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Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants

Stephen A. Newman*

In its amendments to the Child Abuse Prevention and Treatment Act, Congress set forth a strict standard for treatment of impaired infants. The statute, shaped by right-to-life groups and certain medical organizations, calls for aggressive treatment in virtually all cases, regardless of the degree of suffering imposed and the burdens and risks involved. The federal rule evidences deep distrust of parental decisionmaking, relegating most parents to a nonparticipatory bystander role.

Congress did not make its rule binding on the states. Rather, it conditioned the receipt of federal funds upon incorporation of the rule into each state's law. Most states have accepted the condition, largely through rulemaking by state child abuse agencies.

This article challenges the authority of state administrators to promulgate these rules, and argues that state constitutions, little mentioned in the Baby Doe debate thus far, may prohibit many states from adopting the federal standard. Ordering medical interventions that perpetuate extreme conditions of physical and mental devastation, subjecting infants to grave suffering for uncertain benefits, and depriving parents of virtually all decisionmaking power violates the norm of governments constitutionally committed to individual liberty, human dignity and family autonomy. A constitutionally sound approach to this issue would permit careful, ethical deliberation, attention to the individual circumstances of each infant Doe and a reasonable degree of parental control.

[S]urely, the interpreter of last resort in this particular ordeal is the conscience of suffering parents wracked by the suffering of their child. Into their private chamber of personal agony and decision, only the most presumptuous among us would dare to tread.¹

One of the most curious pieces of legislation ever passed by the

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¹ *CBS Evening News With Dan Rather* 13 (CBS television broadcast, Nov. 10, 1983)(editorial commentary by Bill Moyers)(transcript on file at CBS, Inc.).

U.S. Congress purports to resolve the tragic medical, legal and ethical dilemmas posed by the birth of severely impaired infants. The amendments to the Child Abuse Prevention and Treatment Act (CAPTA),² strongly influenced by the right-to-life philosophy,³ set a norm for aggressive, even relentless, treatment, with little regard for the suffering and grave burdens such aggressive care may generate. The few exceptions to mandatory maximal treatment are narrowly drawn, virtually eliminating parental decisionmaking discretion.⁴

Yet Congress, despite the passage of such a strongly worded standard, significantly blunted its potential impact in two ways. First, it deprived the United States Department of Health and Human Services (HHS), the agency most likely to enforce the new statute vigorously, of all direct enforcement authority.⁵ Second, Congress did not make the rule binding upon the states. Instead, the federal infant Doe rule is merely a condition attached to a minor federal grant program, in which state participation is voluntary.⁶ The CAPTA program makes funds available to states for their child abuse and neglect agencies. Funding levels for CAPTA have been extremely low, providing a meager monetary incentive to the states to comply with the federal infant Doe provision. States are given the choice of applying for CAPTA money and conforming their laws to the federal infant Doe standard, or making their own infant Doe law and forfeiting the relatively small amount of CAPTA funds.

Thus the federal law, far from finally resolving the complex infant Doe treatment issue, leaves the matter where it originally rested, in the hands of the states. A carrot is offered to those states adopting the strict federal rule, but no state is obligated to accept it. To date, from the point of view of those supporting the federal rule, the response of the states has been positive. Some states have legislated a standard imitative of the federal rule.⁷ Many others have responded by administrative rulemaking; the state agencies who stand to gain from CAPTA grants have adopted the federal rule as their own, claiming the power to do so under state child abuse and neglect laws.⁸ Despite the appear-

² 42 U.S.C. §§ 5101-05 (1984).

³ Right to life groups played a major role in negotiations leading to the enactment of the statute. For an account of the negotiations from the right to life perspective, see Gerry & Nimz, *The Federal Role in Protecting Babies Doe*, 2 ISSUES L. & MED. 339 (1987).

⁴ *Id.* at 349.

⁵ *Id.* at 354.

⁶ *Id.*

⁷ See, e.g., 17 MINN. STAT. ANN. § 260.015 (10)(e) (Supp. 1988); MONT. CODE ANN. § 41-3-102 (Supp. 1987); OKLA. STAT. ANN. tit. 10, § 1101 (West 1987).

⁸ See, e.g., Neglect and Dependency, MINN. STAT. ANN. § 260.015 § 2(a)(5) (West 1989); Reporting of Maltreatment of Minors, MINN. STAT. ANN. § 626.556 § 2(c) and 10(c) (West 1989); Definitions for Alleged Withholding of Appropriate Nutrition, Hydration, Medication,

ance of satisfaction with the federal infant Doe rule, I suggest that a new round of controversy and sharp legal debate lies ahead. This is so because: (1) the assumption of rulemaking authority by state child protective agencies raises serious questions about the legitimacy of that authority; (2) the adoption of the federal infant Doe rule by states raises serious questions of state constitutional law; and (3) many state policy makers not heard from in the debate thus far may be less receptive to the right-to-life philosophy than the federal government was in the middle years of the Reagan Administration. Indeed, a social consensus may be building — or already exist — for the view that infants already facing the hard reality of an injury-ridden existence need not suffer the additional burdens imposed by the federal rule.⁹

I. THE FEDERAL STATUTE

The federal infant Doe rule, contained in the Child Abuse Amendments of 1984, asks the states to prohibit the withholding of medically indicated treatment from a disabled infant with a life-threatening condition. The key provision states:

the term “withholding of medically indicated treatment” means the failure to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician’s or physicians’ reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician’s or physicians’ reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances

or Medically Indicated Treatment from Disabled Infants with Life-Threatening Conditions, OHIO. ADMIN. CODE §§ 5101:2-35-76, 5101:2-35-77 (1985). Investigation of Reports of Suspected Medical Neglect of Handicapped Infants Including Instances of Withholding of Medically Indicated Treatment for Disabled Infants with Life-Threatening Conditions, Circular Letter No. SSA 86-3 (1985)(issued by the Md. Dep’t of Human Resources); WYO. DEP’T OF HEALTH & SOCIAL SERVICES, PROCEDURES FOR RESPONDING TO REPORTS OF WITHHOLDING MEDICALLY INDICATED TREATMENT FROM DISABLED INFANTS WITH LIFE-THREATENING CONDITIONS, 6 CHILDREN & FAMILY SERVICES MANUAL (1987).

⁹ See *infra* text accompanying note 26.

would be inhumane.¹⁰

A violation of this rule would constitute "medical neglect" of the infant, calling for appropriate intervention by state child abuse authorities.¹¹

The extent to which treatment is made compulsory by the federal rule is astonishing. Even where treatment would be inhumane, that by itself is insufficient reason to stop treating; exception (C) requires that treatment be inhumane *and* have virtually no chance of saving the life of the infant. A slim chance of survival apparently justifies inhumane treatment as does some chance of a survival wracked by excruciating pain, severe abnormalities and a torturous regime of medical interventions. HHS has even gone on record with the suggestion that under the statute, infants suffering from Tay-Sachs disease plus a life-threatening intestinal blockage, must undergo intestinal surgery.¹² The surgery would repair the blockage, enabling such infants to live for perhaps a year or two until the inevitable, prolonged and agonizing death of Tay-Sachs ends their lives. Such a compulsory treatment requirement for the infant with Tay-Sachs, commented the Yale University School of Medicine, "should be viewed, and would be viewed by medical opinion and loving parents, as an act of abuse and inhumanity."¹³

At the same time as it mandates extraordinarily aggressive care, the statute exhorts doctors to use "reasonable medical judgment." This judgment is limited, however, to applying the terms of the statute to individual infants. The physician is not free to allow considerations of suffering, medical ethics and burdens of treatment to enter into his

¹⁰ 42 U.S.C. § 5102 (1984).

¹¹ 42 U.S.C. § 5103 (1984).

¹² 49 Fed. Reg. 48,164 (1984)(to be codified at 45 C.F.R. § 1340)(proposed Dec. 10, 1984). Although the HHS did not include this and other examples in its final rules, it did not disavow its extreme views. Rather, it explained that its examples of specific diagnoses were deleted to "avoid the essential thrust of the interpretive guidelines being lost amidst uncertainty regarding how the addition or subtraction of particular complications or medical nuances might affect the examples." 50 Fed. Reg. 14,880 (1985)(to be codified at 45 C.F.R. pt. 1340).

¹³ YALE UNIV. SCHOOL OF MEDICINE, COMMENTS ON DEPARTMENT OF HEALTH AND HUMAN SERVICES PROPOSED REGULATIONS ON THE CARE OF HANDICAPPED INFANTS 4 (Jan. 25, 1985)(available at Yale Univ. School of Medicine, Dep't of Pediatrics).

Professor Nancy Rhoden describes Tay Sachs disease as follows:

Tay-Sachs is an inherited metabolic disorder found predominantly in persons of Ashkenazic Jewish descent. A Tay-Sachs baby may appear normal at birth, but within a few months develop some degree of motor weakness. As muscle tone deteriorates, Tay-Sachs infants will develop difficulty in swallowing, followed by increasing paralysis, spasticity, deafness, blindness, and convulsions. By age two or three, they become virtually vegetative, and they die by age four or five. Because these infants will get recurrent infections, treatment decisions may involve artificial respiration, resuscitation, or aggressive use of antibiotics.

Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1292 (1985).

“reasonable medical judgment.”¹⁴ Clinical decisionmaking for all patients can hardly disregard such matters, and we should be appalled at any medical education that taught its students to do so. Yet such is the teaching of this statute.

Not even mentioned in the statute are the people who are legally, socially and morally responsible for the infant's welfare — its parents. Reading the statute, one may easily forget that parents normally decide upon medical care for children. Their informed consent is required by law. Both law and society regard parents as the primary protectors of their child's best interests.¹⁵ Under this statute, however, loving, conscientious parents, as well as uncaring, neglectful ones, are deprived of decisionmaking rights as the state assumes the traditional parental role of making critical choices for the child with the medical guidance of a physician. Indeed, underlying the statute seems to be a view of parents as suspect bystanders, presumptively ready to commit child abuse by depriving their infants of necessary medical care.

Another striking feature of the statute is its preference for state rather than federal enforcement. Two years prior to the statute's enactment, President Reagan personally directed the HHS to monitor the treatment of handicapped newborns.¹⁶ The HHS responded with regulations, purportedly authorized by Section 504 of the Rehabilitation Act of 1973, requiring hospitals to post notices in hospital nurseries warning parents, doctors and nurses that the babies in their care were under the protection of the federal government. The notices contained a 24-hour telephone hotline number available for reporting suspicious physician behavior.¹⁷ Ready to respond to the calls were federally organized “Baby Doe squads” that visited reported hospitals, investigated treatment plans and interrogated health care providers, generally disrupting hospital routines and infant care, in the process.¹⁸ Getting

¹⁴ *Id.* at 1297.

¹⁵ See generally *id.* at 1283.

¹⁶ S. REP. NO. 246, 98th Cong., 2d Sess. 4 (1983), reprinted in 1984 U.S. CODE CONG. & ADMIN. NEWS 2918, 2922. The Secretary of the HHS promptly notified hospitals not to withhold medical or surgical treatment or nutrition from handicapped newborns, and suggested that if parents refused to consent to any treatments the hospital should evict the newborn from its facilities. 47 Fed. Reg. 26,027 (1982).

¹⁷ 48 Fed. Reg. 9631 (1983); 45 C.F.R. § 84.61 (1985). The key provisions of the regulations were invalidated by the Supreme Court in *Bowen v. American Hosp. Ass'n*, 476 U.S. 610 (1986). A valuable account of the medical, social and political developments surrounding the infant Doe rules is found in Reiser, *Survival At What Cost? Origins and Effects of the Modern Controversy on Treating Severely Handicapped Newborns*, 11 J. HEALTH POL. POL'Y & L. 199, 199-212 (1986).

¹⁸ Strain, *The American Academy of Pediatrics Comments on the “Baby Doe II” Regulations*, 309 NEW ENG. J. MED. 443 (1983). One of the six Senate sponsors of the statute said she was deeply troubled by the aggressive actions of the HHS. 130 CONG. REC. S9321 (daily ed. July 26, 1984)(statement of Sen. Kassebaum).

this extraordinarily intrusive federal agency out of the hospital nursery was no doubt a high priority for the medical profession, and the statute gives the HHS no direct role in enforcing the medical care rules established by the law.¹⁹ Turning away from the enthused, zealous HHS enforcers, the law selects the understaffed, often overwhelmed personnel of state and local child abuse agencies to carry out its mandate. Given declining federal monetary assistance²⁰ and high case loads involving more and more serious physical injuries, incest, rape and other forms of sexual abuse, it is doubtful the Congress could have seriously contemplated any significant diversion of state personnel and resources to infant Doe enforcement efforts.

Compounding the doubt about the strength of Congressional dedication to the bill is the fact that it is not mandatory upon the states; by giving up the miniscule funding provided by Congress in the Act, any state is free to disregard the infant Doe rules. The funds specifically earmarked for the massive, ever-increasing problem of child abuse and neglect are worth a closer look. The total outlay for the entire nation in fiscal year 1987 was only \$9 million.²¹ Basic state grants ranged from \$45,000 to \$680,000. The median amount was \$152,000. For a problem on which large states annually spend hundreds of millions of dollars, the CAPTA grant program is a sparse one, providing only a tiny fraction of a state's general child abuse budget. Three states — California, Pennsylvania and Indiana — with expensive child abuse efforts do not even bother to participate in the CAPTA grant program.²²

Congressional supporters of the Baby Doe bill cited a "consensus" reached on the law by various groups. There were a number of groups

¹⁹ The HHS, limited to promulgating rules concerning state grant qualifications under the funding program of which the infant Doe rule is a part, took advantage of the opportunity left to it to issue its own "interpretations" of the law, attempting to narrow the treatment exceptions even further. Adverse criticism, including some from the Congressional sponsors of the law, caused the HHS to retreat from some but by no means all of its interpretive positions. See 50 Fed. Reg. 14,878, 14,879-80, 14,889 (to be codified at 45 C.F.R. § 1340)(appendix of non-binding "interpretative guidelines").

²⁰ See HOUSE SELECT COMM. ON CHILDREN, YOUTH AND FAMILIES, ABUSED CHILDREN IN AMERICA: VICTIMS OF OFFICIAL NEGLECT, H.R. DOC. NO. 260, 100th Cong., 1st Sess. 43 (1987)[hereinafter ABUSED CHILDREN IN AMERICA].

²¹ Other federal grant programs, such as Title XX of the Social Services Block Grants and Titles IVB and IVE of the Social Security Act, may distribute considerably greater sums. ABUSED CHILDREN IN AMERICA, *supra* note 20, at 43-44. None of these other federal grant programs requires states to adopt the federal Baby Doe rule.

²² State by state allocations for F.Y. 1987 are available from the National Center on Child Abuse and Neglect in Washington, D.C. The House Select Committee Report noted that in F.Y. 1985, a number of states, including California, Florida, Illinois, Michigan, New Jersey, Pennsylvania and Texas, spent over \$100 million on child abuse programs. ABUSED CHILDREN IN AMERICA, *supra* note 20, at 64-65. Figures for the three states not participating in the CAPTA grant program: Pennsylvania spent \$245,431,035 in F.Y. 1985 (measured in constant 1982 dollars); California spent \$480,603,448; and Indiana spent \$46,288,642. *Id.*

that negotiated with each other and with Congressional staffers to produce a bill acceptable to each of them. The negotiations were essentially between right-to-life and disability groups, on the one side, and professional medical organizations on the other.²³ The medical community did not reach a consensus supporting the bill. While a number of professional groups did agree to the negotiated compromise, the nation's largest medical organization, the American Medical Association (AMA), did not.²⁴ Perhaps most significantly, the Association of American Medical Colleges (AAMC), representing 127 medical schools, over 80 academic societies, and more than 350 teaching hospitals (where care for the majority of incapacitated infants in the nation takes place), voiced strong opposition to the law and to proposed HHS regulations under it.²⁵

Recent polls of both physicians and the general public further indicate that the claimed "consensus" supporting the infant Doe statute does not in fact exist. For example, a 1987 Louis Harris & Associates poll asked respondents whether they agreed or disagreed with the following statements: (1) "Doctors should do everything in their power to preserve the life of a newborn baby even if it is very seriously deformed

²³ See *infra* note 201.

²⁴ See American Med. Ass'n, Statement to the Dep't of Health and Human Services 7 (Feb. 8, 1985) ("In summary, the AMA objects to the approach taken by the Child Abuse Amendments of 1984 because they interfere with familial autonomy; they impose inferior governmental judgments regarding the degree of discretionary treatment for seriously ill newborns; and they rely on imprecise and ambiguous language." The AMA also found the HHS proposed regulations improperly incorporated "a bias toward reducing parental autonomy to the greatest degree possible").

²⁵ In a letter to the HHS Secretary Margaret Heckler, the AAMC explained its opposition to the legislation:

The chief reason the AAMC and others refused to sign onto this compromise agreement was its failure to recognize that many severely ill newborns cannot be classified into the categories of those who will live or those who will die. These infants often have devastating neurological conditions which are so grave that they will preclude the infant from ever functioning as an independent human being; they may not be able to experience even the most fundamental human functions, such as recognizing their parents. Commonly, they have other medical conditions that require treatment if they are to survive. In making decisions about these infants, it is necessary to take into account the extent of neurological damage and the severity of the other diagnoses, the full range of treatment possibilities, and the risks associated with each. There are no quick or easy answers; there is no formula applicable to every infant with the same general diagnoses. A decision about each child must be made by the concerned parents and family and the physicians who have first hand knowledge about the condition of the child in question. . . . The difficult decisions occur when medical care is not clearly beneficial because it can reverse only certain aspects of the infant's condition, but cannot correct or reverse the underlying disease or the permanent brain damage. Resolving this dilemma is even more difficult when the treatment carries with it the significant possibility of terrible complications.

Letter from Dr. John A. D. Cooper, President of the Association of American Medical Colleges to the Hon. Margaret Heckler (Feb. 7, 1985) (available from the Association of American Medical Colleges, Washington, D.C.).

and will never be able to live a normal life." Of 1,250 adults nationwide, 50% agreed with the statement, 45% disagreed, and 5% were not sure; of 200 physicians, 26% agreed, 69% disagreed, and 6% were not sure. (2) "If a child is born with very serious brain damage and will never have a normal life, its parents should be able to ask the doctor not to take any special steps, such as major surgery, to keep it alive." Of 1,250 adults, 70% agreed, 27% disagreed, and 3% were not sure. Of 200 physicians, 95% agreed, 5% disagreed and 1% were not sure. A 1985 Associated Press/Media General poll asked a question similar to the second question in the Harris poll: "In general when a severely retarded infant is born with other defects that will kill that child without surgery, do you think the baby's parents should or should not be allowed to order surgery withheld?" Of 1,532 adults nationwide, 61% said parents should be allowed to do this, 22% said they should not, and 17% were not sure.²⁶

Questionnaires answered by 494 neonatologists around the nation revealed that 60% of these doctors thought the infant Doe statute did not allow adequate consideration of an infant's suffering; only 5% believed that the rules would result in improved care to all infants.²⁷ In considering three hypothetical cases posed by the survey, many of the physicians felt there was a conflict between the rule's mandates and their duty to act in infants' best interests. Most felt the current federal rule was a mistake, encouraging or requiring overtreatment of infants.²⁸

Further evidence that the federal statute does not represent a consensus comes from the fact that a distinguished commission,²⁹ appointed by the president to study the thorny issues presented by modern biomedical advances, made recommendations on this issue that differ markedly from the terms of the statute. The commission, discussing cases in the difficult "gray areas" of decisionmaking, recognized the virtues of both parental decisionmaking and a best interests test that considers and weighs the benefits and burdens of treatment.³⁰ The commission's restrained approach, recognizing the agonies of decisionmaking, and respectful of the loving and conscientious concern

²⁶ Polling data available from The Roper Center for Public Opinion Research in Storrs, Connecticut. For additional data on the public's views concerning medical life support, see discussion and citations in *In re Jobes*, 529 A.2d 434, 446 n.11 (N.J. 1987).

²⁷ Kopelman, Irons & Kopelman, *Neonatologists Judge the "Baby Doe" Regulations*, 318 NEW ENG. J. MED. 677, 679 (1988).

²⁸ *Id.*

²⁹ PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983)[hereinafter PRESIDENT'S COMM'N].

³⁰ *Id.* at 214-18.

of parents, is a far cry from the treatment demands insisted upon by the federal statute.

Other signs of dissension exist. The nation's most populous state, California, which stood to gain the most from CAPTA funding, dropped out of the grant program due to the infant Doe eligibility condition. A bill to conform California law to comply with the federal statute was introduced into the state legislature in 1987, but it was killed in committee.³¹ Eleven state child protective agencies, responding to a survey by the HHS, stated that because of the medical and ethical issues involved, their responsibility for infant Doe cases was not appropriate.³² Despite the generally positive HHS report on the federal law, its own Inspector General conceded: "[i]t is not clear what impact the Federal legislation and increased State responsibility have had on the incidence or handling of baby Doe reports."³³

II. AGENCY RULEMAKING AUTHORITY

A. THE IMPROPER ASSUMPTION OF LEGISLATIVE POWERS

State child protective agencies charged with the goal of pursuing instances of child abuse and neglect have sometimes assumed the authority to promulgate regulations and to make policy decisions that determine when treatments may be withheld from handicapped newborns. Is the exercise of such authority legitimate? A quick look at the matter might suggest a positive answer, because state statutes often use broad terms to define neglect³⁴ and delegate broad enforcement power to the relevant state agencies.³⁵ But the matter is more complex than it first appears.

Legislatures, it is true, routinely delegate broad responsibilities to state agencies. But agencies may not use their delegated power to perform legislative functions. As the New York Court of Appeals recently phrased the issue in *Boreali v. Axelrod*:³⁶ "[W]e must . . . inquire whether, assuming the propriety of the Legislature's grant of authority, the agency exceeded the permissible scope of its mandate by using it as a basis for engaging in inherently legislative activities."³⁷ There is, in

³¹ S. 1596, Cal. Leg. (1987)(available from the office of California Sen. Joseph B. Montoya).

³² OFFICE OF INSPECTOR GENERAL, U.S. DEP'T OF HEALTH AND HUMAN SERVICES, SURVEY OF STATE BABY DOE PROGRAMS 11 (1987).

³³ *Id.* at 13.

³⁴ New York's Family Court Act speaks of the failure to provide "adequate" medical care. N.Y. FAM. CT. ACT § 1012(f) (Consol. 1987).

³⁵ See, e.g., 12A MO. ANN. STAT. § 199-210.110(5) (Vernon 1987)(discusses tuberculosis sanatoriums); N.Y. SOC. SERV. LAW § 34, 424 (Consol. 1987).

³⁶ 71 N.Y.2d 1, 517 N.E.2d 1350, 523 N.Y.S.2d 464 (1987).

³⁷ *Id.* at 9, 517 N.E.2d at 1353, 523 N.Y.S.2d at 468.

the court's words, a "difficult-to-define line between administrative rulemaking and legislative policy-making."³⁸ In *Boreali*, a public health agency had issued anti-smoking regulations under a broad statute empowering it to "deal with any matters affecting the . . . public health."³⁹ Noting that the state judiciary had long approved very broad delegations of power by the legislature in many other areas, the court deemed the general grant of authority to the Public Health Council an appropriate means to safeguard the public health. But the action of the agency in promulgating anti-smoking rules, purportedly under this authority, was deemed an encroachment into the legislative domain, in violation of the state constitutional separation-of-powers principle. "Striking the proper balance among health concerns, cost and privacy interests," the court decided, "is a uniquely legislative function."⁴⁰ The court found that the agency had assumed the power to resolve a difficult, much-debated social problem, without any legislative policy to guide it. It had done so in an area where the legislature had itself failed to act despite the substantial public debate on the issue and the introduction, but not passage, of bills addressing the issue.⁴¹

Of course, the problem of treatment or nontreatment decisions for infants differs in many ways from the issue of smoking in public places. But several features of the treatment refusal issue raise identical concerns about the propriety of solving infant Doe dilemmas through administrative rulemaking. Like the smoking issue, treatment dilemmas represent a controversy that has recently come to the forefront of public debate. Also like the smoking issue, the problem involves the balancing of ethical, social, medical, economic and privacy concerns. Infant Doe treatment dilemmas obviously implicate competing moral and social values, and touch upon sensitive family and infant privacy interests. Any solution will affect the physician/family relationship and the professional practice of modern medicine. Economic concerns are also present. Neonatal intensive care is enormously expensive,⁴² both to families and to states that pay substantial sums for newborn care through public health insurance programs. In an era of rising health costs, compulsory neonatal treatment rules of questionable worth impose economic obligations that legislatures setting limits on state health care budgets may not necessarily choose to incur. As many have pointed out,⁴³ funds to help handicapped newborns may be better

³⁸ *Id.* at 11, 517 N.E.2d at 1355, 523 N.Y.S.2d at 469.

³⁹ N.Y. PUB. HEALTH LAW § 225(5)(2) (Consol. 1987).

⁴⁰ *Boreali*, 71 N.Y.2d at 12, 517 N.E.2d at 1355, 523 N.Y.S.2d at 470.

⁴¹ *Id.*

⁴² Kirkley, *Fetal Survival—What Price?*, 137 AM. J. OBST. & GYN. 873 (1980).

⁴³ See, e.g., Young, *Caring for Disabled Infants*, HASTINGS CENTER REP., Aug. 1983, at 15; Lantos, *Baby Doe Five Years Later*, 317 NEW ENG. J. MED. 444 (1987); Stevenson, Ariagno, Kut-

spent in prenatal programs that prevent birth defects and in long term programs that provide better institutional care, nursing, physical therapy and other services desperately needed by handicapped children. States considering mandatory care must also consider the economic question raised when hospitals with intensive care nurseries refuse admittance to those who cannot afford to pay. Will the state allocate funds to provide the mandated treatment for the uninsured and the inadequately insured?

It is reasonable to conclude that the resolution of such difficult societal problems, implicating so many competing interests, is not a function for an administrator. This is especially so when the administrator lacks any guidance from the state legislature on the issue, as is the case in most of the states on the infant Doe issue.⁴⁴ Traditional child abuse and neglect statutes certainly do not focus on the complex questions of care for severely birth defective newborns. Administrators relying on these statutes for infant Doe rulemaking powers are entirely on their own, without legislative instruction or direction on the basic policy questions involved. They are in reality making new law, not merely carrying out the legislative mandate entrusted to them.

This conclusion is buttressed by the fact that a number of legislatures and governors have created task forces to advise them on the range of bioethical issues arising from recent advances in medical technology, including the treatment of handicapped newborns.⁴⁵ When the legislature or the governor is actively searching for public policy recommendations on a new and unprecedented social issue, the matter can not properly be foreclosed by an administrative agency independently deciding on a new legal direction. A judicial opinion handed down when the HHS attempted to make binding rules for the treatment of infant Does further supports the view that this area calls for legisla-

ner, Raffin & Young, *The 'Baby Doe' Rule*, 255 J. A.M.A. 1909, 1911 (1986). Other programs, like universal prenatal care, compete for limited funding and may be more effective than after-the-fact intensive care in reducing the number and severity of birth defects. Lantos, *supra*, at 446-47. Such programs are also cost-effective. *\$400 Births That Cost \$400,000*, N.Y. Times, Aug. 22, 1988, (Editorial), at A18, col. 1. Furthermore, strong moral arguments have been made that government must first provide better care and facilities for children who survive with severe mental and physical incapacities; to compel treatment without providing for basic post-treatment needs is "patently hypocritical." J. LYONS, *PLAYING GOD IN THE NURSERY* 263 (1985); see also PRESIDENT'S COMM'N, *supra* note 29, at 228-29. For further discussion of this point, see *infra* notes 212-19 and accompanying text.

⁴⁴ See statutes cited *supra* note 7.

⁴⁵ See, e.g., N.Y. Task Force on Life and the Law; N.J. Comm'n on Legal and Ethical Problems in the Delivery of Health Care. A former Solicitor General of New York writes that "legislative inaction on issues of consequence and controversy must be considered, in a very meaningful sense, to be governmental action. And if it is to provide a rationale for any posture by an administrative agency, that posture, the courts are saying, should be a respectful repose." Hermann, *What Is Going On Here?*, N.Y.L.J., Apr. 18, 1988, at 2, col. 4.

tive, not administrative, action. The U.S. Court of Appeals for the Second Circuit, considering an early attempt by the HHS to promulgate Baby Doe regulations, declared that "[I]t is congress, rather than an executive agency, that must weigh the competing interests at stake in this context in the first instance."⁴⁶

State agencies may attempt to legitimate their rulemaking by pointing to the existence of the federal infant Doe statute, but this will not suffice. The federal law is not binding on the states; it does not dictate what state law must be, but merely offers modest funding to states that conform their laws to the federal model. States must still determine for themselves what their law will be and how far the rulemaking power of state agencies extends in making that law. This is a vital matter because each state has a critical interest in preserving the integrity of its own lawmaking structure. The federal law cannot resolve this issue for any state. Rather, each state must address the difficulties suggested here concerning proper limits on the power of the state's own administrative bodies.

Indeed, the federal law, rather than legitimating state agency rulemaking, provides another reason to be wary of it. Because the federal law establishes its infant Doe rule as a condition of a grant program providing funds to state child protective agencies, these agencies have a direct financial interest at stake in promulgating the rule precisely as dictated by the federal funders. To enhance its own budget, a state agency may be less reliable in carefully considering and weighing all competing interests. Courts may justifiably be suspicious of agency claims to rulemaking powers that simultaneously enlarge both agency jurisdiction and the agency budget.⁴⁷

In the first instance, it is the state legislature or judiciary that must determine the state's infant Doe policy. Lawmakers and judges must decide: (1) whether the federal infant Doe rule is in harmony with the state's own beliefs, traditions and public philosophy; (2) whether trends in the state's medical, legal and popular thought may be moving away from the federally preferred solution; and (3) whether state constitutional mandates conflict with the federal proposal. As the Arizona Supreme Court wrote in 1987, treatment refusal issues are "fraught with moral, ethical, social, medical, and legal considerations. . . . Only the Legislature [can] . . . synthesize the vast . . . information . . . [and weigh] the rights and interests of the many individuals and institutions

⁴⁶ *United States v. University Hosp.*, State Univ. N.Y. at Stonybrook, 729 F.2d 144, 161 (2d Cir. 1984).

⁴⁷ *Cf. Society for Good Will to Retarded Children, Inc. v. Carey*, 572 F. Supp. 1298, 1299 (E.D.N.Y. 1983)(distorting effect of budgetary pressures on sound professional judgment).

involved in these tragic situations.”⁴⁸

B. IMPROPER ASSERTION OF STATUTORY AUTHORITY

Agency rulemaking is also challengeable on a related but legally distinct ground. The assertion of authority, under child abuse and neglect statutes, over infant Doe decisionmaking poses a classic issue of statutory interpretation; does the typical child abuse and neglect statute contemplate coverage of treatment decisions for seriously ill infants? Typically, state statutes prohibit “medical neglect” but do not define the term beyond a somewhat vague reference to parental failure to provide adequate medical care to a child.⁴⁹ Under such a statute, an agency might assert its freedom to define neglect in virtually any fashion it sees fit in order to adjust to the many different ways in which children are deprived by the neglectful behaviors of their caretakers. Thus, if the agency chooses to regulate treatment decisions for impaired infants, it could claim it is merely interpreting the meaning of neglect in a medical context.

Examining the matter more closely, it appears that certain important shared understandings inform the common legal usage of the term “neglect.” Primary is the notion of a *fundamental disregard for a child’s needs*. The neglectful parent ignores basic needs of his child, hence harm results from and is attributable to the parent’s heedless, uncaring behavior. In the context of medical neglect, the behavior is usually the failure to seek competent medical attention when serious medical problems exist.⁵⁰

Compare this common understanding of neglect with the scenario surrounding an infant Doe treatment decision. The parents, far from disregarding their child’s interests, focus intensely on them. They contemplate their child’s suffering, precarious state of health and potential future life. Trusted family, friends, religious advisers and others are consulted, for wisdom, solace and support. Harm to the child, or death, constitutes a grievous, painful loss, almost beyond comprehension. Instead of thoughtless and uncaring behavior, there is profound concern, empathy and love. The burden of responsibility is not carelessly evaded or casually assumed; it is borne, in all its tragic dimension, with anguished dignity. Medical attention, far from lacking, appears in

⁴⁸ *Rasmussen v. Fleming*, 154 Ariz. 207, 225, 741 P.2d 674, 692 (1987)(opinion by Gordon, Chief J.)[hereinafter *Rasmussen II*]; see *Rasmussen v. Fleming*, 154 Ariz. 200, 741 P.2d 667 (1987)(opinion by Howard, J.)[hereinafter *Rasmussen I*].

⁴⁹ See *supra* note 34.

⁵⁰ See, e.g., *In re Ray*, 95 Misc. 2d 1026, 408 N.Y.S.2d 737 (Fam. Ct. 1978). Parents may not use their own religious beliefs to deny needed medical care for their child. See, e.g., *In re Hamilton*, 657 S.W.2d 425 (Tenn. App. 1983); *In re Gregory S.*, 85 Misc. 2d 846, 380 N.Y.S.2d 620 (Fam. Ct. 1976).

its most modern technological dress. Parents and physicians, confronting the suffering caused by some of the most devastating conditions known to medicine, may view aggressive care as inappropriate and even inhumane. Can their rejection of aggressive care rationally be deemed "neglect" when it proceeds from a profound concern on the part of loving parents, rests on sound medical advice and is founded upon reasoned judgment about what is best for the child?

The disparity between this scenario and the common understanding of neglect is so vast that the latter cannot reasonably be said to subsume the former. Traditionally, child abuse and neglect law is concerned with the universally condemned vices of those who act callously toward children. Such laws exist in every state, testament to their root in society-wide agreement. It seems beyond rational dispute that they were never meant to deal with the medically complex and morally ambiguous problems of bioethics, morality and law posed by the infant Doe dilemma.⁵¹

Further support for this conclusion may be found in certain judicial and legislative actions that clarify the scope of neglect laws in some states. California, for example, amended its definition of neglect in 1987 to include the statement that: "[A]n informed and appropriate medical decision made by parent or guardian after consultation with a physician or physicians who have examined the minor does not constitute neglect."⁵² This may exclude virtually all infant Doe situations from the coverage of the neglect statute.

In New York, the state's highest court interpreted its child neglect statute in a similar way. In *In re Hofbauer*,⁵³ the parents of an eight-year-old child with Hodgkin's disease sought laetrile injections and nutritional therapy for him. The parents rejected the conventional treatment of radiation and chemotherapy recommended by one physician, and found another doctor who advocated the laetrile treatment. The county social services department initiated a child neglect proceeding. The Family Court found the parents were concerned, loving and conscientious in their efforts to secure medical care for their son. The neglect petition, based on a statute generally requiring parents to supply "adequate" medical care, was dismissed. On appeal, the New York

⁵¹ "Neglect" hardly describes the behavior of parents or doctors. As an editorial in the New England Journal of Medicine observed, "most parents would give their lives for their children," and doctors "are often accused of many wrongs in our society, but lack of therapeutic aggressiveness is not one of them." Angell, *Handicapped Children: Baby Doe and Uncle Sam*, 309 NEW ENG. J. MED. 659, 660 (1983); see also Nolan, *Imperiled Newborns*, 17 HASTINGS CENTER REP. 5 (1987)(new definitions "could include as abusers clinicians struggling to provide sensitive and humane care for infants").

⁵² CAL. PENAL CODE § 1165.2 (West Supp. 1988).

⁵³ 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936 (1979).

Court of Appeals declared that while the statute did require the parents to seek medical attention for their child, "great deference must be accorded a parent's choice as to the mode of medical treatment to be undertaken and the physician selected to administer the same."⁵⁴

This decision, as well as accepted scholarly treatments of the subject of neglect,⁵⁵ views the legal concept of neglect as a minimalist one: so long as parental behavior comes within a broad range of acceptable conduct, parents need not fear intervention or prosecution by the government. A child protective agency that exercises rulemaking authority over caring, responsible decisionmaking for infants by parents and physicians is improperly expanding the meaning of medical neglect and consequently is acting beyond its statutory authority.⁵⁶

III. STATE CONSTITUTIONAL LAW

State constitutions form the fundamental "law of the land" in a state. Should a state court, examining its own constitutional principles, determine that the infant treatment standards enacted by Congress invade the rights of parents or of the infants themselves, then the federal

⁵⁴ *Id.* at 655, 393 N.E.2d at 1013, 419 N.Y.S.2d at 940. Parents may rely upon the advice of a duly licensed physician, the court continued, even if the advice is not "widely embraced by the medical community." *Id.* at 652, 393 N.E.2d at 1011, 419 N.Y.S.2d at 938. In a statement with significant implications for typical infant Doe situations, the court wrote:

[U]ltimately, however, the most significant factor in determining whether a child is being deprived of adequate medical care, and, thus, a neglected child within the meaning of the statute, is whether the parents have provided an acceptable course of medical treatment for their child in light of all the surrounding circumstances. This inquiry cannot be posed in terms of whether the parent has made a 'right' or 'wrong' decision, for the present state of the practice of medicine, despite its vast advances, very seldom permits such definitive conclusions. Nor can a court assume the role of a surrogate parent and establish as the objective criteria with which to evaluate a parent's decision its own judgment as to the exact method or degree of medical treatment which should be provided, for such standard is fraught with subjectivity. Rather, in our view, the court's inquiry should be whether the parents, once having been made aware of the seriousness of their child's affliction and the possibility of cure if a certain mode of treatment is undertaken, have provided for their child a treatment which is recommended by their physician and which has not been totally rejected by all responsible medical authority.

Id. at 656, 393 N.E.2d at 1014, 419 N.Y.S.2d at 940-41.

⁵⁵ Two leading articles are: Wald, *State Intervention on Behalf of "Neglected" Children: Standards for Removal of Children From Their Homes, Monitoring the Status of Children in Foster Care and Termination of Parental Rights*, 28 STAN. L. REV. 623 (1976); Areen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Neglect and Abuse Cases*, 63 GEO. L.J. 887 (1975).

⁵⁶ As for any claim that the federal law, by placing its infant Doe choices in a definition of medical "neglect," adequately has defined neglect for the states, consider an instructive riddle traditionally attributed to Abraham Lincoln: "If you call a tail a leg, how many legs has a dog? Five? No; calling a tail a leg don't make it a leg." J. BARTLETT, *THE SHORTER BARTLETT'S FAMILIAR QUOTATIONS* 218(d) (1961). Similarly, calling nonaggressive care for infants suffering terribly from incurable conditions "neglect" doesn't make it neglect as that term has long been used and understood. Lawyers and lawmakers above all must be aware of the difference between semantic labelling and the reality those labels purport to describe. See *supra* note 51.

standards must yield to those rights. As Judge Hans Linde, writing for the Oregon Supreme Court in *Salem College & Academy v. Employment Div.*⁵⁷ explains, "the state cannot violate its own constitution in order to satisfy a federal program that Congress has not made obligatory under the Supremacy Clause."⁵⁸ The *Salem College* case concerned a Congressional statute that provided a monetary incentive to states to set up unemployment systems with certain prescribed features. Non-compliance, the court observed, would mean forfeiting federal funding.⁵⁹ Such a federal scheme does not invoke the Supremacy Clause, which would otherwise make the federal law binding on the states.⁶⁰ The court held that the Oregon state legislature, however eager to qualify for federal dollars, could not accept the federal conditions concerning exemptions from coverage for certain religious schools, because the conditions violated state constitutional provisions.⁶¹

The federal infant Doe law is conceptually similar to the unemployment insurance statute considered by the Oregon Supreme Court. It is part of a funding statute — the Child Abuse Prevention and Treatment Act of 1974.⁶² To qualify for federal benefits, a state must adopt the federal rule on required treatment for defective newborns. Failure to do so is not a violation of the Supremacy Clause, but merely a disqualification from receiving the offered funding. Practically and politically, states may covet such funding, but legally they are not compelled to accept Congress' conditions.

Do state constitutions prohibit some of the conduct that Congress insists upon in its infant Doe law? In many states, the probable answer is yes. The answer for any particular state depends upon a variety of factors including its constitutional text, interpretive history, precedent and logic, positions taken on related legal and moral issues and traditions of respect for individual rights, family autonomy and family privacy. Case law about medical care for gravely ill infants is sparse, but a study of the value choices underlying treatment refusals for such infants leads to serious doubts about the acceptability of the federal infant Doe law under state constitutions.

Textually, relevant provisions of state constitutions are clauses protecting the right to privacy and the right to due process, and clauses preserving unenumerated individual rights. "Privacy" is not mentioned explicitly in the U.S. Constitution, but it does appear in several state charters. The constitutions of the states of Arizona and Washing-

⁵⁷ 298 Or. 471, 695 P.2d 25 (1985).

⁵⁸ *Id.* at 484, 695 P.2d at 34.

⁵⁹ *Id.* at 477, 695 P.2d at 30.

⁶⁰ *Id.* at 477, 695 P.2d at 29.

⁶¹ *Id.* at 484-92, 695 P.2d at 34-39.

⁶² 42 U.S.C. § 5101-5 (1984).

ton, for example, both declare: "[n]o person shall be disturbed in his private affairs. . . ." ⁶³ The Alaska constitution states: "[t]he right of the people to privacy is recognized and shall not be infringed." ⁶⁴ The California constitution recognizes "pursuing and obtaining safety, happiness, and privacy" as an inalienable right. ⁶⁵ Montana's constitution holds: "[t]he right of individual privacy is essential to the well-being of a free society and shall not be infringed without the showing of a compelling state interest." ⁶⁶ In addition to such privacy clauses, various state constitutional provisions reserve unenumerated rights to the people ⁶⁷ and guarantee due process of law, ⁶⁸ in much the same terms as the federal Constitution.

Constitutional texts rarely give definitive answers to complex questions of due process, privacy and liberty. Brief constitutional sentences or phrases beget the enduring and difficult problem of interpreting the scope of individual rights in a wide variety of contexts. Hence precedent, history, tradition and contemporary community understandings of constitutional values all play a role in constitutional analysis. ⁶⁹ Moreover, while states interpret their own constitutions according to their own lights, they often take note of federal constitutional developments. Since the privacy doctrine has been most visibly developed and debated by the United States Supreme Court, it is worthwhile to examine the privacy concept enunciated by the Court.

Following the landmark case of *Griswold v. Connecticut* ⁷⁰ in 1965, establishing the right of married couples to use contraceptives in their own homes, claims raised in the Supreme Court about privacy have often centered around personal and family life decisionmaking prerogatives. The Court stated, even prior to *Griswold*, that there is a "realm

⁶³ ARIZ. CONST. art. II, § 8; WASH. CONST. art. I, § 7.

⁶⁴ ALASKA CONST. art. I, § 22.

⁶⁵ CAL. CONST. art. I, § 1.

⁶⁶ MONT. CONST. art. II, § 10.

⁶⁷ See, e.g., COLO. CONST. art. II, § 25; MICH. CONST. art. I, § 23.

⁶⁸ See, e.g. ARIZ. CONST. art. II, § 4; ILL. CONST. art. I, § 24; IOWA CONST. art. I, § 25; MICH. CONST. art. II, § 17.

⁶⁹ Writing of the importance of tradition, history and values in federal due process analysis, Justice Harlan once wrote of the crucial

balance struck by this country, having regard to what history teaches are the traditions from which it developed as well as the traditions from which it broke. That tradition is a living thing. A decision of this Court which radically departs from it could not long survive, while a decision which builds on what has survived is likely to be sound. . . . The decision of an apparently novel claim must depend on grounds which follow closely on well accepted principles and criteria. The new decision must take its place in relation to what went before and further [cut] a channel for what is to come.

Poe v. Ullman, 367 U.S. 497, 542-44 (1961)(Harlan, J., dissenting)(citation omitted).

⁷⁰ 381 U.S. 479 (1965).

of family life which the State may not enter."⁷¹ Each person, under the Constitution, enjoys "a certain private sphere of individual liberty . . . largely beyond the reach of government."⁷² The right to privacy established by *Griswold* and its progeny is first and foremost a *decisionmaking* right.⁷³ Among the matters left to private determination "are personal decisions relating to marriage, procreation, contraception, family relationships, and child rearing and education."⁷⁴ Broadly speaking, the Court has said the sorts of decisions worthy of constitutional protection are those which are "personal and intimate, . . . properly private . . . basic to individual dignity and autonomy."⁷⁵

Parental decisionmaking for children is touched upon in several Supreme Court decisions. In *Stanley v. Illinois*⁷⁶ the Court, striking down a presumption of Illinois law that unwed fathers are always unfit to care for their own children, underlined the importance of maintaining the integrity of the family unit and stated: "[i]t is plain that the interest of a parent in the companionship, care, custody, and management of his or her children 'comes to this Court with a momentum for respect lacking when appeal is made to liberties which derive merely from shifting economic arrangements.' "⁷⁷

In *Parham v. J.R.*⁷⁸ the Court elaborated upon its belief in the primary role of parents in the social and legal order:

Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children. Our cases have consistently followed that course; our constitutional system long ago rejected any notion that a child is 'the mere creature of the State' The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has recognized that

⁷¹ *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

⁷² *Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747, 772 (1986).

⁷³ "This right of personal privacy includes 'the interest in independence in making certain kinds of important decisions'." *Carey v. Population Serv. Int'l*, 431 U.S. 678, 684 (1977)(quoting *Whalen v. Roe*, 429 U.S. 589, 599-600 (1977)).

⁷⁴ *Id.* at 684-85 (quoting *Roe v. Wade*, 410 U.S. 113, 152-53 (1973)).

⁷⁵ *Thornburgh*, 476 U.S. at 772. A new majority of the Court apparently has retreated from such phrasing, speaking more narrowly of interests which are "implicit in the concept of ordered liberty . . . or deeply rooted in our Nation's history and tradition." *Bowers v. Hardwick*, 478 U.S. 186, 191-92 (1986). Yet even under this standard, parental autonomy still should be protected. See *infra* text accompanying notes 78-80.

⁷⁶ 405 U.S. 645 (1972).

⁷⁷ *Id.* at 651 (citation omitted).

⁷⁸ 442 U.S. 584 (1979)(upholding Georgia's informal, non-adversarial procedures permitting parents to commit child to a state mental institution).

natural bonds of affection lead parents to act in the best interests of their children.⁷⁹

The Court recognized that some parents disregard their child's interests, but concluded that this "is hardly a reason to discard wholesale those pages of human experience that teach that parents generally do act in their child's best interests. The statist notion that governmental power should supersede parental authority in *all* cases because *some* parents abuse and neglect children is repugnant to American tradition."⁸⁰

The Court has never had occasion to address the constitutional liberty and privacy questions raised by the infant Doe rule under consideration here. The argument might be made that the rule merely defines a species of child neglect that is within the recognized power of the state to regulate. I have previously suggested that most parental decisions to forego aggressive treatments for infants do not at all resemble the classic cruelties of child abuse and neglect which the Court undoubtedly had in mind when acknowledging the proper legal limits on parental authority and independence.⁸¹ How the Court would view a privacy claim made by loving and concerned parents seeking to avoid state-mandated aggressive treatment for a severely damaged infant is not predictable from the precedents established by the Court so far. Dramatic confrontations among the justices have occurred in the 1980s over the scope of privacy rights, signaling perhaps a greater resistance to new claims under the privacy doctrine.⁸²

But where the U.S. Supreme Court leaves off, state supreme courts have often ventured on, construing their own constitutions so as to expand and fortify personal privacy rights. As aptly expressed by Justice Pollock of the New Jersey Supreme Court: "[a]lthough the state constitution may encompass a smaller universe than the Federal Constitution, our constellation of rights may be more complete."⁸³ Nationwide, the "rediscovery by state supreme courts of the broader protections afforded their own citizens by their state constitutions . . . is probably the most important development in constitutional jurisprudence of our times."⁸⁴

⁷⁹ *Id.* at 602.

⁸⁰ *Id.* at 602-03.

⁸¹ See *supra* text accompanying notes 50-55.

⁸² Compare *Bowers v. Hardwick*, 478 U.S. 186, 187 (1986) (majority opinion by White, J.) with *Bowers*, 478 U.S. at 199, 214 (dissenting opinions by Blackmun, Stevens, JJ.), and *Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747, 785 (1986) (dissenting opinion by White, J.) with *Thornburgh*, 476 U.S. at 772 (concurring opinion by Stevens, J.); see also *supra* note 58.

⁸³ *Right to Choose v. Byrne*, 91 N.J. 287, 300, 450 A.2d 925, 931 (1982).

⁸⁴ Collins, *Looking to the States*, NAT'L L.J., Sept. 29, 1986, at S-1 (quoting Justice William J. Brennan, Jr.).

State courts have in fact developed a second line of cases that significantly affects the legal analysis of infant Doe treatment rules. This set of cases, cutting across state boundaries (and, therefore, more aptly termed a "front" of cases rather than a "line" of cases) suggests the existence of an individual liberty/privacy interest belonging to the infant. Several key propositions have been established among the states. First, there is a right to refuse ordinary medical treatment of any character,⁸⁵ including modern technological techniques that sustain life without restoring health.⁸⁶ This right is widely recognized as originating in fundamental constitutional guarantees of individual liberty and privacy. Indeed, several state courts have held this right to be protected by both state and federal constitutions.⁸⁷

Second, state courts have held that individuals who are not competent to make fundamental decisions for themselves, nevertheless still have constitutionally protected liberty and privacy interests, despite the inability of the individual to exercise them. A leading case is *Conservatorship of Valerie N.*,⁸⁸ in which the Supreme Court of California confronted state laws which provided no mechanism for authorizing the sterilization of a severely mentally retarded 29-year-old woman. The woman was unable to make choices for herself about bearing children or using contraception. Her parents felt sterilization was the preferable choice for her.

The court asked whether this woman had the "constitutional right to have these decisions made for her, in this case by her parents as conservators, in order to protect her interests in living the fullest and most rewarding life of which she is capable."⁸⁹ The interests of the incompetent woman, the court concluded, required that some procreative choices be made. While acknowledging her lack of decisionmaking capacity, the court held that in the area of procreative choice, "the interests of the incompetent . . . do not differ from the interests of women able to give voluntary consent to this procedure."⁹⁰ The decision to allow sterilization was grounded in both the Fourteenth Amendment and in the privacy clause of the state constitution. Other state supreme courts agree with this approach, assuring that fundamental privacy rights are extended to incompetents in a variety of decisionmaking

⁸⁵ *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914)(majority opinion by Cardozo, J.).

⁸⁶ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied*, 429 U.S. 922 (1976).

⁸⁷ *See, e.g., Rasmussen II*, 154 Ariz. 207, 741 P.2d 674 (1987); *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (1986); *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).

⁸⁸ 40 Cal. 3d 143, 219 Cal. Rptr. 387, 707 P.2d 760 (1985).

⁸⁹ 40 Cal. 3d at 160, 219 Cal. Rptr. at 393, 707 P.2d at 771.

⁹⁰ 40 Cal. 3d at 162, 219 Cal. Rptr. at 399, 707 P.2d at 772.

contexts.⁹¹

If incompetent persons have privacy rights, and if privacy rights include the right to refuse medical treatments, then presumably incompetent patients possess the right to refuse treatments. The Arizona Supreme Court accepted this principle in *Rasmussen v. Fleming*.⁹² The court considered the case of a woman in a nursing home existing in what doctors diagnosed as a chronic vegetative state. She lay in a fetal position, sustained by the administration of food and fluids through a nasogastric tube. Her physician entered both a "do not resuscitate" order (no medical resuscitation effort if she suffered cardiac arrest) and a "do not hospitalize" order on her chart. As a consequence, she received comfort care, but in the words of the court, "certain diseases, such as pneumonia, gangrene, and urinary tract infections were to run their natural course."⁹³

Ms. Rasmussen, though incompetent and never having previously expressed her wishes concerning withholding of medical treatment, continued to have a constitutional right to refuse medical treatment, the court ruled. The value involved, said the court, was the value of human dignity, which extends to competent and incompetent alike.⁹⁴ Since the right to refuse treatment could not be exercised by the individual, a substitute decisionmaker had to be found. In the absence of evidence of the patient's desires, that decisionmaker should be guided by the best interests of the patient.⁹⁵ Family members are the obvious choice to serve as decisionmakers for patients unable to make their own health care choices. Numerous state decisions support this designation.⁹⁶ Parents, of course, are traditionally the health care decisionmakers for children; their status as such is buttressed by the constitutional cases discussed earlier.⁹⁷

⁹¹ *In re C.D.M.*, 627 P.2d 607 (Alaska 1981); *In re Moe*, 386 Mass. App. Ct. 555, 432 N.E.2d 712 (1982); *In re Grady*, 85 N.J. 235, 426 A.2d 467 (1981); *Rivers v. Katz*, 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986); *In re Guardianship of Hayes*, 93 Wash. 2d 228, 608 P.2d 635 (1980).

⁹² *Rasmussen II*, 154 Ariz. 207, 741 P.2d 674 (1987).

⁹³ *Id.* at 212, 741 P.2d at 679.

⁹⁴ *Rasmussen I*, 154 Ariz. 200, 205-06, 741 P.2d 667, 668 (1987). The dignity value is recognized in other cases. See, e.g., *Rivers v. Katz*, 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

⁹⁵ *Rasmussen II*, 154 Ariz. at 221, 741 P.2d at 688.

⁹⁶ *In re Quinlan*, 70 N.J. 10, 53, 335 A.2d 647, 670 (1976), cert. denied, 429 U.S. 922 (1976); *In re Jobes*, 108 N.J. 394, 416, 529 A.2d 434, 445 (1987); *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1021, 195 Cal. Rptr. 484, 493; see also Newman, *Treatment Refusals for the Critically and Terminally Ill: Proposed Rules for the Family, the Physician, and the State*, 3 N.Y.L. SCH. HUM. RTS. ANN. 35 (1985).

⁹⁷ *In re Quinlan*, 70 N.J. at 53, 355 A.2d at 670; *In re Jobes* 108 N.J. at 416, 529 A.2d at 445; *Barber*, 147 Cal. App. 3d at 1021, 195 Cal. Rptr. at 493.

These points are now largely uncontroversial. Much agreement exists as to the extension of privacy rights to incompetents, the use of substitute decisionmakers and the use of a best interest standard for making the decision when no evidence of the incompetent's own wishes exists. Substantial agreement also exists for the proposition that sometimes "a patient's best interests are served when medical treatment is withheld or withdrawn."⁹⁸ The task remains of applying the foregoing principles to a new legal problem. Whether parental decisionmaking for impaired newborns is within the sphere of family privacy and the individual liberty rights of infants depends upon an assessment of the values underlying these concepts.

At root, the privacy and liberty rights found in some form in all state constitutions spring from a cluster of values viewed as basic in American legal and social culture. First is the value of autonomy, the freedom to make key life choices without government coercion. Another is privacy in its classic sense, the right to keep personal matters confidential, away from the probing scrutiny, meddling and possible exploitation of others. A third is self-expression, the need to develop, articulate and act upon one's moral, religious and philosophical values. A fourth is intimacy, the experience of relating to certain others in a unique way that nurtures the spirit and provides care and comfort through difficult times. A fifth is the deep-seated desire to find purpose and meaning in life, a goal which must be defined individually but which includes a widely shared rejection of the sort of empty, meaningless existence that medical technology sometimes offers. Finally, notions of privacy and liberty are founded upon a tradition of respect for the dignity of each human being. All of these interests, though separately stated, relate to each other in various and complex ways. Translating these values into legal rules and applying them to difficult situations is a formidable task, but one which a constitution of broad majestic principles compels judges (and other public officials, who too often leave such matters to judges) to undertake. In giving concrete meaning to terms such as "liberty" and "privacy," courts are acting on Justice White's observation that a constitution "is a document announcing fundamental principles in value-laden terms that leave ample scope for the exercise of normative judgment by those charged with interpreting and applying it."⁹⁹

Privacy cases typically feature a combination of these basic human values. For example, the contraception and abortion cases protect the

⁹⁸ *Rasmussen II*, 154 Ariz. at 221, 741 P.2d at 688; see also *In re Conservatorship of Torres*, 357 N.W.2d 332 (Minn. 1984).

⁹⁹ *Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747, 788-89 (1986)(White, J., dissenting).

autonomy of individuals in making the key life choice of whether to bear or beget a child. In addition they preserve the privacy of intimate, sexual relationships. Further, they permit couples to act upon their moral and philosophical values, even as to controverted matters like abortion and its troubling questions about the proper regard due to incipient human life. Medical decisionmaking by parents for their infants also promotes society's realization of the values underlying privacy and liberty rights. The value of human dignity, explicitly cited in several judicial opinions sanctioning treatment refusals,¹⁰⁰ surely extends to infants. This value is manifest in the infants' profound interest in humane treatment decisions that take into account their pain, their suffering and their need for peace and respite from the sometimes strenuous and stressful treatment regimes involved in high technology neonatal intensive care. In the context of treatment decisions for desperately ill newborns, parents need the autonomy, privacy, intimacy and freedom to express deep moral values that important family decisionmaking requires. They must consider the most difficult issues of life, suffering and the prospect of death.¹⁰¹

What families need most in this tragic circumstance is a protective cocoon for healing, reflection, sorrow and the expression of intimate thoughts and emotions. Aggressive, intrusive outsiders are a disruptive and unwelcome presence in these situations. The New York Court of Appeals, criticizing the attempt by a right-to-life advocate to force treatment decisions upon parents of a severely impaired infant, wrote that the interfering outsider "would catapult [himself] into the very heart of a family circle, there to challenge the most private and most precious responsibility vested in the parents for the care and nurture of their

¹⁰⁰ *Rasmussen I*, 154 Ariz. at 205-06, 741 P.2d at 668; see also *Rivers v. Katz*, 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

¹⁰¹ As I have written previously:

family privacy doctrines reflect the fact that we view family self-governance as a highly prized value in American life. Its protected status under the Due Process Clause evidences concern that majorities not regulate family decisionmaking in its most intimate and sensitive functions. Responding to a severely incapacitating, irreversible illness of a member of the family unit is one of these functions. The impending death, permanent loss of consciousness, or near-complete mental and physical incapacitation of a parent, spouse, or child is one of the most emotionally intense experiences of family life. Dealing with such events requires family members to gather their emotional strength, to seek solace from trusted intimates, and to bring their personal moral, philosophical or religious convictions to bear for guidance and comfort. By necessity, the experience must be shared with the strangers who render care for the ill, but it is one that is otherwise entitled to a respectful and decent privacy.

Newman, *supra* note 96, at 49-50 (citations omitted).

children. . . ."¹⁰² This criticism of outside intrusion logically ought to extend to government officials as well, should they routinely attempt to interject themselves into these tragic situations.¹⁰³

State invasion into family privacy at this time must be carefully limited to those situations in which it is clearly justified. While there is a role for rulemaking in this area, legislatures and administrative officials need to act with a circumspection appropriate to the "precious responsibility" being dealt with. As the *Rasmussen* court pointed out, the law must address complex treatment issues "*within permissible constitutional limits*."¹⁰⁴ As the next section demonstrates, the infant Doe rule being pressed upon the states by the federal government fails to respect the basic values at stake in these situations, thereby breaching the constitutionally permissible limits of lawmaking.

IV. SPECIFIC CLAUSES: INFIRMITIES UNDER STATE CONSTITUTIONS

In this section I will examine several specific situations in which infant care questions are addressed by the federal infant Doe rule contrary to sound state constitutional principles. In the section following, I will discuss the more general failure of the rule to meet emerging state constitutional norms.

A. THE PERSISTENT VEGETATIVE STATE

The federal law permits withholding of treatment for infants who are "chronically and irreversibly . . . comatose."¹⁰⁵ Consider the case of an infant in a persistent vegetative state (PVS), a condition that is medically distinct from coma. With PVS, there is a sleep/wake cycle, some random eye movement and some reflective response to deeply painful stimuli. There is no consciousness, however, and no interaction

¹⁰² *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 213, 456 N.E.2d 1186, 1188, 469 N.Y.S.2d 63, 65, *cert. denied*, 464 U.S. 1026 (1983).

¹⁰³ As Professor Clark has written, "[N]o court or state official and certainly no legislature is able to experience the moral dilemma the parents face in these cases with the profound concern which informs the parents' decision." 1 H. CLARK, *LAW OF DOMESTIC RELATIONS IN THE UNITED STATES* 589 (2d. ed. 1987).

¹⁰⁴ *Rasmussen II*, 154 Ariz. at 225, 741 P.2d at 692 (emphasis added). Of course, the roles of legislatures and administrative agencies would, if the constitutional protections apply, be severely circumscribed, since, as Justice Jackson once eloquently wrote:

The very purpose of a Bill of Rights was to withdraw certain subjects from the vicissitudes of political controversy, to place them beyond the reach of majorities and officials and to establish them as legal principles to be applied by the courts [F]undamental rights may not be submitted to vote; they depend on the outcome of no elections.

West Virginia State Bd. of Educ. v. Barnette, 319 U.S. 624, 638 (1943).

¹⁰⁵ 42 U.S.C. § 5102(3)(A) (1984).

with others or with the environment.¹⁰⁶ It is truly a "twilight zone of suspended animation"¹⁰⁷ which many, perhaps most people, would not choose to prolong with noncurative techniques of medical maintenance.

But it is not, medically speaking, a coma, which is a state of unconsciousness resembling sleep. Since medical organizations were actively involved in the drafting of the bill, it is quite possible a court would give to the term "coma" its medical meaning, believing Congress to have chosen the word based upon medical knowledge and input. One lower court in Minnesota has concluded that "coma" does not include PVS, and that PVS is not covered by any of the other exceptions in the statute allowing nontreatment.¹⁰⁸ This also appears to be the position of the HHS.¹⁰⁹

Yet broad legal support exists for the termination of life support systems for patients in the vegetative state, including those who never expressed their treatment/nontreatment preferences, upon the request of the patient's family or guardian. State high courts have authorized such nontreatment decisions.¹¹⁰ The President's Commission also supported withdrawal of treatment in cases of PVS.¹¹¹ The landmark case involving Karen Ann Quinlan¹¹² permitted that young woman's father to decide to turn off the mechanical life support apparatus that supported her existence in an irreversible vegetative state. "We have no hesitancy in deciding," the court declared, "that no external compelling interest of the State could compel Karen to endure the unendurable, . . . to vegetate . . . with no realistic possibility of re-

¹⁰⁶ Cranford, *The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)*, 18 HASTINGS CENTER REP. 27, 28 (1988).

¹⁰⁷ *Rasmussen II*, 154 Ariz. at 211, 741 P.2d at 678.

¹⁰⁸ *In re Steinhaus*, No. J-86-92 (Minn. Fam. Ct. Sept. 11, 1986)(order denying motions to dissolve a temporary restraining order preventing antibiotics treatment and to order that aggressive treatment not be required). The court held that the exception for treatment that merely prolonged dying, for example, did not apply since a person may continue in a persistent vegetative state for an indefinite time extending over many years. Neurologist Ronald E. Cranford calls the statutory terminology "misleading" and a "medical oxymoron." He adds: "I doubt that the various parties responsible for the language of the Amendments had a clear idea of what they intended to mean and which specific neurologic conditions fell under the designation 'chronically and irreversibly comatose.'" Cranford, *supra* note 106, at 28-29.

¹⁰⁹ In the report of the Inspector General of the HHS, six incidents of non-compliance with the statute were cited, anonymously. One involved an infant in the persistent vegetative state; another involved an infant described only as having a brain stem, a condition that excludes the possibility of cognitive existence. OFFICE OF INSPECTOR GENERAL, *supra* note 32, app. D, at 3.

¹¹⁰ See *Rasmussen II*, 154 Ariz. 207, 741 P.2d 674; *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983).

¹¹¹ PRESIDENT'S COMM'N, *supra* note 29, at 189-92.

¹¹² *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied*, 429 U.S. 922 (1976).

turning to any semblance of cognitive or sapient life."¹¹³

The Supreme Court of Georgia, in *In re L.H.R.*,¹¹⁴ held that parents have the right to exercise their infant child's constitutional right to refuse treatment in the case of an infant who suffered a "medical catastrophe" 15 days after her apparently normal birth. The infant was left in a chronic vegetative state, alive but with much brain tissue destroyed. The Court's opinion noted the agreement of the attending neurologist and an *ad hoc* infant care review committee composed of two pediatricians, a nurse, a social worker and the parent of a handicapped child.¹¹⁵ Similarly, a Florida appeals court in *In re Guardianship of Barry*¹¹⁶ found a permanently, irreversibly unconscious infant had a privacy right, exercisable by his parents, to reject medical treatment to maintain his existence. The court, somewhat confusingly, referred to the infant's condition both as a "chronic permanent vegetative coma" and as a "permanent vegetative state."¹¹⁷ Neurologists testified that if mechanical ventilation were continued, the child would live anywhere from one to five years.¹¹⁸ While the court was not concerned with distinctions in medical terms between coma and PVS, there is little doubt that the shared feature of both — a permanent irreversible lack of consciousness — led to the court's decision.

The Arizona Supreme Court in *Rasmussen v. Fleming* specifically considered the differences between coma and PVS, and concluded that for legal purposes there was no "material significance between the two physical conditions."¹¹⁹ The court recognized the constitutional right to refuse treatment in a PVS case involving an adult woman. There is, it is submitted, no reason to deny an infant "living" in a hopeless vegetative state the same constitutional consideration. The federal infant Doe law, however, appears to sanction such a denial.

B. VIRTUALLY FUTILE, INHUMANE TREATMENT

The statute creates an exception to required treatment when "the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."¹²⁰ There are two problems raised by this provision, each so fundamental to infant and parental interests as to constitute likely breaches of state constitutional law. This is the only time the

¹¹³ *Id.* at 39, 355 A.2d at 663.

¹¹⁴ 253 Ga. 439, 321 S.E.2d 716 (1984).

¹¹⁵ *Id.* at 439, 321 S.E.2d at 718.

¹¹⁶ 445 So. 2d 365 (Fla. Dist. Ct. App. 1984).

¹¹⁷ *Id.* at 376.

¹¹⁸ *Id.* at 368.

¹¹⁹ *Rasmussen II*, 154 Ariz. 207, 218, 714 P.2d 674, 685 (1987).

¹²⁰ 42 U.S.C. § 5102(3)(C) (1984).

statute mentions humaneness as a consideration in making treatment decisions for infants. It limits humane concerns to only those infants for whom treatment would be virtually futile, (*i.e.*, to those whose deaths, even with treatment, are all but certain). Other infants, however intense their suffering and however severe and permanent their physical and mental defects, are denied such humane consideration. Their suffering, and the inhumaneness of adding to it by administering painful and stressful treatment, is not recognized by the statute as relevant to the decision to treat. If their chances of survival are low, but not low enough to make treatment "virtually futile," then they must be treated, however inhumanely.¹²¹

Theologian John J. Paris poses the case of a very premature infant with signs of viral encephalitis.¹²² There is extensive brain damage, severe mental retardation and the risk of uncontrollable convulsions, deafness, blindness and quadraplegia. The infant may die, but there is some chance she will survive with all of these handicaps. If the infant develops more difficulties — life-threatening infections, cardiac arrest — must treatments be given to keep the infant alive? Under the statute, aggressive care is required. To mobilize the full panoply of intensive care technology to keep this infant alive through all the medical crises that beset her, no matter how painful and invasive the treatments, and in total disregard of her already profound suffering and nearly total incapacitation, seems senseless and cruel. To suggest that the opposition of parents and physicians to vigorous treatment efforts must be overridden by law is an extreme assertion of state power over the infant, the family and the medical profession. State courts that have acknowledged the legitimacy of such factors as painfulness and invasiveness of treatment, level of functioning expected after treatment and suffering of the patient, in decisionmaking for incompetent adults, would be hard pressed to dismiss these factors in decisionmaking for infants.¹²³

This provision does more than require extensive and painful treatment without regard for the infant's overall suffering. An equally disturbing, constitutionally challengeable feature of this provision is its insistence that in some cases, treatments judged to be "virtually futile" must nevertheless be performed. Under the statute, treatments that are virtually futile may be foregone only if the treatments also are "inhumane." It is a plausible interpretation of this joint requirement of

¹²¹ See *supra* text accompanying notes 12-13.

¹²² Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 LAW MED. & HEALTH CARE 120 (1982).

¹²³ For a recent case considering these and other factors, see *In re Beth Israel Med. Center*, 136 Misc. 2d 931, 519 N.Y.S.2d 511 (Sup. Ct. 1987). For a discussion of factors relevant to infant Doe decisions, see *infra* text accompanying notes 204-19.

virtual futility and inhumaneness that certain treatments, those not so painful or invasive as to be deemed inhumane, must be performed even if doctors have little expectation that they will work.

Requiring virtually futile treatment, even relatively mild treatments, traverses the proper constitutional bounds of a compulsory treatment statute. To tell parents they must agree to treatments that are deemed virtually hopeless by their doctors, in all probability doing nothing more than prolonging suffering for their infant, is morally offensive and a substantial infringement of the privacy and liberty interests previously outlined. As the appellate panel in *Barber v. Superior Court* observed, in upholding a family decision to reject treatment for a family member: "[A] treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition."¹²⁴

The infant Doe law fails here because of its focus on the treatment instead of the patient. As John J. Paris has written of artificial feeding techniques:

[N]o matter how simple, inexpensive, readily available, noninvasive, and common the procedure, if it does not offer substantial hope of benefit to the patient, he has no moral obligation to undergo it, nor the physician to provide it, nor the judge to order it.¹²⁵

A sick person, whether infant or adult, has a right to decisionmaking that turns on benefit to the patient, not on categorization of the treatment. The federal law's perverse insistence that infants undergo a wide range of "virtually futile" treatments surely contravenes these infants' fundamental interests in care that is not merely aggressive, but also effective.

C. FOOD, FLUIDS AND MEDICATION

The federal law requires the administration of "appropriate nutrition, hydration, and medication,"¹²⁶ even in the extreme medical circumstances that justify the withholding of all other life sustaining interventions. The meaning of "appropriate" in this context is hardly clear. Is it appropriate to feed an infant who is unable to suck or swal-

¹²⁴ *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1019, 195 Cal. Rptr. 484, 491 (1983); see also *Rasmussen II*, 154 Ariz. at 222, 741 P.2d at 689 (for patient in vegetative state "any medical treatment . . . would have provided minimal, if any, benefits;" no medications or even hospitalization required).

¹²⁵ Paris, *When Burdens of Feeding Outweigh Benefits*, HASTINGS CENTER REP., Feb. 1986, at 30, 32.

¹²⁶ 42 U.S.C. § 5102(3) (1984).

low, or whose damaged system is unable to digest? Is it appropriate to insert feeding tubes into an infant who is in a permanent vegetative state? Can the benefits and burdens of artificial feeding be weighed in determining appropriateness, or must the benefit be assumed to be worth any burden associated with the treatment technique that successfully provides food, water and medication?

The single word "appropriate" does not contain enough meaning to answer these questions. In the absence of a clear directive on the point, courts may rely on professional medical practice in the community, perceived overall statutory purposes, selected statements in the legislative history or on notions of what is right. Predicting judicial outcomes under such circumstances is a hazardous undertaking. "Appropriate" could mean that the intervention should confer a net benefit upon the patient, considering the patient's prognosis, life expectancy, state of consciousness or the lack thereof and other factors pertinent to a benefits and burdens analysis.¹²⁷ But the overall restrictiveness of the statute and the plausible implication that food, water and medication are "routine care" for even the sickest patient, may lead courts to interpret "appropriate" as merely a grant of medical discretion to choose a suitable technique.

Requiring food and water sounds appealing, and where infants are concerned, feeding has a strong emotional component symbolizing caring and closeness. But in the medical context, these positive connotations often pale beside the reality of incurable disease, invasive techniques and the risks and complications that attend all medical interventions.¹²⁸ Does the fatally stricken child whose suffering is intense truly benefit from efforts to force nutrients into the body? Does the permanently vegetative infant, whose damaged brain can support vital signs but not consciousness, truly benefit from feeding tubes that may prolong a vegetative existence for years? The statute is unconcerned with such questions, but they are ones which parents may rightfully consider in making decisions about medical treatments for their severely damaged newborn. Making the provision of food, water and medication compulsory in all cases in which it is technically possible may keep lives going after respirators and mechanical monitors have been turned off. But if death is merely drawn out as a result, this requirement violates state constitutional norms that permit the refusal of treatments that merely prolong death.¹²⁹

¹²⁷ For discussion of all factors, see *infra* text accompanying notes 204-19.

¹²⁸ For a discussion of treatment problems associated with artificial feeding, see *In re Hier*, 18 Mass. App. Ct. 200, 201-06, 464 N.E.2d 959, 961-62 (1984).

¹²⁹ See *Rasmussen II*, 154 Ariz. 207, 741 P.2d 674 (1987); *In re Hamlin*, 102 Wash. 2d 810, 689 P.2d 1372 (1984); *Severns v. Wilmington Med. Center*, 421 A.2d 1134 (Del. 1980). For further compelling examples, see Paris & Fletcher, *Infant Doe Regulations and the Absolute Re-*

The special status the federal rule gives to medical interventions that provide food and fluids has been rejected by state courts across the country.¹³⁰ The New Jersey Supreme Court, rejecting a special distinction between medical interventions generally and interventions that provide food and fluids, observed:

Once one enters the realm of complex, high-technology medical care, it is hard to shed the "emotional symbolism" of food. However, artificial feedings such as nasogastric tubes, gastrotomies, and intravenous infusions are significantly different from bottle-feeding or spoonfeeding — they are medical procedures with inherent risks and possible side effects, instituted by skilled healthcare providers to compensate for impaired physical functioning. Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own.

Furthermore, while nasogastric feeding and other medical procedures to ensure nutrition and hydration are usually well tolerated, they are not free from risks or burdens; they have complications that are sometimes serious and distressing to the patient. Nasogastric tubes may lead to pneumonia, cause irritation and discomfort, and require arm restraints for an incompetent patient. The volume of fluids needed to carry nutrients itself is sometimes harmful.

Finally, dehydration may well not be distressing or painful to a dying patient. For patients who are unable to sense hunger and thirst, withholding of feeding devices such as nasogastric tubes may not result in more pain than the termination of any other medical treatment. Indeed, it has been observed that patients near death who are not receiving nourishment may be more comfortable than patients in comparable conditions who are being fed and hydrated artificially. Thus, it cannot be assumed that it will always be beneficial for an incompetent patient to receive artificial feeding or harmful for

quirement to Use Nourishment and Fluids for the Dying Infant, 11 LAW MED. & HEALTH CARE 210 (1983).

¹³⁰ See, e.g., *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (1986); *Corbett v. D'Alessandro*, 487 So. 2d 368 (Fla. Dist. Ct. App. 1986); *Brophy v. New Eng. Sinai Hosp.*, 398 Mass. 417, 527 N.E.2d 626 (1986); see also *In re Caulk*, 125 N.H. 226, 480 A.2d 93 (1984) (constitutional right to die recognized, but state interest in preventing prisoner hunger strike overrides).

him not to receive it.¹³¹

Professional medical authorities,¹³² the President's Commission,¹³³ scholars¹³⁴ and physicians¹³⁵ accept this position as well. While none of the cases on this point involved the infant Doe statute, infants as well as adults have an important constitutional interest in having the benefits, burdens and risks of medical feeding techniques carefully weighed and balanced, not ordered by rule of law.

What has been said about the right to reject artificial nutrition and hydration techniques applies to medications as well. In *Rasmussen v. Fleming*,¹³⁶ the Arizona Supreme Court permitted a "do not resuscitate" (DNR) and a "do not hospitalize" (DNH) order to be entered for an elderly nursing home patient in an irreversible vegetative state. The effect of the DNH order was to permit medical personnel "to provide only basic comfort care. Certain diseases, such as pneumonia, gangrene, and urinary tract infections, were to run their natural course."¹³⁷ The court accepted the proposition that the patient, through a guardian assessing and asserting her best interests, had the constitutional right to refuse medical treatment. No special status was afforded to medications for pneumonia or other infections commonly regarded as treatable. Requiring treatment, the court noted, would serve only to postpone Ms. Rasmussen's death, rather than to improve her life.¹³⁸

The federal law's insistence on medication, even for the comatose and the fatally ill newborn, fails to take account of the truth that some kinds of deaths are worse than others. If an infant is dying of Tay-Sachs disease, a non-medicated pneumonia infection may present an alternative cause of death less beset with terrible pain and suffering. As Professor M. Pabst Battin has written, "certain conditions will produce a death that is more comfortable, more decent, more predictable, and more permitting of conscious and peaceful experience than others."¹³⁹ Choosing not to medicate is sometimes a way to achieve a more humane outcome. It should be, as the *Rasmussen* court held, part of the

¹³¹ *In re Conroy*, 98 N.J. 321, 372-74, 486 A.2d 1209, 1236 (1985)(citing *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1016, 195 Cal. Rptr. 484, 490 (1983)).

¹³² See, e.g., *In re Peter*, 108 N.J. 365, 381-82, 529 A.2d 419, 427-28 (1987); *Brophy*, 398 Mass. at 439-40, 497 N.E.2d at 68.

¹³³ *Supra* note 29, at 90, 201.

¹³⁴ See, e.g., Rhoden, *supra* note 13, at 1283; Paris & Fletcher, *supra* note 129, at 210.

¹³⁵ See, e.g., Lo & Dornbrand, *Sounding Board: Guiding the Hand that Feeds — Caring for the Demented Elderly*, 311 NEW ENG. J. MED. 402, 403-04 (1984); Cranford, *supra* note 106, at 31.

¹³⁶ *Rasmussen II*, 154 Ariz. 207, 741 P.2d 674 (1987).

¹³⁷ *Id.* at 212, 741 P.2d at 679.

¹³⁸ *Id.* at 217, 741 P.2d at 684; accord *In re Hamlin*, 102 Wash. 2d 810, 689 P.2d 1372 (1984); *Severns v. Wilmington Med. Center*, 421 A.2d 1334 (Del. 1980).

¹³⁹ Battin, *The Least Worst Death*, HASTINGS CENTER REP., Apr. 1983, at 13, 15.

constitutional right to refuse treatment, exercisable on an incompetent's behalf by a surrogate decisionmaker.

D. LOW BIRTH WEIGHT INFANTS

The federal statute does not make special note of the dilemmas of care for very premature infants. Yet these infants experience a wide range of complex medical problems which they often do not survive, and are at serious risk of mental retardation, cerebral palsy, disorders of vital organs, bleeding in the brain and blindness.¹⁴⁰

The treatment of very low birth weight, premature infants constitutes one of the frontiers in neonatal medicine. Survival rates drop dramatically at low birth weight levels. One study¹⁴¹ reported the survival rate for infants born in a three year period at a major perinatal hospital to be 98 percent for infants weighing between 1500 and 2499 grams, 86 percent for those weighing 100 to 1499 grams, 67 percent for those weighing 750 to 999 grams and 26 percent for those weighing 500 to 749 grams. All infants below 500 grams died. The researchers conducting the study compiled data on 98 live-born infants who weighed less than 750 grams. Fifty-six died in the delivery area; twenty-two others died in the intensive care unit (NICU). The authors reported that "[d]eath among the infants transferred to the NICU during the first year of the study tended to be ascribed to immature lung development whereas during the second and third years, as the infants lived longer, the causes of death tended to be disease-related or treatment-related. . . ."¹⁴² Aggressive treatment thus had a double-edged effect: it initially sustained the lives of some of the smallest infants, but in a state so fragile that the diseases *and treatments* of prematurity killed them.

Infants recorded as intensive care unit survivors may not fare well after discharge. They may be re-hospitalized, institutionalized or die of their condition.¹⁴³ Noting the high economic costs involved, the high

¹⁴⁰ Hack & Fanaroff, *Changes in the Delivery Room Care of the Extremely Small Infant (<750 g); Effects on Morbidity and Outcome*, 314 NEW ENG. J. MED. 660, 662 (1986); Sinclair, Torrance, Boyle, Horwood, Saigal & Sackett, *Evaluation of Neonatal Intensive-Care Programs*, 305 NEW ENG. J. MED. 489, 489 (1981); Lyons, *Physical and Mental Disabilities In Newborns Doubled In 25 Years*, N.Y. Times, July 18, 1983, at A1, col. 3.

¹⁴¹ Hack & Fanaroff, *supra* note 140, at 660.

¹⁴² *Id.* at 662.

¹⁴³ The researchers reported:

[T]hree mothers of the 11 survivors born during the period July 1982 to June 1984 did not assume full care of their children. One infant was placed for adoption, one was placed in a long-term care facility, and the third was placed in foster care because of suspected abuse five months after discharge. Seven children (64 percent) were rehospitalized during the first year of life, including one child with chronic lung disease who required a tracheostomy and assisted ventilation for nine months and then multiple hospitalizations until death at two years of age. Neurologic and develop-

incidence of mortality and morbidity and the prolonged hospital stays, the authors of the study questioned the value of the trend "whereby intensive care is applied to progressively smaller immature infants."¹⁴⁴ This trend may take on a momentum of its own. At their own hospital, the authors reported, "[t]he increased application of neonatal intensive care . . . did not result from a specific policy, but evolved gradually over the three-year period reviewed."¹⁴⁵

The assault on a medical frontier is usually associated with new medications or procedures that are frankly and unambiguously experimental. Although there has not been much discussion of this aspect of neonatal care, there is reason to believe that a good deal of what goes on in the intensive care nursery is in some important sense experimental. In 1983, a committee of distinguished physicians and lawyers of the American Society of Law & Medicine observed that "many of the treatments are experimental" in newborn care.¹⁴⁶ Shelp writes that "much of neonatal medicine is research and experimentation — it is an 'infant' subspecialty that utilizes innovative procedures in the hope of acceptable results."¹⁴⁷ Jonsen and Lister, writing in 1978, observed that "[p]erinatal medicine, despite its intended therapeutic function, is, in a most thorough sense, experimental medicine."¹⁴⁸

Robert Weir notes that the conservative Christian ethicist Paul Ramsey, whose writings strongly favor treatment of neonates under most circumstances, felt that "treatment often given premature infants does not seem directed at caring for them as individual patients but rather appears to be experimental in nature."¹⁴⁹ Even HHS at some point in its attempts to assert regulatory authority over newborn care noted that it would be proper to withhold "extraordinary care from an extremely low birthweight infant."¹⁵⁰

The matter is, or should be, one of considerable legal significance.

mental assessments were performed at a mean corrected age of 8 and 20 months, respectively. [Footnotes omitted.] Four infants had transient hypotonia during their first year. None have cerebral palsy or hydrocephalus. One child is blind.

Id. at 663.

¹⁴⁴ *Id.* at 664.

¹⁴⁵ *Id.* at 663.

¹⁴⁶ Committee on the Legal and Ethical Aspects of Health Care for Children, *Comments and Recommendations on the "Infant Doe" Proposed Regulations*, 11 LAW MED. & HEALTH CARE 203 (1983).

¹⁴⁷ E. SHELPS, BORN TO DIE? DECIDING THE FATE OF CRITICALLY ILL NEWBORNS 99 (1986).

¹⁴⁸ Jonsen & Lister, *Newborn Intensive Care: The Ethical Problems*, 8 HASTINGS CENTER REP. 15, 16 (1978).

¹⁴⁹ R. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS 149 (1984).

¹⁵⁰ 45 C.F.R. § 84, app. § 84 C(a)(5)(iv), 48 Fed. Reg. 30,846, 30,852 (1983); *see also* 49 Fed. Reg. 1654 (daily ed. Jan. 12, 1984). The HHS did not reiterate this suggestion in its interpretive rules for the infant Doe statute. It did acknowledge the general proposition that experimental procedures cannot be compelled by law. 50 Fed. Reg. 14,886 (1985).

For all areas of medicine, there is a strong tradition in law and ethics requiring informed consent as a precondition to ethically performed research on human beings.¹⁵¹ Parental consent is required of all research involving children, including experimental therapy offered with the genuine hope that it will benefit the child.¹⁵² A law like the federal infant Doe rule, which deprives parents of the right to make treatment decisions, would face serious constitutional challenge if found to apply to fundamentally experimental procedures. The difficulty comes in defining what is "experimental." Experimental techniques are clear when unprecedented procedures are used in a protocol formally submitted to a hospital's institutional review board. When doctors at Loma Linda University Medical Center transplanted a baboon's heart into a baby girl in 1984, for example,¹⁵³ there was no doubt that the transplant was experimental. There was also no doubt that the consent of the infant's parents was essential.

When medical hypotheses are rigorously tested, presented in the professional literature and subject to widespread scrutiny and criticism, truly worthy techniques pass from the domain of research to the domain of accepted conventional therapy. The precise moment of passage is impossible to ascertain. Indeed, there is no exact moment, but a transition time in which a therapeutic idea is more or less accepted, more or less regarded as useful in certain generally defined situations. Reservations and clarifications follow any breakthrough, limiting and defining it until the new idea takes its proper place in the grand order of things medical. Apparent successes that fail to withstand the process of professional scrutiny eventually, perhaps years later, fall by the wayside.

Thus the line between experimental and conventional medicine is not always laser sharp. Line-drawing is made even more difficult by the fact that many treatment therapies which are in use do not go through the rigors of meticulous scientific research and analysis. Among other factors, logistics, costs and the availability of capable researchers and willing participants, limit the amount of research done in any given part

¹⁵¹ See Annas, *Death and the Magic Machine: Informed Consent to the Artificial Heart*, 9 W. NEW ENG. L. REV. 89, 91 (1987). For a classical article on the ethical blindness of enthused medical experimenters, see Beecher, *Ethics and Clinical Research*, 274 NEW ENG. J. MED. 1354 (1966); see also Rothman, *Ethics and Human Experimentation: Henry Beecher Revisited*, 317 NEW ENG. J. MED. 1195 (1987)(review of Beecher article on the twenty-first anniversary of its publication).

¹⁵² NAT'L COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, REPORT AND RECOMMENDATIONS: RESEARCH INVOLVING CHILDREN 12-19 (1977)[hereinafter RESEARCH INVOLVING CHILDREN].

¹⁵³ See generally Capron, Regan, Reemtsma, Sheldon, McCormick & Gore, *The Subject is Baby Fae*, 14 HASTINGS CENTER REP. 8 (1985)(collection of articles).

of medicine.¹⁵⁴ In the absence of a scientifically documented research base, practitioners resort to innovation and medical improvisation based loosely on experience, guesswork, limited data and hope.¹⁵⁵ While improvisation appeals to physicians trying to save lives, it can have some deleterious, even tragic, effects on newborns. As Jonsen and Lister observed in 1978:

[The neonatologist] can apply a multiplicity of medicines and procedures that are sound elsewhere but that may be useless or harmful in this new patient. Indeed, the rapidly growing body of scientific information may often create therapeutic havoc: in the enthusiasm to apply the information to management of the newborn its highly experimental or even untested origins are forgotten.¹⁵⁶

A national report on research involving children, commenting on the "history of misadventures from . . . untested and unvalidated innovation" conveys the danger of new medical techniques in the hospital nursery:

[I]ntroduction of the practice of supplying oxygen in high concentrations to premature infants with hyaline membrane disease to enable them to survive was successful in many cases. However, the price paid for this course of action was the blinding of thousands of children due to retrolental fibroplasia before it was found that high oxygen levels had a toxic effect on the blood vessels supplying the retina in premature infants.

Another iatrogenic disease whose cause went undetected for years was the "gray-baby syndrome," which resulted in the death of many newborn infants until a research project (terminated early because the results were so clear) demonstrated that the drug chloramphenicol was responsible. This drug was an effective and generally safe antibiotic in adults, and it had been extended to use in children and infants without special study. . . . Another antibacterial agent, sulfisoxazole, was also abandoned for use in newborn infants after it was shown to cause severe neural injury (kernicterus) and cerebral palsy. . . .

¹⁵⁴ BAILAR, INTRODUCTION TO CLINICAL TRIALS: ISSUES AND APPROACHES 11 (1983) ("practical constraints ensure that most treatments escape . . . vigorous evaluation").

¹⁵⁵ This is evident when reading accounts of everyday experiences in neonatal intensive care units. See, e.g., F. FROHOCK, SPECIAL CARE (1986); J. GUILLEMIN & L. HOLMSTROM, MIXED BLESSINGS: INTENSIVE CARE FOR NEWBORNS (1986). The authors of MIXED BLESSINGS suggest that very low birthweight and other newborns whose conditions involve poor chances of clinical success be "clearly designated as experimental patients," in order "to foster an overt acknowledgment that latent experiments are taking place, sometimes as erratic forays in clinical problem solving." J. GUILLEMIN & L. HOLMSTROM, *supra*, at 274.

¹⁵⁶ Jonsen & Lister, *supra* note 148, at 16.

Use of Vitamin K to prevent hemorrhagic disease of the newborn was a major advance, but its use in excessive doses also produced many cases of kernicterus due to its destruction of red blood cells with resultant increase in bilirubin levels, until research demonstrated this danger and established a safe and effective dose. . . . In sum, there is historical evidence of undesirable consequences resulting from the introduction of innovations in pediatric practice without adequate research.¹⁵⁷

The federal infant Doe rule ignores the problems posed by innovative medical treatments. If such treatments, lying in the twilight zone between pure experimentation and conventional medical therapy, present a hope of survival that is not futile (or virtually futile and inhumane), these treatments are arguably required under the rule despite any parental objection. This interpretation of the rule may seem quite plausible to a court or administrative official, particularly if medical professionals do not admit the full extent of their untested, risk-prone, uncertain and stressful interventions. Physicians' inclinations, it has often been noted, tend toward aggressive treatment.¹⁵⁸ Doctors may represent their treatment choices as "conventional" rather than "experimental." Those already oriented toward medical intervention may see their decisions as "medically indicated" (in the words of the statute)

¹⁵⁷ RESEARCH INVOLVING CHILDREN, *supra* note 152, at 23-26. The report said further that:

Even such a seemingly simple matter as feeding and hydrating a newborn infant has, without proper research, been subject to faddism and untested innovation. Because premature infants tend to look edematous, for years it was routine practice to give them no food or water for 48 to 72 hours after birth, with a high incidence of brain damage ensuing from an excessive amount of sodium in the blood of the few who survived the drying out procedure. Despite abandonment of such practices and conduct of much research, there still exists no general agreement on when to begin feedings for premature infants and how much of what to give.

Another standard treatment, whose adverse effects continue to be manifested 20 to 30 years later in the form of radiation-induced thyroid cancer, was prophylactic radiation to the neck and chest, used in the 1940's to shrink an infant's thymus. This treatment was administered on the hypothesis that it would prevent the sudden infant death syndrome, with no basis in fact other than the observation that many victims of the syndrome had an enlarged thymus at autopsy. . . . There are other standard practices whose effects remain matters of speculation. For example, concern is currently being expressed over the practice of isolating premature infants from their parents in intensive care nurseries, based on evidence from research that shows the importance of very early physical contact between the mother and infant for the establishment of parental bonding, and the significantly higher incidence of child abuse of premature infants.

Id. at 24-25.

¹⁵⁸ See, e.g., J. GUILLEMIN & L. HOLMSTROM, *supra* note 155, at 282 ("[A] major problem in the high-level nursery is the automatic, even routine nature of aggressive intervention." It is overtreating newborns, rather than failing to treat, that is the "more common jeopardy."); Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'*, 67 PEDIATRICS 315, 316 (1981).

rather than as personal or professional preferences for innovative or experimental rescue attempts. It is also part of human nature to justify what one wants to do by portraying it as necessary and good for others.¹⁵⁹

Courts must be alert to the use of "untested and unvalidated" procedures in neonatal medicine. When such procedures go under the name "innovative," they become associated with that term's positive connotations of progress and ingenuity. But innovation has its dark side of risk, mistake and failure. Parents confronted with the benefits and burdens of "the latest" in neonatal treatment techniques should not be forced to put their infants through the rigors of treatments that carry little guarantee of success. Based upon the liberty and privacy interests previously identified,¹⁶⁰ the state should let caring parents weigh the risks, dangers and uncertainties of proposed treatments that are reasonably capable of classification as "experimental," including "innovative" techniques now in use. Some parents, of course, will opt for these techniques, finding the risks acceptable. But others may choose to forego procedures that are chancy and perilous, and they should have the right to do so.

V. THE CONSTITUTIONAL REQUIREMENT OF A BENEFITS AND BURDENS ANALYSIS

The foregoing section shows that the federal infant Doe standard improperly requires treatment in a variety of specific situations. In some instances, it requires treatment even if that treatment offers no substantial hope of benefit to the infant. In others it requires treatment when treating would produce, prolong or increase intense suffering. In still others it would mandate treatment even if its sole realizable aim would be to preserve a life of total, permanent and devastating incapacity. In each of these instances, the federal rule violates widely recognized state constitutional norms.

The federal law fails on a more general level as well, by not making the consideration of benefits and burdens of treatment the linchpin of analysis for medical decisionmaking for impaired infants. Underlying the statute is a presumption that treatment is always a benefit except when death is all but certain. It is dismissive of all the burdens that severely ill or deformed infants must bear, and of parents who would

¹⁵⁹ Professor Joseph Goldstein begins an article with this quotation: "Of all tyrannies a tyranny sincerely exercised for the good of its victims may be the most oppressive . . . [T]hose who torment us for our own good will torment us without end for they do so with the approval of their own conscience." Goldstein, *Medical Care For The Child At Risk: On State Supervention Of Parental Autonomy*, 86 YALE L.J. 645, 645 (1977)(quoting Lewis, *The Humanitarian Theory of Punishment*, 6 RES JUDICATAE 224, 228 (1952)).

¹⁶⁰ See *supra* notes 86-104 and accompanying text.

consider and weigh the perils of treating against the chances of success. To deny parents the right to consider and weigh all the risks and burdens that treatment regimes entail is a defect that may render the statute unconstitutional on its face.

In reading the statute it is easy to overlook the burdens that infants must sometimes endure. A severely compromised existence may involve a degree of pain and suffering that is difficult to comprehend. Some of nature's work is extremely brutal. Requiring medical interventions to prolong the survival, even for a number of years, of the victims of Tay-Sachs disease or Lesch-Nyhan syndrome, for example, ignores the cruelty of their afflictions. Weir has written of these conditions:

[N]ewborns who inherit the autosomal recessive condition of Tay-Sachs disease . . . appear normal for approximately six months, then have an inexorable decline toward a totally vegetative existence followed by death when they are three or four years of age. The progressive loss of contact with parents and the environment is characterized by profound mental retardation, convulsions, paralysis, blindness, inability to feed orally, and severe weight loss.

Male neonates who inherit the X-linked recessive condition of Lesch-Nyhan syndrome also appear normal at birth, then at approximately six months begin a process of neurological and physiological deterioration first evidenced by athetosis (ceaseless, involuntary writhing movements). Along with severe mental deficiency, the most striking neurological feature of this condition is compulsive self-mutilation that requires placing the elbows in splints, wrapping the hands in gauze, and sometimes extracting the teeth. Even then, children with this condition often bang their heads against inanimate objects or take out their aggression on other persons.¹⁶¹

Other conditions can so severely deform, incapacitate and cause pain to their victims that the worth of efforts to sustain their lives is legitimately open to question. It would be impossible to compile a catalogue of conditions that burden afflicted infants with, in Englehardt's telling phrase, "the injury of continued existence."¹⁶² A few conditions, such as Tay-Sachs, Lesch-Nyhan, and the permanent vegetative state, are clearly included. But for others, judgment must be founded upon a knowledge of, and an empathy with, the particular infant's suffering.

¹⁶¹ R. WEIR, *supra* note 149, at 237 (citations omitted). For a description of a number of other devastating birth defects, see Rhoden, *supra* note 13, at 1287-94.

¹⁶² Engelhart, *Euthanasia and Children: The Injury of Continued Existence*, 83 J. PEDIATRICS 170 (1973).

Infants must bear burdens beyond those associated with their afflictions, including those imposed by treatment itself. Some treatments are highly invasive and painful. Tube insertions and replacements, drawing of blood, administration of medications, resuscitations and surgery may be required repeatedly. The pain of certain procedures may be increased by common medical practices, including the performance of surgery without anesthesia.¹⁶³ Some treatments are dangerous to the newborn. Hyaline membrane disease, a common problem in very premature infants, is a lung disorder with often fatal consequences for its victims. These infants, notes the President's Commission, "must be placed on mechanical ventilators to counteract the insufficient oxygen supply associated with this condition; *like the disorder, this treatment can cause substantial morbidity and mortality.*"¹⁶⁴ In a footnote the Commission elaborates:

[S]ome infants will require long-term tracheostomy, in which a tube is inserted in the neck to create an adequate airway. These infants cannot make sounds and require continuous special nursing care. Therapeutic doses of oxygen used to treat RDS [respiratory distress syndrome, caused by hyaline membrane disease] can also lead to retrolental fibroplasia, a cause of blindness. And the mechanical ventilation can cause permanent and sometimes progressive lung damage.¹⁶⁵

Jonsen and Lister, in an article describing the perils of the relatively new specialty of perinatal medicine, state:

Iatrogenicity is endemic in perinatology. It is often generated by the application of common therapeutics to the immature organism; it is aggravated by the application of these therapeutics in desperate situations. . . . [Iatrogenic problems] haunt the nursery every day.¹⁶⁶

The duration of treatment also affects the extent to which it is burdensome. As Dr. Erich Loewy observes: "[i]mposing a burden briefly may be defensible; imposing one lasting a longer time is more open to

¹⁶³ Two Harvard researchers report that "[n]ewborns are frequently not given analgesic or anesthetic agents during invasive procedures, including surgery. Despite recommendations to the contrary in textbooks on pediatric anesthesiology, the clinical practice of inducing minimal or no anesthesia in newborns, particularly if they are premature, is widespread." Anand & Hickey, *Pain and Its Effects in the Human Neonate and Fetus*, 317 NEW ENG. J. MED. 1321 (1987). Other procedures are performed routinely without consideration of pain. Fletcher, *Pain in the Neonate*, 317 NEW ENG. J. MED. 1347 (1987).

¹⁶⁴ PRESIDENT'S COMM'N, *supra* note 29, at 200 (emphasis added).

¹⁶⁵ *Id.* at 200 n.17.

¹⁶⁶ Jonsen & Lister, *supra* note 148, at 16 (Iatrogenicity is an abnormal condition induced in a patient by the effects of treatment by a doctor).

question.”¹⁶⁷ Stays in the neonatal intensive care unit can last for several months, with treatments of various kinds administered daily.¹⁶⁸ Lengthy hospitalization deprives infants of the physical, psychological and developmental benefits of home life and parental nurturance. When an infant dies despite painful, prolonged treatment that provided no substantial hope from the outset, parents and others rightfully wonder whether the baby’s best interests were served by pressing on with aggressive treatment efforts. The infant who undergoes extensive treatment may experience a terrible, tormenting existence. The parents of an infant born near the frontier of viability, weighing 800 grams, with lung problems and various other complications associated with prematurity, described their son as having been “saved” by the respirator to endure countless suctionings, tube insertions, blood samplings and blood transfusions.

“[S]aved” to develop retrolental fibroplasia, numerous infections, demineralized and fractured bones, an iatrogenic cleft palate, and, finally, as his lungs became irreparably diseased, pulmonary artery hypertension and seizures of the brain. He was, in effect, “saved” by the respirator to die five long, painful and expensive months later of the respirator’s “side effects.” One doctor explained Andrew’s continued dependence on the respirator and lack of effort to breathe for himself by suggesting that, with all those broken ribs, it “hurts like hell every time he takes a breath.”¹⁶⁹

Given the potential for grave burdens accompanying treatment, infants, like all other incompetent individuals, deserve the right to have harms to themselves given full consideration in health care decision-making. In dire medical circumstances, there are no absolutes. We know from experience and from wide discussion of the notion of death with dignity that people in extreme circumstances care deeply about the nature of their existence and give careful consideration to the difficulties of submitting to medical treatment regimes, even life-saving ones, that place heavy burdens on themselves. Legal, medical and ethical thinking support the centrality of a benefits/burdens analysis to

¹⁶⁷ Loewy, *Treatment Decisions in the Mentally Impaired*, 317 NEW ENG. J. MED. 1465, 1468 (1987).

¹⁶⁸ See F. FROHOCK, *supra* note 155 (describing cases of long term treatment in neonatal intensive care units); J. GUILLEMIN & L. HOLMSTROM, *supra* note 155, at 241-42; see also Fisher & Stevenson, *The Consequences of Uncertainty: An Empirical Approach to Medical Decision Making in Neonatal Intensive Care*, 258 J. A.M.A. 1929 (1987) (“In any setting other than an intensive care unit, a daily routine that involved restraining neonates in bed, placing plastic tubes . . . into various body orifices, and pricking the feet with needles . . . would be considered torture.”).

¹⁶⁹ Stinson & Stinson, *On the Death of a Baby*, ATLANTIC, July 1979, at 64, 65; see R. STINSON & P. STINSON, *THE LONG DYING OF BABY ANDREW* (1983).

proper decisionmaking. This is so because the ultimate question is one of helping the patient, providing not merely survival in whatever inhuman condition but some *genuine net benefit* for the person. To determine if a net benefit accrues, all benefits to and all burdens on that person must be taken into account.

Courts across the country have supported the right of adults to refuse medical treatment, rejecting claims that to do so might violate norms of preserving life and preventing suicide.¹⁷⁰ They have done so not merely out of respect for any person's right to do whatever he or she wants, however strange or bizarre the choice; explicit or implicit in almost every case is the acceptance of the soundness and legitimacy of nontreatment decisions, when such decisions avoid the burdens of pain, suffering and loss of humanity and dignity. Only a handful of decisions have involved infants.¹⁷¹ In three cases,¹⁷² parents of infants in a permanently unconscious state were allowed to forego the medical machines that would sustain their infants' lives. A New York case permitted parents of a child stricken with spina bifida and related complications to forego life prolonging surgery.¹⁷³

Attempts to impose medical treatment upon incompetents in other contexts have also led courts to adopt a benefits and burdens analysis. In *Rivers v. Katz*,¹⁷⁴ the New York Court of Appeals deemed the balancing of benefits and burdens necessary to the evaluation of a mentally ill

¹⁷⁰ See, e.g., *Rasmussen II*, 154 Ariz. 207, 741 P.2d 674 (1987); *John F. Kennedy Memorial Hosp., Inc. v. Bludworth*, 452 So. 2d 921 (Fla. 1984); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977). The New Jersey Supreme Court observed that a balancing of factors reflects "a basic aspect of right-to-die cases." *In re Jobes*, 108 N.J. 394, 436 n.7, 529 A.2d 434, 455 n.7 (1987).

¹⁷¹ The dearth of cases concerning newborns is itself significant. As Professor Clark observes:

[N]otwithstanding the extensive publicity given to some of the cases in which treatment for newborns has been withheld, the existing legal sanctions are seldom invoked. When the cases do come to court, it is usually in the context of a proceeding to seek court approval for the action or nonaction which the parents and perhaps the physicians wish to adopt. One must conclude from this that the state officials responsible for civil or criminal proceedings recognize that the parents' decision to withhold treatment is morally justified in some circumstances, a recognition which is shared by at least some commentators. If the treatment involves intrusive, painful or very uncomfortable procedures for the child without countervailing benefits, or substantial risk of death or a further impairment of physical or mental capacity, the parental refusal to authorize it seems justified.

H. CLARK, *supra* note 103, at 588 (citations omitted).

¹⁷² *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982).

¹⁷³ *Weber v. Stony Brook Hosp.*, 95 A.D.2d 587, 467 N.Y.S.2d 685, *aff'd on other grounds* 60 N.Y.2d 208 (1983). The Court of Appeals, in affirming on other grounds, did term the treatment course "responsibly decided upon" by the parents. *Weber*, 60 N.Y.2d at 210.

¹⁷⁴ 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986).

patient's state constitutional liberty interest in refusing medical treatment. The opinion gave these directions to lower courts:

If . . . the court concludes that the patient lacks the capacity to determine the course of his own treatment, the court must determine whether the proposed treatment is narrowly tailored to give substantive effect to the patient's liberty interest, taking into consideration all relevant circumstances, including the patient's best interests, the benefits to be gained from the treatment, the adverse side effects associated with the treatment and any less intrusive alternative treatments.¹⁷⁵

As in the law, the balancing of benefits and burdens is an integral part of medical practice. Here the balance must be struck between the honored principles of prolonging life and of doing no harm (*primum non nocere*, in the Hippocratic Oath) by prolonging suffering:

There are times when the principle goals of medicine — prolonging life and relieving suffering — come into conflict. The statutes do not recognize the reality or the moral relevance of suffering in neonatal medicine. Physicians should not be required to prolong life by all available means and in disregard of the agony the patient may experience.¹⁷⁶

The AMA Judicial Council has similarly declared that:

In the making of decisions for the treatment of seriously deformed newborns . . . the primary consideration should be what is best for the individual patient. . . . Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when the prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical. . . .¹⁷⁷

¹⁷⁵ *Id.* at 497, 495 N.E.2d at 344, 504 N.Y.S.2d at 81.

¹⁷⁶ Feldman & Murray, *State Legislation and the Handicapped Newborn: A Moral and Political Dilemma*, 12 LAW MED. & HEALTH CARE 156, 162 (1984); accord Jonsen, Phibbs, Tooley & Garland, *Critical Issues in Newborn Intensive Care: A Conference Report and Proposal*, 55 PEDIATRICS 756 (1975).

¹⁷⁷ AMERICAN MED. ASS'N, CURRENT OPINIONS OF THE JUDICIAL COUNCIL § 2.14 (1984). Dr. A. G. M. Campbell, writing of the burdens justifying nonaggressive care, has observed:

[M]any pediatricians would probably agree that the most important medical criterion is severe abnormality, disease, or damage to the central nervous system, especially the brain, which will have devastating consequences for development. . . . Specific examples include infants with hydranencephaly, severe neural tube defects, gross hydrocephalus if complicated by infection, and chromosomal disorders such as trisomy 13 and 18. Infants with extensive and fully documented . . . brain damage after asphyxia and hemorrhage might also be included.

Campbell, *Which Infants Should Not Receive Intensive Care?*, 57 ARCH. OF DIS. IN CHILDHOOD 569-71 (1982), quoted in Young, *Caring for Disabled Infants*, 13 HASTINGS CENTER REP. 15 (1983).

Ethical norms that are widely accepted in our society also support a benefits/burdens approach to medical decisionmaking. If a person is not competent to make an autonomous choice, then he or she deserves the consideration of all benefits and all burdens as part of the respect due to persons, whatever their condition. This ethical notion has been defined as "the obligation that each person be acknowledged as a unique being, and dealt with in terms of his or her own desires, needs and purposes."¹⁷⁸ Coupled with the ethical principle of beneficence, which "requires both the provision of benefit and avoidance of harm,"¹⁷⁹ ethical decisionmaking must encompass a balancing of benefits and burdens that takes all vital interests of the individual into account. By imposing treatment without considering the attendant burdens, the federal infant Doe rule ignores a basic ethical duty owed to all persons in another's care, especially children: the duty to shelter them from harm.

The federal rule, exalting a chance at survival above all else, and preempting the full consideration of all burdens associated with aggressive treatment for individual infants, violates critical norms of law, medicine and ethics. As a consequence, it fails to satisfy basic constitutional principles that flow from these norms. These principles are set forth in the following section.

VI. GUIDELINES FOR CONSTITUTIONALLY PERMISSIBLE RULEMAKING

I suggest that certain principles, useful in guiding constitutionally permissible rulemaking, emerge from the analysis so far. These principles reflect the interwoven cultural and constitutional values that limit government to a more modest (and more constructive) role in decisionmaking for infant Does.

A. EVERY INFANT DOE DESERVES INDIVIDUAL, SENSITIVE AND CAREFUL CONSIDERATION

Rulemakers must take into account the potentially vast application of decisionmaking standards for newborns. Infant Does are a heterogeneous population with widely differing medical conditions. For some infants, the "facts" of their ailments are imperfectly known due to the limits of medical knowledge and the awesome variability of abnormal birth conditions. The over 3,000 kinds of birth defects¹⁸⁰ defy com-

Young notes that there is "substantial agreement with Campbell's position on this issue, not only in Britain and in Sweden, but here in the United States as well." Young, *supra*, at 16.

¹⁷⁸ RESEARCH INVOLVING CHILDREN, *supra* note 152, at 135.

¹⁷⁹ *Id.* at 123.

¹⁸⁰ MARCH OF DIMES BIRTH DEFECTS FOUND., ANNUAL REPORT 4 (1986).

plete understanding. When identified, medical conditions vary from individual to individual in their severity, in their course of development over time, and in their debilitating effect upon the patient.¹⁸¹ Changing conditions make decisionmaking for a newborn a continuous rather than a one-time task.¹⁸² The common presence of multiple defects and diseases renders each infant's condition unique and not subject to easy categorization. One parent's experience dramatically illustrates this: "[w]hen the baby finally died, three months after her birth, the hospital asked if they could perform an autopsy and we consented. *The list of abnormalities filled both sides of an 8 1/2-by-11 inch sheet of paper, single spaced. I looked at it and wept. . . .*"¹⁸³

The federal infant Doe law attempts to divide up this complex reality into a handful of decisionmaking categories. The attempt fails because, as the Supreme Court once observed in another context, "[t]he versatility of circumstances often mocks a natural desire for definitiveness."¹⁸⁴ Simplistic legal categories cannot address the complexity of these problems, nor will they promote the separate, detailed and distinct consideration of treatment and nontreatment alternatives that is every infant's due.

B. RULES MUST TAKE INTO ACCOUNT WIDELY SHARED SOCIETAL RESERVATIONS ABOUT THE USE OF NON-CURATIVE MEDICAL TECHNOLOGY

The current federal law, by reducing a sensitive, multifaceted problem to a one-dimensional medical inquiry "solves" ethical dilemmas of care by ignoring them (or by implicitly presuming that the right-to-life ethic is so morally superior that all other ethical concerns must be swept aside). But questions about the humaneness of treatment, the preservation of basic human dignity and the disproportionality of benefits and burdens must be addressed, in order to give the individual's fundamental liberty interests their appropriate scope. To do so implies no rejection of the sanctity of life ideal in our society, but rather recognizes that the sanctity of life principle finds its limit in precisely the area addressed by the infant Doe statute.

¹⁸¹ See, e.g., PRESIDENT'S COMM'N, *supra* note 29, at 202 (spina bifida "causes physical and/or mental impairments that range widely in severity and frequently involve many organ systems.") Doctors at the Stanford University School of Medicine argue that the complexity and uncertainty of diagnosis and prognosis for the premature infant makes the federal standard an unworkable one for all infants whose conditions are not easily categorized. Stevenson, Ariagno, Kutner, Raffin & Young, *supra* note 43, at 1909.

¹⁸² See, e.g., F. FROHOCK, *supra* note 155 (discussing accounts of infant care).

¹⁸³ *The Parents Doe*, NATION, Feb. 25, 1984, at 213 (emphasis added)(parent author requested anonymity).

¹⁸⁴ *Weiner v. United States*, 357 U.S. 349, 352 (1958).

In the context of critical illness, when restoration of health is impossible or improbable, other values compete with treatment imperatives. We recognize as reasonable the desire of people to avoid the "living death" of an existence maintained solely by medical machines. Pain and suffering are sometimes too extreme a price to pay for the continuation of life; turning down "heroic" attempts to preserve life is an accepted notion in our culture. To insist on maximal treatment in extreme circumstances converts the sanctity of life notion into a requirement of martyrdom. Treatment to ensure survival in extreme states of incapacitation and suffering contradicts medical notions of humaneness in treatment and undermines essential moral qualities of empathy, mercy and compassion. Compelling painful and burdensome treatment, even when survival is doubtful, reflects a severe ideology that the State, justified only in promoting children's best interests, cannot impose.

C. RULES MUST DELEGATE DISCRETION; THEY CANNOT SPECIFICALLY COVER ALL SITUATIONS IN WHICH TREATMENT DILEMMAS ARISE

If, as argued here, the relatively simple premise of the federal rule, that virtually any chance at survival mandates aggressive treatment, violates state constitutional standards, lawmakers will have to confront the true complexity of medical decisionmaking for infant Does. In so doing, they will find that the problem of treatment choice simply does not lend itself to precise rulemaking. Rather, it resembles the kind of problem that the law deals with by general directives, for example, to consider "the totality of the circumstances" and do what is "in the best interests" of a child or other person, with further elaboration coming over time as societal consensus forms around certain norms. This approach seems indicated when, as here, a problem's individual manifestations vary so much from one another, a multiplicity of factors bear upon the decision in any particular case and assigning exact mathematical weights to the relevant factors is impossible.

The reference to "reasonable medical judgment" in the statute may seem like a concession to the need for discretion, but it is not. Reasonable medical judgment normally takes account of the risks and burdens of treating, in addition to the potential benefits.¹⁸⁵ Because the statute does not permit these decisional elements to be carefully weighed and balanced, it in fact abrogates physician discretion.

¹⁸⁵ Kopelman, Irons & Kopelman, *supra* note 27, at 682-83; Stevenson, Ariagno, Kutner, Raffin & Young, *supra* note 43, at 1911.

D. RULES MUST GIVE DUE RESPECT TO THE DECISIONMAKING ROLE OF PARENTS

For the government to displace parents as decisionmaker, under the rubric of child abuse and neglect or otherwise, it must appear that parents have failed in their constitutionally recognized role as primary caretakers of the child. At the extremes, failure is easily identified and parental decisions properly superseded. In the "gray" areas, where doubts about what is right and wise persist and agonizing choices must be made, deference to family decisionmaking is our cultural and constitutional heritage. Even the HHS acknowledged in its interpretive guidelines to the federal law that "parents are the decisionmakers concerning treatment for their disabled infant."¹⁸⁶ But the law and the HHS guidelines go on to exclude parents from virtually all medical decisionmaking for their child.

VII. RULEMAKING TASKS

These general principles allow some room for choice in policymaking, while recognizing that important limits on the power of judicial and legislative rulemakers flow from state constitutional and common law commitments to the liberty of individuals, the rights of incompetents and the privacy of the family. The choices open to lawmakers, and the restraints on them, will be discussed in the context of three key rulemaking tasks:

- (1) identifying the proper range of decision in which parents can exercise their own best judgment;
- (2) identifying the factors that are relevant and those that are not relevant to decisionmaking; and
- (3) identifying what procedures, if any, may be imposed on the decisionmaking process.

TASK 1: IDENTIFYING THE RANGE OF PARENTAL DECISION

In identifying the range of decision for parents, it is readily apparent that there are extreme cases for which decisions, however tragic, are uncontroversial. Anencephalic infants (born with large portions of their brain tissue absent) are not able to survive.¹⁸⁷ Infants with other fatal, incurable problems and very brief life expectancies pose no dilemmas of care. Neither do infants on the other side of the spectrum, those who are ill but readily curable, or restorable to health although suffering from a mild degree of mental retardation. Parental discretion

¹⁸⁶ 50 Fed. Reg. 14,880 (daily ed. Apr. 15, 1985).

¹⁸⁷ PRESIDENT'S COMM'N, *supra* note 29, at 181.

to deny life sustaining medical help need not be so broad as to encompass every infant with a medical problem.

The key question is how far in from these extremes can and should rulemaking lines be drawn. A number of statements in the medical, ethical and legal literature offer helpful guidance on the matter. The statements, it should be noted, were not necessarily intended as legal standards, but they are helpful in formulating legal standards. Consider in this light the following:

1. [H]andicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant [N]et benefit is absent only if the burdens imposed on the patient by the disability or its treatment would lead a competent decisionmaker to choose to forego the treatment.¹⁸⁸
2. If the treatment involves intrusive, painful or very uncomfortable procedures for the child without countervailing benefits, or substantial risk of death or a further impairment of physical or mental capacity, the parental refusal to authorize it seems justified.¹⁸⁹
3. [The issue is whether a parent's decision refusing a medical procedure is a] reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child.¹⁹⁰
4. In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when the prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life support means is ethical provided that the normal care given an individual who is ill is not discontinued.¹⁹¹
5. The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail. In the absence of the patient's choice or an authorized proxy,

¹⁸⁸ *Id.* at 218-19.

¹⁸⁹ H. CLARK, *supra* note 103, at 588 (citations omitted).

¹⁹⁰ *United States v. University Hosp.*, 729 F.2d 144, 149 (2d Cir. 1984)(quoting district court opinion).

¹⁹¹ AMERICAN MED. ASS'N, *supra* note 177, at § 2.14.

- the physician must act in the best interest of the patient.¹⁹²
6. The Vatican's position . . . states that the physician may also judge that the technique imposes on the patient strain or suffering which is out of proportion to the benefit to be gained.¹⁹³
 7. [Treatment should be required only] if the medical profession agrees on a proper course of treatment, *and* if treatment will enable the child to make progress in growth and development, *and* if the failure to treat would result in the child's death.¹⁹⁴
 8. There are instances when guardians, fulfilling their duty to act beneficially for their wards, may decide that the treatment would inflict too great a burden on the patient. A guardian has a special duty to benefit his ward. It would be illogical to allow guardians to refuse treatment for themselves because of the gravity of the burden, and yet never allow them to refuse treatment for their wards; guardians have a stricter duty to benefit, and therefore reduce burdens to, their wards than they do to themselves. Therefore, grave burden must be a legitimate criterion for guardians to refuse treatment on behalf of their wards as long as the burden may reasonably be considered gravely burdensome.¹⁹⁵
 9. If the patient's views are unknown the . . . guardian should be given some discretion in deciding what is in the best interest of the patient. Such guardians should be able to choose from among the reasonable available treatment choices and should not be constrained to choose the most objectively attractive option. The decision must be a reasonable one, but we should not insist upon the single most reasonable one. . . . A decision would not be unreasonable because it lacked popular approval.¹⁹⁶

These statements generally support a standard (of net benefit, grave burden, reasonableness, competent decisionmaking) that allows the many factors¹⁹⁷ in these complex situations to come into play.

The President's Commission endorsed parental decisionmaking in ambiguous cases and approved of treatment refusal if a "competent decisionmaker" would agree.¹⁹⁸ A competent decisionmaker might be considered to be one who adopted some reasonable point of view. This

¹⁹² Statement of Council on Ethical and Judicial Affairs of the A.M.A., *Withholding or Withdrawing Life Prolonging Medical Treatment* (1986).

¹⁹³ Paris, *supra* note 122, at 124 (describing the Vatican's 1980 Declaration on Euthanasia).

¹⁹⁴ Shatten & Chabon, *Decision Making and the Right to Refuse Lifesaving Treatment for Defective Newborns*, 3 J. LEGAL MED. 59, 74 (1982).

¹⁹⁵ Veatch, *Limits of Guardian Treatment Refusal: A Reasonableness Standard*, 9 AM. J.L. & MED. 427, 435-36.

¹⁹⁶ *Id.* at 442, 466.

¹⁹⁷ See *infra* text accompanying notes 204-19.

¹⁹⁸ PRESIDENT'S COMM'N, *supra* note 29, at 218-19.

is not necessarily a majority view but one, of perhaps several choices, that is supported by good reasoning. We know that reasonable, competent decisionmakers consider benefits and burdens, and make some tradeoffs between quality of life and longevity.¹⁹⁹ They contemplate such matters as shortness of life expectancy with and without treatment, degree of pain and suffering, severity of incapacitating impairments, developmental potential, future dependence on machines and life-restricting technologies and awareness of and ability to interact with others. They do not always seek maximal care.

The constitutional soundness of the kind of broad approach articulated in these statements is clear. The elements of concern to the individual infant are allowed serious attention. Discretion, essential to the ability to tailor responses to individual needs in a complex and at times rapidly changing factual context, is preserved. Diverse (but not aberrational) moral and ethical values, characteristic of a free society, find expression. Parents and their advisers have the space provided by a broad standard to discuss, ponder, seek wisdom and gather strength.

The broad approach has another critical advantage. In a controversial area, when ideas and ideals need to be discussed and debated, broad rules permit room for the evolution of societal conceptions about ethics, moral values and law. Premature legal answers to difficult social questions can inhibit debate when it is most needed. This may have occurred in the infant Doe debate itself. Although there were important precursors, the principal initial impetus to widespread discussion of the issue was the national publicity given to the case of an infant Doe born in Bloomington, Indiana.²⁰⁰ Professional, academic and public debate flourished, although public debate unfortunately centered around only a very few dramatized cases. Yet this debate seemed to have subsided considerably after Congress enacted the federal infant Doe law in 1984. The statute resulted not from public consensus, but from political bargaining among organized interest groups.²⁰¹ The

¹⁹⁹ See McNeil, Weichselbaum & Paulker, *Speech and Survival: Tradeoffs Between Quality and Quantity of Life in Laryngeal Cancer*, 305 NEW ENG. J. MED. 982 (1981); Lane v. Candura, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978).

²⁰⁰ The official records in this case, universally acknowledged as a focal point in the legislative debate on the federal statute, are sealed. *In re Infant Doe*, No. GU 8204-004A (Ind. Ct. App. Apr. 12, 1982), *writ of mandamus dismissed sub nom. State ex rel. Infant Doe v. Baker*, No. 482 § 140 (Ind. Sup. Ct. May 27, 1982), *cert. denied*, 464 U.S. 961 (1983). Various informal accounts of it appear in articles and books. See, e.g., J. LYONS, *supra* note 43, at 21-39 ("[N]o single event in years had so galvanized . . . reformers as the death of Baby Doe.").

As Professor Jay Katz has pointed out, legislative proposals spurred by one tragic event "are often insufficiently considered," creating more problems than they solve. J. KATZ & A. CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* 130, 159 (1982).

²⁰¹ The bargaining was among disability groups, right-to-life advocates, and medical groups. Kerr, *Negotiating the Compromises*, HASTINGS CENTER REP., June 1985, at 6. For an excellent recap of the gains and losses of the organized groups and the unorganized parents,

public debate prominently included parents;²⁰² the political bargaining did not. The necessary public discussion may have been truncated by the appearance of a solution, a deeply flawed one that ignored actual interests of both families and infants.

In the case of infant Does, a continuing period of elaboration is needed to spell out liberty and privacy ideals in a technological context that we have not yet managed to control. The best law can do, for now, is to design broad rules in keeping with our basic beliefs in freedom for private decisionmaking in matters of conscience, intimacy and tragic choice. Thus, legislatures or courts may proceed by adopting some variant of the best interest/benefits and burdens standard. This can be elaborated upon by citing specific decisionmaking factors that validly come into play.²⁰³

TASK 2: IDENTIFYING FACTORS RELEVANT TO DECISIONMAKING

In determining the best interests of infant Does, it is possible to specify factors that should and those that should not play a role in decisionmaking. Factors that clearly are important include: medical diagnosis; clinical course of medical conditions since birth; length of life expectancy; survival chances with and without treatment; expected neurological, physical and mental impairment; developmental potential; availability of corrective treatment; extent of treatment benefits if cure is not possible; pain and suffering associated with medical condition; pain and suffering associated with treatment; invasiveness, stressfulness, and duration of treatment; need for repeated medical interventions; need for lengthy hospitalization or institutionalization; risks associated with treatment; and the proven, experimental, or untested nature of treatment. As stated earlier, only in individual circumstances can the importance and weight of all of these factors be assessed, and benefits and burdens properly analyzed.

It is also possible for policymakers to exclude certain factors from consideration. The President's Commission reasonably suggests that

see Lantos, *Baby Doe Five Years Later: Implications for Child Health*, 317 NEW ENG. J. MED. 444 (1987)(unorganized parents "were not a great source of concern among politicians").

²⁰² See R. STINSON & P. STINSON, *supra* note 169; *The Parents Doe*, *supra* note 183, at 213.

News articles and editorials also reported parental views and concerns: *Cruelty and Baby Jane*, N.Y. Times, Nov. 1, 1983, (Editorial), at 26; Chambers, *Advocates for the Right to Life*, N.Y. Times, Dec. 16, 1984, (Magazine), at 94; *Big Brothers and Baby Doe*, N.Y. Times, July 28, 1984, (Editorial), at 22, col. 1.; *CBS Evening News with Dan Rather*, *supra* note 1.

²⁰³ See *infra* text accompanying notes 204-14. A statutory model from another child-protective context is the Michigan child custody law. It sets forth the basic principle that custody shall be determined according to the "best interests" of the child and lists nine particular factors important to the ultimate judgment on best interest. The factors listed are not exhaustive; decisionmakers are free to consider matters not listed if they bear on the child's interest. 18 MICH. STAT. ANN. § 25.312(3) (1984).

"idiosyncratic" views of parents — for example, a belief that blood transfusions are always morally unacceptable — are improper factors in decisionmaking.²⁰⁴ The example of religion-based refusals of proven medical techniques seems clear. Abhorrence of technology is an unacceptable reason for treatment choice. So, for that matter, is idolization of technology manifested by doctors who feel compelled to use technology "because it is there." Such doctors — and the literature indicates there are a substantial number²⁰⁵ — are as idiosyncratic in their views as are parents who absolutely reject blood transfusions. As long as "idiosyncratic" is so understood, its exclusion from decisionmaking is perfectly sound. Other interests are clearly dispensable. Doctors' interests in keeping treatment going so as to reap research benefits, to perfect medical technologies or to help train younger doctors in neonatal care techniques²⁰⁶ do not commend themselves as mandatory influences on decisionmaking, even when they are motivated by a desire to benefit future infants. Neither do doctors' interests in promoting their own personal moral standards over those of parents (assuming parental values are not aberrational and so beyond the proper range of decision).²⁰⁷ Institutional interests of hospitals, in their survival statistics, research reputations, and income generation from highly priced intensive care units, similarly can be dismissed as factors in decisionmaking.

The interests of parents have also been suggested as dismissible²⁰⁸ but with some reservations and disagreement. The suffering of parents

²⁰⁴ PRESIDENT'S COMM'N, *supra* note 29, at 218.

²⁰⁵ See, e.g., Silverman, *Mismatched Attitudes about Neonatal Death*, 11 HASTINGS CENTER REP. 12 (1981); Keyserlingk, *Non-Treatment in the Best Interests of the Child: A Case Commentary of Couture-Jacquet v. Montreal Children's Hospital*, 32 MCGILL L.J. 413, 422 (1987); Frader, *Difficulties in Providing Intensive Care*, 64 PEDIATRICS 10 (1979).

As theologian John J. Paris has written:

[I]t is the evolution of technology to the ultimate value that has created the problems we see today and that has distanced us so far from the kind of wisdom every caring grandmother in this country would know how to apply to these questions.

Paris, *supra* note 122, at 122.

²⁰⁶ Neonatal intensive care units (NICU) rely heavily on young physicians who must be trained; training needs are "potentially at odds with the well-being of patients." J. GUILLEMIN & L. HOLMSTROM, *supra* note 155, at 278. Research, status, hospital reputation and financial returns are all concerns of NICU life likely to increase resistance to needed improvements. *Id.* at 185-87. Physicians "have a long history of using the sick to learn about diseases, to transmit knowledge and to make a living . . ." Duff, *supra* note 158, at 318 (emphasis in original). "The need for observation and data may push a clinician, even unconsciously, to extend a course of care beyond reasonable limits of benefit to the patient." Jonsen, Phibbs, Tooley & Garland, *supra* note 176, at 763.

²⁰⁷ Although doctors ordinarily can reject patients who ask them to act contrary to their own morality, letting such patients seek out another doctor, this is not possible in the typical infant Doe situation, where the infant is in the effective custody of the hospital nursery. Parents can not move very sick infants or go "doctor shopping" when infants are in intensive care units.

²⁰⁸ See PRESIDENT'S COMM'N, *supra* note 29, at 211; H. CLARK, *supra* note 103, at 588.

is a part of the entire tragedy of serious birth defects, and prolonging that suffering is a harm legitimately to be avoided. Since their suffering is directly related to the suffering of their infant, and since caring parents naturally want their child to live, this parental interest in practical terms will not usually conflict with the infant's own interests.

Another interest of parents is the avoidance of financial burdens and other demands on the family presented by a severely ill neonate. Eliminating cost considerations is easy when imagining parents who do not want to give up their vacation at the beach to pay for infant care. But the real life cases are more difficult. Extravagantly high costs in intensive care units can have ruinous effects on families, depriving parents and existing children of their economic security. If a state will not itself pay these astronomical bills, should it tell a family to take the risk of going bankrupt for a chance, perhaps slim, that an infant will survive, but with a lifelong, incurable major impairment? When conditions of extreme hardship exist, amid factors which make the choice for treatment problematic, there is a colorable claim that the infant's interests, while of primary importance, need not be totally exclusive.²⁰⁹ The state itself makes finances a key factor in decisions that affect lives (for example, when a legislature votes to stop funding certain expensive operations).²¹⁰ If the state can do this, it would be anomalous to say families, in a more limited way, are barred from even thinking about costs. A possible solution might be to permit the consideration of cost as a factor only when the infant's chances for a reasonably intact survival are poor. Bankrupting a family when hope is dim and success speculative seems an unnecessary and cruel compounding of the family's ordeal.

It is sometimes said that "social factors" such as the caretaking

²⁰⁹ Veatch, *supra* note 195, at 436-37. An example given by Veatch illustrates the point: [J]ustification for guardian treatment refusal on behalf of an incompetent patient should focus almost exclusively on the burden to the patient; however, there are exceptional situations where the door must be opened to consider the burdens to others. It would be unrealistic not to recognize such exceptions.

Consider the situation of a family with moderate means consisting of husband, wife, and three children including an infant with a severe immune deficiency. The infant is not expected to live, but the physician advises that if the infant were flown immediately across the country to an East Coast research facility, there would be about one chance in one thousand that the baby would survive. The treatment would not be painful to the child. The cost of the transportation and care would be approximately \$100,000. The family has net worth including equity in their house of \$60,000, but they could borrow the remainder. Most reasonable people would say that the parents are under no moral obligation to borrow the money to provide the infant this slim chance of survival; yet, if only benefit to the patient were considered, they ought to be required to do so.

Id. at 436.

²¹⁰ Egan, *Rebuffed by Oregon, Patients Take Their Life-or-Death Cases to Public*, N.Y. Times, May 1, 1988, at 26, col. 1 (state legislature reallocates public funds from transplant operations to prenatal care).

ability of the family and the nature of public and private institutions that care for severely handicapped children should be excluded from decisionmaking for the severely damaged infant because such factors "potentially can be ameliorated by societal change."²¹¹ Caution is in order, however, before dismissing such matters from the decisionmaking matrix. Often enough, home care for an infant with severe medical problems is not a realistic possibility for the family. A fragile child may need frequent monitoring and special equipment, require continual help with feeding and personal care, exhibit behavioral difficulties, experience seizures or generally need close supervision every day. If a family cannot provide home care for an incapacitated child, it may have to resort to institutions operated by private entrepreneurs or by the state. Parents may have no choice but to accept any placement offered, even if they have strong doubts or reservations about its basic quality, because of the shortages in available care.²¹²

While societal change is theoretically possible, children salvaged by aggressive infant treatment must live in the real world where too often only limited help to them is available, even help of the most elementary kind. In Texas, for example, a federal judge hearing a suit brought by parents of children in a Fort Worth institution, reported by the New York Times to be the *newest* and smallest of the state's thirteen facilities for the mentally retarded,²¹³ found the state had violated the children's constitutional rights by severely mistreating them and by generally failing to provide minimally adequate care.

In Massachusetts, a pediatric nursing home system was established in 1971 to provide better care for multiply handicapped children than overcrowded state institutions had provided. Yet a 1983 study²¹⁴ revealed that the new system was plagued by fundamental health care deficiencies and other major problems. Most of the children were in

²¹¹ Rhoden, *supra* note 13, at 1322.

²¹² See Glick, Guyer, Burr & Gorbach, *Pediatric Nursing Homes: Implications of the Massachusetts Experience for Residential Care of Multiply Handicapped Children*, 309 NEW ENG. J. MED. 640, 643 (1983); see also *Society for Good Will v. Cuomo*, 572 F. Supp. 1300, 1337 (E.D.N.Y. 1983); Mincer, *Day Care for Sick Children*, N.Y. Times, July 2, 1987, at C9, col. 1 (reporting opening of nation's only nonprofit day care center for children with special needs).

²¹³ The court's findings were sobering:

[J]udge Sanders said today that the state had violated the constitutional rights of the mentally retarded youths sent to state schools "by failing to provide constitutionally adequate medical care, constitutionally adequate safety, constitutionally adequate freedom from undue restraint, and constitutionally adequate habilitation." Judge Sanders spelled out in harrowing detail some cases of inadequate care and neglect. He described residents lying in their own feces and urine, cases of sexual abuse of residents and residents being beaten by staff members.

Appelborne, *Texas Held in Contempt Over Treatment of Mentally Retarded*, N.Y. Times, Aug. 14, 1987, at A10, col. 1.

²¹⁴ Glick, Guyer, Burr & Gorbach, *supra* note 212, at 642.

dire medical condition — bedridden, nonverbal, suffering from a wide range of chronic disorders, with prognoses of “significant impairment of growth and development and severe limitation of independent functioning.”²¹⁵ Of the total resident population, 79% had severe or profound mental retardation; 72% had seizures. Most of those with seizures also had cerebral palsy. Hereditary disorders, prenatal and perinatal problems were the overwhelming causes of the children’s disabilities.²¹⁶

The study found low standards of care, insufficient funding, financing schemes that provide “little incentive . . . to upgrade care substantially,” shortages of residential places and bureaucratic disputes that leave “many children in the homes [receiving] fewer services and less individualized professional attention than do residents of other facilities.”²¹⁷ The study also found that “if a child requires an unusually intensive program of intervention, such as behavior modification or special feeding, it is often impossible to find staff or funding to implement it.”²¹⁸

As both the Massachusetts and Texas experiences demonstrate, the child’s future medical status, as well as his emotional and psychological health may be in considerable jeopardy after placement in these institutions.²¹⁹ Policymakers hoping to encourage aggressive treatment choices would do better to upgrade the facilities and services that exist in their states, rather than compel parents to preside over dreadful lives for their afflicted children.

TASK 3: IDENTIFYING PROCEDURES FOR DECISIONMAKING

Lawmakers generally enjoy considerable freedom in devising procedural rules to govern the assertion of substantive constitutional rights. Procedures cross constitutional boundaries, however, when they destroy or inhibit the exercise of rights by imposing unduly burdensome, cumbersome or intimidating conditions. Procedures may also undermine rights by imposing non-neutral conditions that hamper

²¹⁵ *Id.* This is one of the criteria for placement in the system.

²¹⁶ *Id.* at 643.

²¹⁷ *Id.* at 644.

²¹⁸ *Id.*

²¹⁹ In the Massachusetts children’s nursing homes, many children had no or few visits from their families. *Id.* See Gross, Cox, Tatgrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983); Shaw, *QL Revisited*, 18 HASTINGS CENTER REP. 10 (1988) (societal resources affect medical outcomes). For cases in which parents challenged conditions in institutions, see *Society for Good Will v. Cuomo*, 572 F. Supp. 1300 (E.D.N.Y. 1983), and cases cited in *Note, Parental Rights and the Habilitation Decision for Mentally Retarded Children*, 94 YALE L.J. 1715, 1737 n.120 (1985). The nation’s poor standard of care for the mentally retarded is recounted in *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985).

individuals who seek to act on their rights.²²⁰ In the context of medical decisionmaking for incompetent individuals, the two procedural mechanisms most frequently discussed are the establishment of special hospital committees and the use of the courts to help resolve infant Doe dilemmas. These will be addressed in turn, followed by a discussion of the use of other procedures.

1. Committees

The federal government encourages but does not mandate the use of hospital committees to participate in decisionmaking.²²¹ The HHS, in its single-minded effort to eliminate ethics from infant Doe decisionmaking, refrains from including ethicists on its list of recommended "core members" or "other permanent members" of such committees.²²² Much of the scholarly literature, however, describes these entities as "ethics committees," recognizing the central role that ethical deliberation must have in true dilemmas of care.²²³

Committees are a mixed blessing in infant Doe scenarios. They may contribute positively by providing a forum for full discussion of the medical, ethical and social ramifications of the various treatment options available, by supplying additional medical expertise to confirm the diagnosis and prognosis of the attending physician, and by defusing emotional conflicts and fostering better communication between parents and physicians. They can help persuade those involved to abandon irrational positions and give support to realistic appraisal and thoughtful deliberation. Unfortunately, these advantages may not always be realized in practice. Committees do not always work effectively (hence the standard joke that a mule is a horse designed by a committee). Committees striving for consensus may reach compromises not wholly satisfactory to anyone but which preserve the aura of group agreement. Committees also tend to shift the burden of responsibility for a decision from each member to the amorphous group. Physicians on these committees may simply reinforce each other's professional bi-

²²⁰ The abortion context offers many examples of non-neutral conditions and burdensome procedures. See, e.g., *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983)(ordinance struck down). For a discussion of the chilling effect of procedures in the area of treatment refusals, see *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983); *In re Jobs*, 108 N.J. 394, 423, 529 A.2d 434, 449 (1987).

²²¹ See HHS, Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893 (daily ed. Apr. 15, 1985).

²²² *Id.* at 14,894, 14,897.

²²³ For more detailed discussion, see Levine, *Questions and (Some Very Tentative) Answers About Hospital Ethics Committees*, HASTINGS CENTER REP., June 1984, at 9; Veatch, *The Ethics of Institutional Ethics Committees*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISIONMAKING (1984); McCormack, *Ethics Committees: Promise or Peril?*, 12 LAW MED. & HEALTH CARE 150 (1984).

ases and tendencies toward aggressive treatment. Hospital administrators on a committee may be influenced, consciously or not, by institutional concerns about legal liability, public image, preservation of government/hospital relations and hospital finances. The committee may be well run or poorly run. Its members may be dedicated and hard working or casual and uninvolved. It may be dominated by one or two individuals or enjoy the active participation of all members. Many proponents of these committees suggest that they should be consultative and advisory, not final decisionmakers.²²⁴ If committees are more than advisory and actually make treatment decisions for newborns, serious problems arise. The committee itself is not authorized to practice medicine and should not be in the position of making final medical treatment choices. Moreover, if parental decisionmaking authority is, as argued previously, a constitutionally-based right, it may not be displaced by a committee. Of course, the committee may advise the hospital to challenge a parental decision in court. Responsibility and accountability for the well-being of children ultimately rest with their parents, not with private committees, however well chosen and intended.²²⁵

2. Courts

While court involvement in all cases of withdrawal or withholding of life sustaining treatment is a theoretical possibility, policy makers are well advised not to impose any such requirement. The courts themselves have rejected routine involvement in cases involving treatment choices for critically ill family members. In the *Quinlan* case,²²⁶ the New Jersey Supreme Court found that the "practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome."²²⁷ The New York Court of Appeals in *Weber v. Stony Brook Hospital*²²⁸ noted its distress with the fact that parents had "responsibly" decided on a conservative course of treatment for their infant daughter (rejecting surgery for spina bifida accompanied by serious complications), yet had been "subjected . . . to litigation through all three levels of our State's court system" and "force[d] . . . to incur the not inconsiderable expenses of extended litigation."²²⁹

²²⁴ See, e.g., Fost, *Baby Doe: Problems and Solutions*, 1984 ARIZ. ST. L.J. 637.

²²⁵ For further discussion of ethics committees, see Newman, *supra* note 96, at 80-81; R. WEIR, *supra* note 149, at 263-66.

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

²²⁷ *Id.* at 50, 355 A.2d at 669.

²²⁸ 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983).

²²⁹ *Id.* at 213, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.

Litigation brings considerable stress and trauma to parents already under the greatest strain. The publicity these cases generate causes loss of personal privacy and sensationally displays the parents' grief and anguish. The time needed to acquaint lawyers and judges with the facts, which do not remain static and may change daily or hourly, renders litigation even more ill-suited to the treatment decisionmaking task. Moreover, burdens of going to court may have a chilling effect on parents desiring to forego aggressive medical care.²³⁰

Two courts considering the withdrawal of life support from hopelessly ill infants deferred to the decision made by the parents, properly recognizing the limited role a court could play in these matters. In one of the cases, *In re Guardianship of Barry*,²³¹ a Florida appeals court wrote:

In the case of a child who has not reached maturity, it is the parents and their medical advisors who generally must make these decisions. And, where judicial intervention becomes necessary or desirable, the court must be guided primarily by the judgment of the parents who are responsible for their child's well-being, provided, of course, that their judgment is supported by competent medical evidence.²³²

The court went on to hold that judicial review was not required before life support could be withheld from a child who is not brain dead, recognizing "that decisions of this character have traditionally been made within the privacy of the family relationship based on competent medical advice and consultation by the family with their religious advisors, if that be their persuasion."²³³

The Georgia Supreme Court in a similar case, *In re L.H.R.*,²³⁴ also held that parents were the final decisionmakers for their infants. While both courts confined their holdings to the cases before them — that of hopelessly vegetative infants — their reasoning extends to other infant Does as well. Deference to parents, except in extreme cases, is constitutionally required, and in any event, courts have little basis for substituting their own judgment for that of responsible parents. As I have previously written about treatment choices by the family on behalf of one of its members:

For those instances in which stopping treatment is not beyond the bounds of society's widely shared sense of morality, judges can not claim any particular competence to make treat-

²³⁰ See *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983); *John F. Kennedy Memorial Hosp., Inc. v. Bludworth*, 452 So. 2d 921 (Fla. 1984).

²³¹ 45 So. 2d 365 (Fla. Dist. Ct. App. 1984).

²³² *Id.* at 371.

²³³ *Id.*

²³⁴ 253 Ga. 439, 446, 321 S.E.2d 716, 723 (1984).

ment/nontreatment decisions for others. Such decisions require a moral, philosophical, or religious set of values; without these it is impossible to determine whether the benefits of treatment outweigh the burdens. Government officials, including judges, should not be selecting among competing, acceptable moral philosophies. Moral diversity . . . exists in the society at large. The government, in a free society, ought to respect that diversity.²³⁵

Courts, of course, should always be available to resolve allegations concerning parental abuse of their decisionmaking authority; such cases would be the exception rather than the rule, however.

3. Other Procedures

Judges or legislatures may be tempted to select procedures from the legal armamentarium of due process and apply them to infant treatment decisions. While the appeal of due process is understandable, policymakers must exercise self-restraint. Procedures do not render any less perplexing difficult substantive legal and ethical conundrums, and the unintended burdens and consequences of legal strictures can be detrimental to those on whose behalf they are imposed and to society.

The legal profession's overuse of procedure parallels the medical profession's tendency to overtreat. As Dr. Alan Stone points out, legal rules concerning medical treatment choices are sometimes "juridicogenic" in that they produce new, law-created problems and ill effects.²³⁶ One of the unwanted side effects of legal process rules that he identifies is the loss of privacy and confidentiality, ironic in the context of substantive rules which try to protect these same values. Another is the damage done when patient-oriented medical care becomes lawyer-oriented.²³⁷ Procedures designed to formalize the decisionmaking process may be seen by the medical profession as a message about

²³⁵ Newman, *supra* note 96, at 76.

²³⁶ Stone, *Judges as Medical Decision Makers: Is the Cure Worse Than the Disease?*, 33 CLEV. ST. L. REV. 579 (1984-85).

²³⁷ Dr. Stone writes:

When doctors see the threatening shadows of the law, they forget that they are doctors with personal responsibility; they act to minimize their own risks; they often call in their lawyers and do what they are told; they often behave very much like bureaucrats. Indeed there is a high correlation between the increasing judicial and legislative intervention in medicine and the increasing bureaucratization of medical care. For every legal intervention another committee is created. Thus, by casting what seem like threatening shadows, the courts have influence far beyond their actual decisions on medical practice. Juridicogenic cures contribute to the bureaucratization of medical care.

Id. at 583.

preferred outcomes. If decisions to treat aggressively are unburdened by formal rules of proceeding, while decisions not to treat are so encumbered, the message conveyed is that treatment is always safe and nontreatment is a legal headache. Aggressive treatment is thereby promoted as a preferred outcome.

As an abstract matter, a "tilt" in the law favoring life-sustaining treatment may be appealing. But policymakers must examine the real world of medicine. If, as so often seems the case, the tendency to treat too aggressively already predominates,²³⁸ a further legal push in that direction will do more harm than good. To help right the imbalance caused by professional dominance in the medical setting, lawmakers might do better to consider a "tilt" toward parental decisionmaking, for example, by requiring clear and convincing evidence before parental choices are overridden.²³⁹

Whatever the procedural proposals, lawmakers must give them careful scrutiny, reacting reflectively rather than reflexively. Procedure, like technology, should not be used simply because it is there.

VIII. CONCLUSION

The wide variety of diseases and incapacitating conditions that afflict newborns pose profound treatment dilemmas for their caretakers. In the Child Abuse Amendments of 1984, Congress offered its solution to these dilemmas by defining when the "withholding of medically indicated treatment" would be unlawful. In less than 200 words, the act purported to resolve all treatment dilemmas for all infants facing every kind of life-threatening disorder. Its rigid provisions, heavily oriented toward aggressive medical interventions, disregard the ethical complexities associated with treatments that offer no substantial hope of cure but impose significant burdens of pain, extended suffering, and risk of further harm. It would perpetuate extreme states of mental and physical devastation, ignore all reservations about the aggressive use of medical technology and routinely deprive parents of discretion to make informed, conscientious decisions for their own children.

States need not accept this federal standard. But most have done so, often through agencies who stand to gain from the limited federal funding that is contingent upon state adoption of the infant Doe rule. I suggest that state and local child abuse agencies do not have the authority to determine their state's law concerning compulsory treatment for infant Does, because of their limited statutory jurisdiction and be-

²³⁸ See *supra* note 158.

²³⁹ On physician dominance of parents, see Malone, *Medical Authority and Infanticide*, 1 J. LAW & HEALTH 77, 96-100 (1985-86); see generally J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984).

cause the issue is one that must initially be addressed by lawmakers, not law administrators.

State constitutions, little discussed in the debate so far, may prevent legislatures from adopting the federal infant Doe rule. Infants have a right, stemming from state constitutional commitments to the liberty, privacy and dignity of all individuals, to have the suffering, risks and perils of aggressive medical treatments balanced against the hoped-for benefits of those treatments. Their parents, whom law and society have long recognized as the proper decisionmakers for children, should make these agonizing decision in the first instance. The government must defer to parents' well-considered choices, interceding not routinely, but only when parental decisions are clearly unreasonable.

In the face of a new and incomplete medical technology that does not offer easy choices, the most the law can do is to provide support and guidance for decisionmaking that is informed, sensitive and compassionate. Perhaps most important of all, state legislators that are truly concerned about the welfare of children should not let compulsory treatment proposals of dubious worth deflect attention away from the need to intensify the effort to prevent birth defects and to provide necessary services to help those who survive with them.