach is to give the parents the decisionmaking authority. Parents currently possess this authority, and no one has made a strong argument to oppose the practice. Of course, there must be mechanisms to ensure that the parents' authority will not abrogate the infant's privacy rights.

Thus, judicial overview is warranted when one parent chooses treatment for the disabled newborn and the other parent opposes treatment, or when another interested party (for example, the state or the medical profession) challenges the parents' decision. With judicial responsibility limited to these situations, with the availability of more specific guidelines on the appropriateness of certain treatment decisions, and with widespread dissemination of information on these guidelines, the majority of medical treatment decisions will not involve court review.

To ensure such a limited judicial role and its proper employment, the government must help familiarize the decisionmakers with the federal constitutional rights and state laws relevant to decisions on medical treatment of disabled newborns. Statutes could inform decisionmakers of the federal and state interests involved and of the circumstances clearly triggering a newborn's right to receive or not to receive medical treatment regardless of the opinion of others. One commentator noted that there is "a bloodless quality about specifying these criteria in such a visible, articulated way."¹³³ A more viable and less formal alternative would be the issuance of administrative agency regulations or of opinions by attorneys general.¹³⁴ Also, the government should promote compli-

seen as an attempt to unify all state practices, *supra* note 43. The use of such state law analogies, however, is not preferable in that in many analogous situations, court action is needed; with disabled newborns judicial action should be far more limited.

133. Burt, *supra* note 45, at 439.

134. For a history of recent unsuccessful regulatory attempts by the Reagan administration, see *American Academy of Pediatrics v. Heckler*, 51 U.S.L.W. 2628 (D.D.C. Apr. 14, 1983). For a more recent attempt, see 48 Fed. Reg. 30,846 (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983). The Los Angeles guidelines for decisions on whether to "pull the plug" on terminally ill patients without seeking a court order" exemplifies such a regulatory directive. See Granelli, *Lawyers, Doctors Establish Guidelines on Withdrawal of Life-Support Systems*, *The Nat'l L.J.*, Apr. 20, 1981, at 6, col. 2. A joint committee of doctors and lawyers developed these guidelines with the participation of the Los Angeles County district attorney. *Id.* There are, however, certain instances where legislation might be appropriate. See generally PRESIDENT'S COMM. FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DEFINING DEATH: MEDICAL, LEGAL AND ETHICAL IS-*

ance by requiring reporting of apparent violations of privacy rights.¹³⁵ Finally, judicial authority must be expressly recognized so that courts are not hesitant to act.¹³⁶

The availability of specific directives regarding treatment decisions and the prospect that judicial action would be sought if the directives were not followed should ensure that private decisions will conform to the guidelines. The important decisional factors are: (1) whether the medical treatment is life-prolonging or life-preserving; (2) the degree of bodily intrusion; and (3) the prognosis for a normal life. A requirement that violations be reported would assure prompt intervention by the courts in those few cases where voluntary compliance failed.

V. CONCLUSION

Recent advances in medical technology for the treatment of severely disabled newborns have not been accompanied by comparable advances in the legal guidelines controlling treatment decisions. As a result, social policy concerning the preservation and sanctity of human life has been undermined. Furthermore, there exists a general confusion among those involved in treatment decisions, as well as an unexplained disparity of treatment for similarly disabled newborns. Although recent commentaries have addressed the inadequacy of contemporary legal guidelines, to date there has

SUES IN THE DETERMINATION OF DEATH (1981) (commission's attempt to draft and develop a statute establishing a uniform definition of death). Legislation which suggests that treatment is always mandated except when the privacy right to refuse lifesaving treatment is implicated also seems an appropriate exercise of legislative authority. Finally, see H.R. 6492, 97th Cong., 2d Sess. (1982) (legislation attempting to establish judicial remedies for handicapped infants who die through the deliberate neglect of health care providers, but which does not address a newborn's privacy right). See also Note, *supra* note 4, at 619-33; Shapiro, *Medical Treatment of Defective Newborns: An Answer to the Baby Doe Dilemma*, 20 HARV. J. ON LEGIS. 137 (1983) (each advocating legislation).

135. Such a requirement could be added to, if not already found within, child abuse reporting laws. Robertson, *supra* note 4, at 233-34 (finding 27 states have criminal laws on child abuse reporting that cover disabled newborns). Reporting would be facilitated in settings where the decision reached by the parents after consultation with their newborn's doctor(s) was made known to others. *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983) (majority suggests hospital prognosis committees made up of physicians to consider *Quinlan*-type cases, while dissent suggests ethics committees composed of physicians, theologians, and social workers; each opinion foresees guardians appointed and possible judicial review in close cases).

136. *Guardianship of Tulley*, 83 Cal. App. 3d 698, 701, 146 Cal. Rptr. 266, 268 (1978), *cert. denied*, 440 U.S. 967 (1979) (appellate court affirms opinion refusing to order sterilization of a mentally retarded girl, finding that "the jurisdiction to exercise such awesome power may not be inferred from the general principles of common law, but rather must derive from specific legislative authorization").

been a failure to appreciate fully the relevance of the emerging federal constitutional right to privacy.

Judicial involvement in treatment decisions should be available, but limited. When judicial involvement is necessary, the court must consider the interests of the newborn, the newborn's parents and family, the medical profession, and the state. The paramount interest, however, must always be that of the newborn.