Beyond State Intervention in the Family: For Baby Jane Doe

Martha Minow
Harvard Law School

Follow this and additional works at: https://repository.law.umich.edu/mjlr

Part of the Family Law Commons, Health Law and Policy Commons, and the Juvenile Law Commons

Recommended Citation
Available at: https://repository.law.umich.edu/mjlr/vol18/iss4/6

This Symposium Article is brought to you for free and open access by the University of Michigan Journal of Law Reform at University of Michigan Law School Scholarship Repository. It has been accepted for inclusion in University of Michigan Journal of Law Reform by an authorized editor of University of Michigan Law School Scholarship Repository. For more information, please contact mlaw.repository@umich.edu.
BEYOND STATE INTERVENTION IN THE FAMILY: FOR BABY JANE DOE

Martha Minow*

Newspapers and broadcasters gave major billing to the story. Headlines announced: "The Life or Death Question of Baby Doe;" and "Baby Doe’s Parents Call U.S. Action Intimidating." The medical care decisions about this infant born with spina bifida, microcephaly, and other severe disabilities, not only attracted mass media attention, but also led to both state and federal court proceedings. Legislative hearings raised the issue of her care. Many commentators debated what should happen to this infant of Long Island parents. This article instead will ask: what was all the attention about?; why are cases like this so riveting?; and might the reasons for public fascination and anguish illuminate alternative legal responses?

Several themes dominated public discussion of the Baby Jane Doe case: first, the scope of the parents’ legal and moral rights to refuse surgery to enclose the spine of their child born with spina bifida and other conditions; second, the role of a person with no relationship to the family who challenged the parents’ decision in both state and federal courts; and finally, the reach of governmental power to obtain information about the child’s medical condition and to review the parents’ decisions about their child’s


The author thanks Sarah Walzer, Zipporah Wiseman, Lloyd Weinreb, Alan Stone, Avi Soifer, Joe Singer, David Shapiro, Lewis Sargentich, Frances Olsen, Robert Mnookin, Jay Katz, Louis Kaplow, Philip Heymann, Marsha Garrison, Mary Joe Frug, Chai Feldblum, Ken Chesebro, David Chambers, Stephen Carter, Katharine Bartlett, Judith Areen, and Bruce Ackerman for their generous and wise counsel.

2. See infra text accompanying note 8 (explaining these conditions).
medical care. Each of these themes poses a question concerning the relationship between the state and the family. Can parents count on the state to secure for them a sphere of private decision making about their child’s medical care? Can a stranger to the family ask the courts to review parents’ medical care decisions about their child? Can the government itself initiate such review, and supplant the parents’ choice? Central to all these questions lies the problem commonly termed “state intervention in the family.” Baby Jane Doe’s case is an emblem of this controversial legal issue.

Thus, the case seems a prime candidate for analysis in this Symposium on state intervention in the family. This article begins by examining arguments over state intervention in the context of legal developments arising around Baby Jane Doe, but it then identifies the conceptual ambiguity and emotional complexity that permit debates on these issues to continue without resolution. The article then rejects the framework of “state intervention” by showing that arguments cast in those terms overlook the variety of possible forms and directions of state intervention, and obscure the inevitable role of the state in any possible allocation of power to decide the infant’s medical treatment.

Further, this article demonstrates how vociferous exchanges over the substantive and procedural choices for the state produce a polarized set of alternatives that fail to express the positions people actually wish to take, much less the complexity of the problem. Rigid and polarized alternatives do not contribute to solutions, and instead express and deepen distrust among potential decisionmakers. Yet the polarized structure of the debates seems to tap conflicting parts of the human psyche and, in particular, conflicts for each individual over identifying with and separating from others. This article maintains that more productive problem solving would emerge by addressing these very sources of conflict and developing approaches that acknowledge both the experiences of separateness and of connection that underlie people’s responses to cases like Baby Jane Doe’s.

As initial steps in this direction, the article proposes processes for decision that: (1) emphasize the obligations of both the state and the family in the continuing care of the infant; (2) provide for exchanges of information in nonadversarial settings to improve estimates of the experiential meaning of the child’s medical condition and the role of the child’s caretakers in shaping that meaning; and (3) promote the development of general treatment guidelines removed from crisis situations and with the par-
ticipation of medical professionals, political authorities, and members of the public. These suggestions are not offered as cures for the problem, but instead as examples of a problem-solving approach that addresses the issues of trust and connection, and distrust and separation in disputes over medical treatment for severely handicapped infants.

These steps will not yield consensus nor will they produce mutual trust. Yet they may frame the problem in forms that challenge preconceptions about the handicapped infant, about the opponents’ positions, and about the decisionmakers’ role in the options available to the infant.

Before suggestions of these sorts can be developed, the prevailing conceptions of the problem must be challenged. Section I of this article takes on the debate over state intervention by demonstrating the multiple meanings signified by “state intervention” in the context of actions taken to affect Baby Jane Doe alone, and rejects the terms of the state intervention debate as ambiguous and distractingly charged with symbolic meaning. Section II recasts the problem as a set of both substantive and procedural choices for the state, and suggests how each of these choices importantly implicates parents, medical and legal personnel, and the broader society in the prospects of the infant. Because these interpersonal connections may remain obscured even when the problem is cast as a set of substantive and procedural choices, the article turns in Section III to reconsider the problem expressly in terms of psychological notions of distrust and identification. On the basis of this psychological analysis, Section III then explores the legal steps that could address sources of distrust between parents and children, families and governments, and families and strangers. The article in essence maintains that deep conflicts about the relationship between the self and others—and about the power of the community to make individual lives more or less meaningful—are implicated in each decision about medical treatment for a handicapped newborn, and that failing to acknowledge these conflicts will not help avoid them. Instead, the article proposes taking such conflicts seriously as the starting point for making decisions, and adopting strategies that help address both these deep conflicts and the power of the community implicated in the decisions made about vulnerable people.
I. STATE INTERVENTION: VARIETIES, HOPES, AND FEARs

In an era when the state intervention problem has manifested itself in such controversial issues as abortion, teen-age contraception, and family violence, framing any given case in terms of state intervention does not lead to an obvious solution. One's view about state intervention often depends upon the result one desires in a particular conflict. For example, amid debates over Baby Jane Doe, individuals who in other situations argue against state intervention in the family found themselves urging state involvement.4

Additionally, state intervention in the family takes various forms. Intervention in each instance involves the state in monitoring or altering conduct or decisions that would take place within a family. The medical treatment of Baby Jane Doe occasioned a variety of governmental actions, not simply an either/or choice about the wisdom of state intervention. This Section examines how the case of Baby Jane Doe illustrates the many dimensions of "state intervention" and implicates broader controversies about power, the family, and the state. This Section suggests that the state intervention framework adopted by both legal and media debate is unhelpful, because it fails to correspond to the variety of choices involved in a case like Baby Jane Doe's, and because it expresses but does not explore deep sources of distrust about the family and the state.

A. Varieties of State Intervention

When people argue about whether the state should intervene in family decisions about infant medical care, they could mean any one of a combination of governmental actions. As a result, arguments cast as a dichotomous choice between "state intervention" and "nonintervention" are misleading and confusing. Once the government has the authority to intervene which it may or may not exercise—and, indeed, the authority to consider its own authority to intervene—the idea of state intervention

fails to have a sharp edge. Debates over medical treatment decisions, however, identify particular governmental powers that could be exercised as instances of state intervention to be challenged or justified. Yet the very variety of governmental powers that could be exercised in a given case, like Baby Jane Doe's, blurs the notion of state intervention as an either/or proposition. Given the legal actions surrounding Baby Jane Doe alone, the meaning of state intervention in medical care decisions made by parents of disabled infants includes: (1) state judicial availability for challenges under *parens patriae* power or state child protection statutes; (2) federal judicial review of whether existing law governing the disabled applies; (3) initiation of federal regulatory action to require new procedures within health care institutions; (4) enactment of new legislation, whether triggered by federal agencies or undertaken independently by state governments. Governmental involvement can take place at both the state and federal level, and can work through legislative, executive, and judicial action.

All these options could share a direction; all could make it more difficult for parents and their own physicians to determine the treatment for a disabled newborn. In the current debate, the argument against state intervention seems to claim this substantive outcome: intervention by the state is opposed in order to secure private choice-making room for parents and doctors. Yet the techniques of governmental activity alleged to threaten this realm of private choice could also be used to enlarge parental and physician choice. In the instance of Baby Jane Doe, this va-

5. Even if the result of the review is a finding that the governing law does not apply, the act of judicial review itself "intervenes" and indeed incurs costs in terms of time, money, and emotional drain. See Chambers, *Baby Doe: Hard Case for Parents and Courts*, N.Y. Times, Jan. 8, 1984, § 21, at 1, col. 1 (noting that Doe's parents incur $36,000 costs in legal fees); Chambers, *Parents of 'Baby Doe' Criticized 'Intrusion' by U.S.*, N.Y. Times, Nov. 6, 1983, at L45, col. 2. The reviewing court in the Baby Jane Doe case combined its own independent assessment of whether the parents' medical decision was "in the best interest of the infant" with a conclusion that because the decision was in the infant's best interests, "there is no basis for judicial intervention." Weber v. Stony Brook Hosp., 95 A.D.2d 587, 589, 467 N.Y.S.2d 686, 687, aff'd, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, cert. denied, 464 U.S. 1026 (1983). Intervention, in this sense, must mean judicial supplanting of the parents' decision rather than the exercise of judicial power to assess whether to supplant the parents' choice. Other meanings of intervention are also possible. See also text accompanying note 52.

6. A form of government intervention may also occur when the government itself asks whether it has the authority "to intervene"—that very inquiry involves government action of some sort. See infra section II. Governmental power to determine its own power is a standard bootstrap and also a self-monitoring device. Cf. United States v. United Mine Workers of Am., 330 U.S. 258 (1947) (every court has capacity to determine its own power to hear the case before it).
riety of strategies for state intervention comes together in one vivid case study.

At the heart of this case was a set of disagreements over the facts of the condition that Baby Jane Doe manifested at birth, and related disagreements over the meanings of those conditions. Press critics disputed the facts initially reported in news stories about Baby Doe. As initially reported in the major newspapers, Baby Jane Doe at birth had multiple medical problems, including an opening of the bones and coverings of the spinal cord, known as spina bifida; an abnormally small head, known as microcephaly; and an accumulation of fluid in the cranial regions, known as hydrocephalus. Doctors told her parents that Baby Jane Doe “probably had brain malfunction” and that “the part of the brain that controls much of our awareness was either missing or not entirely formed.” After lengthy consultation with medical, religious, and social work professionals, her parents chose to decline the option of surgery to close the spinal opening; they approved other measures to respond to the infant’s conditions. Perhaps, given a different set of descriptions of her conditions and her prognosis, Baby Jane Doe’s parents would have decided differently. As other private and public actors entered the case through a range of intervention strategies, each brought their construction of the facts to decisions about the infant.

1. **State judicial review**— Within two weeks of Baby Jane Doe’s birth, the state trial court in Suffolk County, New York, agreed to hear a challenge to the parents’ choice of medical treatment for the infant, and authorized a guardian ad litem to consent to surgical procedures on the infant’s behalf. This action represented several kinds of state involvement. First, the state permitted a person unconnected to the family to invoke state judicial power to review the parents’ decision about the infant.
fant's treatment. Second, the state appointed someone other than the parents to stand as guardian for the infant. Third, the state authorized that guardian to consent to surgery for the child but did not authorize the guardian to reiterate the parents' decision to forego surgery. The trial court used the notion of state intervention to mean an opportunity for judicial review of the parents' decision, and to mean judicial authority to supersede the parents' decision through an appointed guardian.

When Baby Doe's parents appealed the trial court decision, the appellate division endorsed the notion that courts have parens patriae power to review parents' choices about medical care for their children. The court nonetheless rejected the exercise of state intervention to supersede the parents' decisions in the Baby Jane Doe case. The court concluded that the parents' refusal of surgery did not constitute a decision to bring about the child's death, as no imminent risk of death absent the surgery existed. The appellate court's opinion itself highlighted the equivocal meanings of state intervention. The court stated that it found "no basis for judicial intervention" even though the court itself intervened by interposing its judgment, independently reviewing the record, and finding the parents' determination "to be in the best interest of the infant." The appellate division also implicitly affirmed the power of the trial court to hear a challenge brought by a private person unrelated to the family.

The initiation of legal proceedings by someone unrelated to the family formed the basis for the decision of the New York Court of Appeals on review. The Court of Appeals reasoned that the petitioner had no direct interest in the medical treatment of the infant because he had no direct relationship to the infant; therefore, the trial court should not have entertained pe-

11. Nonrelatives are commonly authorized or even obliged to become involved in family health problems through state child abuse and neglect reporting requirements placed on teachers, doctors, and other professionals who routinely encounter children. See generally R. Gottesman, The Child and the Law 42-43 (1981) (reporting statutes). The premise of such requirements is that such individuals have some relationship with the child or some professional obligation to guard against risks to children. The person permitted to initiate judicial review of the decision by Baby Jane Doe's parents did not fall within these categories, and did not act under authorization from a child neglect reporting statute, but claimed a sense of obligation to the infant from afar.


titioner's suit. The court did acknowledge that the state Department of Social Services properly could have invoked review of the parents' decision by the state judiciary. As the state agency did not take this route, the state judiciary did not belong in the medical care decision. Accordingly, the highest state court limited the power of the state judiciary to cases brought by the state bureaucracy rather than by a private person with no relationship to the family. And the New York state court identified the state Department of Social Services as the avenue for state governance of family affairs.

2. Federal judicial review—Another form of state intervention arose with federal action in the case. The federal government entered the fray when the Department of Health and Human Services (HHS) filed suit in federal district court against the hospital treating Baby Jane Doe under the federal statute prohibiting discrimination against the handicapped, section 504 of the Rehabilitation Act of 1973. The federal court accepted the suit as a proper invocation of federal judicial authority under the statute, but rejected the agency's claim because the government failed to establish that the hospital violated the statute and discriminated against a handicapped person. The court additionally concluded that section 504 did not authorize the federal government to force the hospital to release its


16. The court neither precluded nor invited suits initiated by other family members, nor did the court define who, in addition to a parent, has "direct interest" in such a case. The court expressly identified only the state child protection agency as entitled to initiate judicial proceedings to challenge parental judgments: "All other persons and entities may only file a petition if directed to do so by the court." Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 212, 456 N.E.2d 1186, 1187, 469 N.Y.S.2d 63, 64. The court additionally warned that any contrary rule permitting others to initiate judicial action in this context would "challenge the most private and most precious responsibility vested in the parents for the care and nurture of their children—and at the very least to force the parents to incur the not inconsiderable expenses of extended litigation." Id. at 213, 456 N.E.2d at 1188, 469 N.Y.S.2d at 65.

17. See infra text accompanying note 34 (describing action taken by N.Y. Department of Social Services).


records to the agency or the court. And the court denied standing to sue to the individual who initiated the state court suit for the appointment of a guardian for Baby Jane Doe.

On appeal, the Court of Appeals for the Second Circuit affirmed the district court's conclusion but rephrased the issue to consider whether section 504 even reached the situation of a parental medical treatment decision for a disabled newborn. The court examined the terms of the statute, which forbid recipients of federal funds from denying to any "otherwise qualified handicapped individual" any benefits of any program receiving federal assistance, and also prohibit discrimination against such persons by these programs. Finding any application of this language to the medical treatment of an infant less than clear, the court concluded that Congress did not intend the statute to deal with the issue raised in the case of Baby Jane Doe, and affirmed the district court's denial of the Department's claim.


24. United States v. University Hosp., 729 F.2d 144, 154-55, 156-61 (2d Cir. 1984), cert. granted, 54 U.S.L.W. 3040 (Aug. 6, 1985) (No. 84-1529). Both courts' reasoning rests on solid ground. The language of § 504 itself gives no authority for federal review of parental decisions about medical treatment for their severely disabled infants. Parents are not governed by the Act, which prohibits discrimination "under any program or activity receiving federal financial assistance." 29 U.S.C. § 794 (1973). The government itself has conceded that parents are not covered by § 504. 49 Fed. Reg. 1631 (1984). And it is the parents' decision, not the hospital's or health care providers—that determines whether medical treatment will be pursued or foregone. Discrimination under § 504 also is an ill-suited rubric to make sense of the complicated medical treatment decisions made by parents. Nor does § 504 authorize federal review of whether health care personnel are fulfilling their state law obligations to report or otherwise respond to instances of child neglect. Indeed, such an interpretation would convert § 504 into a master key to open all state law enforcement practices to federal scrutiny on the issue of discrimination.

Should there be any ambiguity in the meaning of § 504 in this context, it should not be resolved to authorize greater federal control of the traditional areas of state concern: family law and regulation of medicine. The 1984 Amendments of the Child Abuse Act acknowledge as much in establishing a federal program that relies on state law and state law enforcement in these areas. See 50 Fed. Reg. 14,878, 14,879 (Apr. 15, 1985) (to be codified at 45 C.F.R. pt. 1340). See also Letter from Senator Hatch to Senator Weicker,
Under this analysis, the HHS wrongly invoked the power of the federal court because the statute asserted to authorize federal involvement did not govern the case. The court thereby removed section 504 from possible bases for invoking the power of the federal courts to review parental medical care decisions. New federal regulatory activity under the statute undoubtedly will alter the course of future litigation.25

3. Federal regulatory action— The Second Circuit decision collided with an ongoing effort by HHS to regulate medical treatment for disabled newborns through administrative action. HHS began this effort in 1982 after an earlier Baby Doe case. A Down's syndrome infant died in Indiana in 1982 after the parents declined to consent to surgery to remedy a malformed esophagus and to allow the hospital to provide nutrition to the infant.26 Responding to public criticism from handicapped rights and right to life groups, President Reagan instructed the Secretary of HHS to notify health care providers that section 504 governed the treatment of handicapped patients.27 HHS in turn notified 7,000 hospitals of this requirement, and later issued

130 Cong. Rec. 12392 (Sept. 28, 1984) ("Throughout the statutory language and accompanying explanatory material, we refer to authority under state law as the mechanism for pursuing legal remedies under our amendment. This legislation does not itself authorize direct federal involvement in individual cases."). Federal hearings about alleged discrimination in parental treatment decisions thus have neither authority nor guidance from the language or legislative history of § 504, or from the traditional allocation of power between the federal and state government in these areas. Especially given the complexity and contestability of treatment decisions for severely handicapped newborns, this hardly seems a wise occasion for straining to invent new interpretations of federal discrimination law.

25. New rules announced by the Department of Health and Human Services (a) add a new definition of "withholding medically indicated treatment" and new exceptions to the definition, see infra note 77; (b) detail the state child protective programs that must be in place before a state may obtain federal support under the statute; (c) provide model guidelines to encourage the development of Infant Care Review committees. Office of Human Development Services, Department of Health and Human Services, Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14,878, 14,893 (Apr. 15, 1985) (to be codified at 45 C.F.R. pt. 1340). Some have argued that the proposed regulations violated the terms of the compromise struck in the governing statute, see id. at 14,879 (reporting comments on proposed rule, including objections by sponsors of the legislation) but the final rules eliminate most terms giving rise to such comments. Litigation challenging the regulations is foreseeable. Still, since the final version of the regulation treats much of its interpretive language simply as guides rather than binding rules of law, id. at 14,880, the courts can hew closely to the language of the statute itself.


regulations that required health care providers receiving federal funds to post large signs in public view warning that discriminatory treatment of disabled newborns violated section 504, and that any observer should report suspected violations to a telephone hotline maintained by HHS. Calls made to the hotline triggered federal investigations. Presumably, if an investigation produced a finding of a violation of section 504, the Department could move to terminate federal funds to the offending facility.

After a federal district court ruled the HHS regulations invalid on procedural grounds, HHS proceeded to reissue the regulations with a few changes. The final version of the rule responded to comments from groups like the American Academy of Pediatrics. As a result, the rule encouraged the use of Infant Care Review Committees within the health care facilities, although HHS refused to allow such committees to substitute for a continued federal presence through the hotline and investigations.


29. In issuing the final version of its section rule, HHS summarized the cases it had handled by that time; most either had resulted in findings of no legal violation or were closed administratively due to insufficient complaint. 49 Fed. Reg. 1622, 1642-43 (1984).


31. The American Academy of Pediatrics challenged the regulations in federal district court as arbitrary and capricious, and on the ground that HHS erroneously issued the regulations without affording opportunity for advance notice and public comment on proposed regulations as mandated by the Administrative Procedure Act, 5 U.S.C. § 551 (1976). Federal District Judge Gerhardt Gesell accepted these challenges, and criticized the regulations on the merits as showing the shallow consideration behind the agency rule; the decision declared the entire interim final rule invalid. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 399-400 (D.D.C. 1983). In dicta, the opinion speculated on the applicability of section 504 and the Constitution. See American Academy of Pediatrics, 561 F. Supp. at 401-03.

32. The required sign was smaller and could be posted in view of authorized medical personnel only instead of in public areas in the health care facilities. 45 C.F.R. § 84.55 (1984). Again HHS relied on section 504 as authority for the rules, but this time the agency made the regulations available for comment in proposed form before issuing final and effective rules.

In summary, the federal agency sought to establish a direct federal review of medical treatment decisions for disabled newborns in addition to the state governmental involvement through *parens patriae* judicial review or state agency action.\(^3\) Yet the federal regulation again proved short-lived; a federal district court struck it down as exceeding the scope of section 504. The court relied expressly on the Second Circuit's decision a few months earlier in the Baby Jane Doe case.\(^3\)

4. Federal and state legislation— Still another federal response to the Baby Jane Doe case, and others like it, came in September, 1984, when both the Senate and House of Representatives agreed on an amendment to an appropriations program intended to combat child abuse and neglect.\(^3\) The amendment added a requirement that states receiving federal grants under the program authorize state child protective agencies to pursue legal remedies to prevent the withholding of "medically indicated treatment from disabled infants with life-threatening conditions."\(^3\)

\(^3\) State agency action did occur finally for Baby Jane Doe; New York State authorities concluded a week and a half after the New York Court of Appeals decision that the Department of Social Services had no basis to intervene in the matter. United States v. University Hosp., 729 F.2d 144, 147 (2d Cir. 1984). State intervention again was given two meanings: the authority for an investigation of a parental decision, which the state did assert, and the exercise of that authority to seek a judicial review of the parental decision, which the agency declined to do here.

\(^3\) American Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (S.D.N.Y. 1984). The district court declined to assess the effect of the Supreme Court's recent decision in Grove City College v. Bell, 465 U.S. 555 (1984), which ruled that federal antidiscrimination requirements associated with federal grants apply only to the programs directly funded by those grants rather than to the entire institution surrounding those programs.


\(^3\) Pub. L. No. 98-457, § 122(3), 98 Stat. 1749 (amending 42 U.S.C. § 5103(b)(2)). Congress defined "withholding of medically indicated treatment" as:

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 would be inhumane.

§ 121(3). Congress also required each state participating in the grants program to establish methods for coordinating and consulting with individuals designated within the
This enactment represents an elaborate version of the final method of governmental involvement, legislation, for here federal legislation seeks to produce state legislation. The child abuse amendment makes federal moneys available to states on the condition that the states undertake legal enforcement of standards established by the federal government to monitor the medical treatment decisions made by parents and their physicians.38

Thus, state and federal judicial, legislative, and regulatory activity each constituted avenues for “state intervention” in the case of Baby Jane Doe. This range of possibilities is obscured by rhetoric favoring or opposing state intervention. Yet the simplistic state intervention argument carries intense commitment and makes opponents appear irreconcilable. Such intensity and antagonism over state intervention in the family, I will suggest, ex-

health care facilities, and notifying these individuals of suspected instances of medical neglect. The Act's requirements for infants specifically apply only to children under one year of age, but Congress also indicated that changes of care should not occur after a child passes that age. Regulations developed under the amendments elaborate these requirements and also include a model for hospital infant care review committees. See 50 Fed. Reg. 14,878-901. These provisions are discussed infra at text accompanying notes 77 and 138.

38. Any argument that this federal requirement might violate the autonomy of the states seems effectively eliminated with the Supreme Court decision overruling National League of Cities v. Usery, 426 U.S. 833 (1976) in Garcia v. San Antonio Metropolitan Auth., 105 S. Ct. 1005 (1985). In Garcia, the Court ruled that any substantive restraint on the federal government's power under the commerce clause stems not from asserted spheres of state autonomy, but instead from the procedural nature of constitutional limitations. Garcia, 105 S. Ct. at 1020-21. Although family law has traditionally fallen within the domain of state sovereign power, the Garcia ruling suggests that this notion of traditional state sovereign powers would not place substantive limits on federal congressional power exercised under the commerce clause. Moreover, the increasing constitutionalization of family law matters undermines the claim that the states alone govern domestic relations. Further, even under National League of Cities, states which chose to take moneys from the federal government subject to conditions like the enactment of state laws advancing specified federal aims may well have been bound to fulfill those conditions, despite any claims of state autonomy.

In any case, state statutory authority may be used to pursue directly the monitoring of parental medical treatment decisions, even absent federal pressure. Three states have already enacted laws that specifically deal with deprivation of care to newborns: Ariz. Rev. Stat. Ann. § 13-3620 (Supp. 1984-85) (requiring medical personnel to report to the state if they have reasonable grounds to believe there has been a denial or deprivation of necessary medical care, surgery, or nourishment with intent to cause or allow death of a child); La. Rev. Stat. Ann. § 40:1299.36.1 (West Supp. 1985) (forbidding denial of nutrition, water, or oxygen with intent to cause or allow the death of a child, but not requiring medical or surgical care when child's parent or parents along with physicians conclude that potential risks outweigh potential benefits of treatment); 18 Pa. Cons. Stat. Ann. § 3212 (Purdon 1983) (requiring customary infant medical care for any infant born alive). See also Feldman & Murray, State Legislation and the Handicapped Newborn: A Moral and Political Dilemma, Law, Med. & Health Care, Sept. 1984, at 156-63 (criticizing state statutes for sloppiness and faulty assumptions).
presses broader issues. What is at stake is not just the merits of arguments over state intervention, but deeper attitudes about the meanings and consequences of basic legal and political arrangements. 39

B. Intervention: Hopes and Fears

As a first effort to see beneath the surface of debates over a case like Baby Jane Doe's, it is worth asking what beliefs underlie arguments about the merits of state intervention into the family, distinct from arguments about the merits of the medical treatment question. Debates about governmental intervention in other issues of family law illuminate this question. Pro-choice advocates in the abortion debate consistently argue for freedom from state intervention in the private decision made by a woman in consultation with her doctor. 40 Legal and political debate concerning a minor's freedom to have an abortion focuses on claims that the state should require notification to the teen's parents before she may elect an abortion. 41 Contraception and new procreative technologies implicate similar questions. 42 Violence in the family, notably child and spouse abuse, have garnered public and legislative attention, but controversy continues over when

39. Similar debates over governmental intervention occupy the attention of scholars and policy makers concerned with state action in the context of federal constitutional law, and also governmental regulation of the marketplace and the workplace. See Friendly, The Public/Private Distinction, 130 U. Pa. L. Rev. 1289 (1982). State intervention in the areas of family and sexuality may be opposed by the very people who favor it in the context of economic regulation and labor relations; similarly, those who oppose governmental involvement in the economy may favor it in the context of family and sexuality, see Mnookin, The Public/Private Dichotomy: Political Disagreement and Academic Repudiation, 130 U. Pa. L. Rev. 1429, 1430-34 (1982). At work in these debates are deep disagreements over visions of society, virtue, and justice, rather than disagreements over the issue of state intervention per se.


42. See generally Note, Reproductive Technology and the Procreation Rights of the Unmarried, 98 Harv. L. Rev. 669 (1985) (discussing state rules governing access to new reproductive technologies and related constitutional protections).
Beyond State Intervention

In all of these areas, advocates sometimes treat state intervention as an intrinsic evil that jeopardizes norms of freedom, autonomy, and intimacy. At other times, participants in public debate cast state intervention as an important force for good, necessary to protect the weak from private oppression and to ensure justice. In a profound sense, the state can be seen as both a force for good and evil. Yet the passions of public debate seem to lead people to emphasize one view and suppress the other. The particular policy context rather than consistent political philosophy appears to determine when a given group approves of state intervention; yet each view of state intervention invokes a contrasting picture of family and family law.

1. The family—A haven of love and respect—One view identifies the family as a cherished enclave, removed from the hustle and cruelty of the marketplace, the impersonal treatment of the state, and the intolerances of majorities. In this view of the family, love and affection, rather than rules, govern; authority should be trusted, not regulated; the powerful have the interests of the powerless at heart; members share property free from the marketplace rules of exchange; and sex between spouses is love and legal. Under this view of the family, the law should keep the state out of the family as much as possible and should shield the family from “state intervention.”

State control of


44. See Olsen, The Family and the Market: A Study of Ideology and Legal Reform, 96 Harv. L. Rev. 1497, 1501, 1504-08 (1983). Yet from another perspective, this same conception entails state ratification of particular family forms and family relationships. Id. The risk of analysis of this sort is its tendency to treat complex, human interactions as simplified abstract concepts like “family” and “state.” Because this simplification characterizes much popular and legal analysis, I explore it in its own terms, infra text accompanying note 148.
how families live violates the purpose of the democratic order, which aims to constrain state tyranny and to promote private freedoms. The law, consequently, should guard families from public intrusions in parents' special authority over decisions about conceiving and raising children. Similarly, the law should shield families from strangers or governmental authorities who might challenge family members' decisions about abortion, discipline, and styles of living. In sum, risks of state abuse pose greater dangers than risks of abuse within the family.

2. The family—a hell of oppression and brutality—A second view portrays the family as a center of oppression, raw will and authority, violence and brutality, where the powerful economically and sexually subordinate and exploit the powerless.


A related conception treats the family as refuge from the public world, but a refuge increasingly intruded upon by professionals and social service agencies. See C. LASCH, HAVEN IN A HEARTLESS WORLD xxiii-xxiv, 165-66, 172-73 (1979); W. McWILLIAMS, THE IDEA OF FRATERNITY IN AMERICA 193, 469 (1973). A contrasting, but compatible, interpretation suggests that the family was never a locus for liberalism, but instead embodied the fading values of an organic society amid the public commitment to “free men and women, tied together only by their contracts.” Walzer, Nervous Liberals, in RADICAL PRINCIPLES: REFLECTIONS OF AN UNRECONSTRUCTED DEMOCRAT 92, 98 (1980). Rather than being unregulated, the family under this interpretation is the central locus of moral and religious socialization and the critical unit for establishing order within the state. See S. TIFFIN, IN WHOSE BEST INTEREST? CHILD WELFARE REFORM IN THE PROGRESSIVE ERA 111 (1982). This interpretation supplies a bridge to the second view of the family, as a center of oppression and domination over its members; the notion of a golden age of stable family authority itself comes under question here. Elder, Approaches to Social Change and the Family, in TURNING POINTS: HISTORICAL AND SOCIOLOGICAL ESSAYS ON THE FAMILY 57 (1978).

46. This view is advanced in efforts to expose the prevalence of the physical and sexual abuse of women and children. See R. KEMPE & C. KEMPE, CHILD ABUSE (1978); F. RUSH, THE BEST KEPT SECRET: SEXUAL ABUSE OF CHILDREN (1980); Eisenberg & Micklow, The Assaulted Wife: 'Catch 22' Revisited, 3 WOMEN'S RTS. L. REP. 138, 138-39 (1977). This picture also includes the violent responses of victims to their victimization. See
Many conclude from this version of the family as hell that law should protect individual family members from one another. The state should regulate or preclude parental decisions about whether children work, learn, drink alcohol, or drive automobiles. Similarly, state officials should scrutinize parental decisions to abort a fetus and to discipline a child.47 Court orders should be available to individuals within the family to restrain other family members from hurting them or denying them their own freedoms of choice.

I have described the alternative views of the family in stark and simplistic terms to clarify the hopes and fears underlying the state intervention debate. Some in the debate seem to fear the family more than the state and others reverse the order of fears. Opponents of state intervention in cases like Baby Jane Doe's argue, in effect, that the family represents a trustworthy enclave in which, presumptively, decisionmakers act from love rather than rules. Therefore, the delicate and anguishing decisions about how to care for a disabled or even dying child should belong to the family.48 In contrast, advocates of state intervention argue that society should not trust the family to make a


What we most certainly know is that, barring the most extreme circumstances, we do not want the decision made by some bureaucrat or some coven of lawyers. The inevitable agony will be much less if these decisions, and any mistakes, are left to families involved; most often the families will decide on the basis of love, and in any event, it is the family that must live with the resulting burden or guilt.

A New York Times editorial based its reasoning on a quotation from the infant's mother: "We know, [Baby Jane Doe's] mother said, that as she grew older she would always be an infant. She would never know love. And while she might feel sorrow and joy, her overall condition would be pain." Baby Jane's Defender, N.Y. Times, Nov. 11, 1983 at A30, col. 1. The appellate division decision expressly noted that Baby Doe's parents were "concededly concerned and loving," Weber v. Stony Brook Hosp., 95 A.D.2d 587, 467 N.Y.S.2d 685, aff'd, 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63, cert. denied, 464 U.S. 1026; see also supra text accompanying note 13 (discussing appellate division decision).
proper decision about the medical care of a disabled infant because the family is an unruly center of oppression, victimizing the vulnerable. 49

Yet this initial effort to peer beneath the surface of public debate raises new questions. Why do alternate pictures of family and state animate public debate? How could anyone latch on to such simplistic images of family or state, when there are reasons to trust and distrust both? Perhaps particular understandings of recent history matter here. The state intervention debate may express varied responses to a widely shared belief that familial relationships have changed over the past several centuries. Families are no longer trustworthy, and professionals now serve functions once served by family members. According to this view, increasing "legalization" of relationships emerges as family members neglect their duties and as individuals must negotiate relationships founded in contract to fill human needs. 50 Whether this shared belief is accurate, 51 people have demanded and created legal solutions to their mounting distrust within social relationships.

Yet a debate cast as though there is an either/or decision—either the state should intervene or not—may tap into these sources of distrust about both the family and the state. Such an either/or debate fails to offer bases for addressing the sources of distrust and obscures the complexity of family and state relations. This debate also hides the varied meanings of state intervention and mistakenly suggests that there can be a simple answer—yes or no—to the question, should the state intervene. The next Section challenges a fundamental assumption that state intervention can be avoided and then examines the conceptual debates that remain after exposing that assumption.

49. A New York Times editorial quotes Dr. Koop as saying, "If we do not intrude into the life of a child such as this, whose civil rights may be abrogated? The next person may be you." Baby Jane's Defender, N.Y. Times, Nov. 11, 1983, at A30, col. 1. See also Biklen & Ferguson, supra note 4, at 4-5 (criticizing those who would subordinate child's life to family's interests in avoiding burdens of disabled child).

50. See C. Lasch, supra note 45; cf. Neal & Kirp, The Allure of Legalization Reconsidered: The Case of Special Education, 48 LAW & CONTEMP. PROBS., 63, 65-89 (1985) (describing educational relationships as increasingly regulated and due process norms interposed; legalization has costs and expresses distrust of the practices that would otherwise prevail).

51. The attribution to a prior era of all the longings of the present may well be at work here. See generally O. Bettemann, The Good Old Days—They Were Terrible (1974) (using archival materials to expose pain and despair of periods called "the good old days").
II. CHOICES FOR THE STATE

The existence of the competing conceptions of family and state partially explains the heat in debates over state intervention in the family. People may fundamentally disagree about their conceptions; people also may be ambivalent and find themselves hotly disagreeing precisely because they can see the power of the opposing view. The debate concerning the propriety of state intervention remains futile because both sides of the debate rely on the faulty assumption that state intervention can ever be avoided. I maintain instead that some degree of state intervention always exists. The argument is not simply that the state always has power to assess its own power to intervene, although it is worth noting how this latent state power casts a shadow over parental decision making. But expressing more than this latent power, the state always intervenes because it allocates power over the medical care decision, whether it carves out a sphere of parental autonomy or instead permits strangers or state officials to challenge and supplant parental decisions.12

There may be important conceptual differences between and among state decisions (1) to order medical treatment (or forbid it), regardless of what parents or doctors would want; (2) to approve or disapprove medical treatment (or nontreatment) as decided by others; or (3) to assign unreviewable decisionmaking power over the medical decision to others (parents or medical personnel). Such conceptual distinctions do not capture the actual array of choices in the prevailing legal order which assigns the medical treatment decision as an initial matter to the parents or guardians, but reserves to the state the power to review that decision. In essence, then, the current debate focuses on the...
range of meanings that could be contained within position (2) above, even though some spokespeople advocate positions sounding like (1) and (3). If all three options were real possibilities, the state could be more or less directly involved in the activities of ordering, approving, and assigning decisionmaking power, yet these distinctions do not touch the central point here—that the state cannot be neutral as to these allocations and their results.

For example, the state intervenes through child abuse and neglect statutes and enforcement mechanisms in every state, even with regard to parents who the state never prosecutes, simply by enacting the laws. Like general criminal statutes that constitute state regulation even for the law-abiding, such standards of parental duty perpetually subject parents to review by state officials and induce parents to internalize norms established by the state. The state also controls parents through rules obliging medical professionals who regularly deal with children to report to the state evidence of possible abuse or neglect of child patients by their parents or others. Further, all states interpose public norms about aspects of child care by requiring attendance at school and regulating work opportunities. The state licenses marriage, establishes child support obligations, and imposes sanctions on parents whose children fail to attend school or run afoul of other laws. Finally, many legal rules sup-


55. On marriage regulations, see H. Clark, Law of Domestic Relations 35-36 (1968). Blackstone described the parental duty of child support as longstanding even when he wrote. 1 W. Blackstone, Commentaries on the Laws of England 446-48. Recent federal efforts have strengthened and complicated state statutes obliging child support. See, e.g., Federal-state "Intercept" program, 9 Fam. L. Rep. 2257 (1983); see also J. Casetty, The Parental Child-Support Obligation (1983) (describing child support laws and enforcement practices); H. Clark, supra, at 187-89 (describing state statutes). Sanctions for parents whose children fail to attend school were at issue in Wisconsin v. Yoder, 406 U.S. 205 (1972). Although the parents in that case were excused, the law itself remained in force. For careful discussions of power relationships among parents, child, and state, see
port a conception of parents as agents of the state, rather than vice versa, concerning matters of child care. 56

Rather than marking a boundary limiting state intervention in the family, then, laws governing the family define the kind of substantive and procedural governance of the family that the state undertakes. Consequently, problems such as those in Baby Jane Doe's case present not questions concerning when the state should intervene, but instead substantive questions about which decisions regarding the child the state should approve, as well as procedural questions about which decisionmakers the state should permit, monitor, or supersede.

Some may claim that the term "state intervention" means, in popular debate, excessive or overt governmental actions supplanting the decisions or freedoms of private persons. Such definitions, however, are deficient because they build into the very term the issues needing exposure to debate: what issues of state power are excessive, and when does a particular state allocation of power stir controversy rather than fade into routine? Accordingly, this article will no longer use the phrase "state intervention" except with reference to the debate itself, and instead will focus on the specific kinds of choices the state must make.

Recasting the issues in this way does not resolve them, but it does lift the controversy from the wooden and ambiguous state intervention debate, with its false dichotomy of intervention versus nonintervention. When one acknowledges the state's substantive and procedural choices, the difficulty of those choices also comes into view. Substantive choices concern what kinds of medical care decisions one should make given competing ideas about life, death, and human relationships. Procedural choices concern who should make those decisions, what forums for challenge should exist, and who should resolve disagreements among the decisionmakers. These issues of substantive and procedural choices present complicated alternatives and the potential for endless controversy. Indeed, the same tendency to oversimplify the problem into dichotomous choices reappears in discussions of the substantive and procedural choices. Yet once again complex and multiple variations more accurately describe the choices for the state, rather than polarized, either/or alternatives. This Section explores these choices.


56. See Kleinfeld, supra note 55.
A. Substantive Choices

Substantive choices concern which results the state should favor, whether by approving certain parental decisions or ordering certain results directly. For Baby Jane Doe, one crucial substantive option did not exist. Her parents could not decide to transform the infant into a child who did not have multiple disorders. No medical treatment now known could remedy the diminishment of her cerebral cortex and the paralysis of her lower body. Available options included surgically sealing the spinal column to guard against infections and repeatedly draining the fluid from her brain. Baby Doe's parents, instead, initially elected antibiotic and nutritional care. After a short time, they agreed to surgery to remove excess fluid from the infant's brain. As a medical prognosis, the infant's life expectancy without surgery was two years, and with surgery many more years.

1. Contrasting medical treatment principles—Representing a choice in results, these different medical options match competing substantive principles for medical treatment decisions. Electing surgery and lengthening the infant's life expectancy relates to a "right to life" medical treatment principle. In an absolute version, this principle demands that Baby Jane Doe's parents should decide to undertake all measures to prolong and

57. The fact that she has these conditions has not been disputed, but there has been dispute about the extent of disability posed by her microcephaly and hydrocephaly, see Baer, supra note 7, at 35, 36-37. This indicates the depth of controversy in such disputes; here the controversy included the meaning of the medical diagnosis in terms of cognitive deficits and life opportunities.

58. Her spinal opening closed by itself over time, and a shunt operation to drain fluid was done when Baby Jane Doe was five months old. See Chicago Sun-Times, Oct. 11, 1984, at 42, col. 1.

59. Id.

60. At trial, the parents' doctors testified that the life expectancy for the child if surgery took place could not be estimated, but conceded when asked that it could be twenty years. Some commentators reported twenty years as the maximum, although it would be plausible to construe this answer as a minimum or average. Tedeschi, Infanticide and Its Apologists, COMMENTARY, Nov. 1984, at 31, 32.

61. See R. Weir, Selective Nontreatment of Handicapped Newborns (1984), at 60-86 (comparing positions of physicians); see also Chambers, Baby Doe: Hard Case For Parents and Courts, N.Y. Times, Jan. 8, 1984, § 21, at 1, col. 1 (Long Island Weekly ed.) (describing right-to-life advocates); see generally Frankena, The Ethics of Respect for Life, in Ethical Principles for Social Policy 1, 2-6 (J. Howie ed. 1983) (articulating contrasting philosophic positions on respect for human life). Parents choosing surgery may experience their choice not as an expression of principle, but instead as an effort to secure any available help for their offspring; acting in this way nonetheless expresses a "right to life" notion in the very effort to protect and promote the infant's life.
preserve the disabled infant's life because preserving and sustaining life represents the primary human commitment. Otherwise, no person's life stands secure from devaluation by others.62

As Surgeon General Koop and others have maintained, opting for the conservative course in this case—choosing not to lengthen the infant's life expectancy—draws from the contrasting principle of "quality of life."63 Varied formulations of this principle exist.64 In general, it postulates that medical personnel should undertake life-prolonging measures only if the infant could know love, form relationships, or partake of other dimensions of human society that give human life a quality worth living.65 The quality of life position may support limited treatment to alleviate pain, withdrawal of life sustaining treatment, or even active acts of euthanasia. In any version, however, the position diverges from the right to life position by rejecting life as the most important human value. Thus, the state faces a substantive choice, whether it acts or approves the actions of others. Should there be efforts to preserve the child's life, whatever the quality of that life, or instead medical treatment based on the predicted quality of the child's life?66


63. R. WEIR, supra note 61, at 60-86. Weir also notes the distinction between disease-oriented care—which makes prolonging life the only goal and death the measure of failure—and person-oriented care—which "places primary emphasis on the quality of life that is to be lived." Id. at 63; see also 42 Cong. Q. 1796 (1984) (presenting American Medical Association's opposition to compromise on Federal Child Abuse Amendments because of failure to consider quality of life for severely handicapped newborns).

64. See Smith, Life and Death Decisions in the Nursery: Standards and Procedures for Withholding Lifesaving Treatment from Infants, 27 N.Y.L. SCH. L. REV. 1125, 1160-64 (1982) (distinguishing decisions to prefer quality over length of life from decisions to end life because it is not worth living).

65. Cf. Frankena, supra note 61, at 34 ("Mere life, whether that of a vegetable, animal, or human organism, has no moral sanctity as such, though it may have aesthetic and other kinds of nonmoral value, and may be a necessary condition of consciousness, rationality, or morality;" life acquires moral sanctity when "it is a condition of something more" like consciousness.).

66. Another substantive principle commonly mentioned in this context is the venerable medical ethic of "do no harm." In the context of disabled newborns, this principle can be cited to support both the right to life and quality of life positions, for some would claim that neglecting any possible measures to prolong life is to do harm, while others would maintain that prolonging life may itself cause harm. R. WEIR, supra note 61, at 86. One expert acknowledges that the desire to do no harm makes him uncomfortable if it means withholding treatment from a child whose parents and doctors have decided to let die, because the result could be a slow and lingering death. Therefore, this physician finds himself at times "in the schizophrenic position of advocating either active euthanasia or vigorous treatment." J. FREEMAN, PRACTICAL MANAGÉMENT OF MENIGOMYELOCELE 24 (1974).
Advocates of both principles of medical treatment point to established legal doctrines for support. Typical state child abuse and neglect statutes oblige parents to provide medical care for their children. Statutory language casting this obligation in terms of the “best interests of the child” supports either the right to life or the quality of life principle. Yet the right to life principle can draw more directly for support on general criminal statutes against murder and specific statutes punishing infanticide or requiring medical care regardless of an infant’s disabilities. At the same time, the quality of life principle gains support from adults’ right to refuse treatment. The quality of life position also draws upon the wrongful life and wrongful birth doctrines. Under those doctrines, parents have argued successfully that incorrect medical advice about genetic risks or other predictable sources of an infant’s disability warrants tort damages based on the diminished quality of the child’s life and the burdens to the attending family.

2. Inherent problems of the medical treatment principles—Conceptual and practical problems abound with both principles. Initially, the right to life position appears to demand maximal treatment, which could produce, at the extreme, the absurd result of requiring heroic efforts to keep everyone alive forever by use of technological life supports. Yet even this interpretation


70. See Fost, Proxy Consent for Seriously Ill Newborns, in NO RUSH TO JUDGMENT: ESSAYS ON MEDICAL ETHICS 16 (D. Smith ed. 1978).
grants too much. The right to life position is more deeply flawed in its inability to guide particular medical care decisions.

Given the variety of treatments, each with risks and benefits, that medical professionals can recommend in a given case with the aim of preserving life, the right to life position provides no selection criteria. Medical experts disagree about what constitutes "standard medical practice" in the care of newborns with serious handicaps. For example, parents may have a choice of surgery or no surgery; a choice from among surgical techniques; a choice in the timing of the surgery or the selection of the surgical team. Additionally, choices about the use of experimental or nonconventional treatments may arise. The principle of "right to life" does not select from among these choices. A given treatment could hold both great promise and great risk; an alternative could hold less promise and less risk. Either choice arguably could advance or defeat the simple goal of preserving life.

Another set of problems for the right to life position arises in determining whether a decision not to act—an omission of possible medical care—violates the right to life principle. Societies historically assigned different consequences to acts of direct killing and more passive conduct producing the death of a child.

This problem raises the classic act-omission distinction drawn in criminal and tort law. In those contexts, an omission becomes culpable as an act where specified duties or obligations to act

---

71. R. Weir, supra note 61, at 59-61; Smith, supra note 64, at 1153-59.
73. The right to life position also rests on a debatable assumption about the sanctity of human forms, regardless of their stage of development or any other characteristic. Medical experts pose one kind of criticism of this assumption by pointing to what they claim are vast differences in the nature of the life presented by individuals at different stages. One expert concludes that it is "as inappropriate to consider the neonate a small child as it is to consider the child a small adult." R. Weir, supra note 61, at 31 (quoting Sheldon Kornones, director of newborn center at City of Memphis Hospital).
74. R. Weir, supra note 61, at 25 (discussing ancient Romans and Renaissance Italians; both societies permitted passive child destruction); see also Smith, supra note 64, at 1166-68 (1982) (comparing active and passive euthanasia as artificial distinctions).
exist, and where the omission causes harm.\textsuperscript{75} The right to life position, however, offers little guidance to establish what constitutes a culpable omission by a parent. A culpable omission depends on a failure to fulfill a well-understood duty, but the existence of such a duty is the unanswered question concerning a disabled infant, and the basis and content for such a duty raise additional unanswered questions. Such a duty could only come from a community consensus specifying what constitutes a culpable omission. Yet this is precisely what is now missing, especially given the range of possible medical treatments. If right to life advocates wish to articulate a duty for parents always to undertake any measures that could promote the life chances for the disabled newborn, they still have a problem in articulating the boundaries of this duty.\textsuperscript{76}

For example, the right to life principle leaves unanswered the problem of "futile" medical treatment, even though proponents of the principle invoke futility as its limit.\textsuperscript{77} Would the right to


\textsuperscript{76} See \textit{Survey Shows Split on Issue of Treating Deformed Infants}, N.Y. Times, June 3, 1983, at A14, col. 1 (reporting Gallup poll showing the public evenly divided on whether a severely handicapped newborn should be allowed to die); \textit{see also Committee on Bioethics, Treatment of Critically Ill Newborns}, 72 \textit{Pediatrics} 565 (1983) (finding no consensus on treatment); \textit{cf.} Regan, \textit{Rewriting Roe v. Wade}, 77 \textit{Mich. L. Rev.} 1569, 1573-79 (1979) (discussing good samaritan law). Difficulties arise from the view that there is a duty to act where life is at stake because it could also be argued that failing to authorize medical treatment for a disabled newborn would not clearly cause harm. Refusing to authorize surgery that would extend an infant's life may cause a shorter life for that person. But the cause may equally be assigned to the infant's disabilities at birth. This alternative causal argument may, however, prove too much; any infant at birth is utterly dependent upon others for nutrition and care, and omissions by parents to meet these needs are commonly treated as culpable omissions. What may distinguish a failure to meet nutritional needs is precisely how obvious this omission appears in light of clear parental duties. As public and professional opinions about children's needs and medical necessity crystallize with a majority view, parental obligations with accompanying culpable omissions can be articulated in terms of the outer limits of individual discretion. Although some would argue that such outer limits are reached in parental decisions about surgery for intestinal blockage in a Down's syndrome child, continuing controversy over that kind of decision shows that no prevailing view has yet emerged. \textit{See Summary and Analysis}, 7 \textit{Mental Disability L. Rep.} 213, 217-18 (May-June 1983) (reporting that President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research would direct surgery, but variety of medical and parental opinions remain); \textit{see also} Gustafson, \textit{Mongolism, Parental Desires, and the Right to Life}, 16 \textit{Persp. in Biology & Med.} 529-30 (1973). In a sense, the debate over medical care for handicapped newborns expresses the search for new consensus in the face of shifting technological and moral landscapes. \textit{Cf.} G. Gilmore, \textit{The Death of Contract} (1974) (describing periods of clarity and chaos in law). \textit{See also infra} text accompanying notes 167-68.

\textsuperscript{77} The recent amendments to the federal child abuse statute redefine child abuse and neglect for purposes of the statute to include "the withholding of medically indicated treatment" from disabled infants with life-threatening conditions: except if the
life principle require medical treatment where medical experts believe the effort would prove futile or where the patient would die soon regardless of treatment? Determining the meaning of "futility," of course, is the problem.

As raised by those who articulate the right to life position, "futility" signifies the condition of a "dying" infant or an infant whose medical condition would remain unameliorated after medical treatment. How would this meaning of futility apply

baby is "chronically and irreversibly comatose;" or if "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 "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 inhuman." Pub. L. No. 98-457, § 121(3), 98 Stat. 1749, 1752 (1984) (amending 42 U.S.C. § 5102). Thus, Congress acknowledged the need for lines drawn between infants for whom medical treatment is worthwhile and those for whom it is not. The line-drawing problem itself is not resolved by the statutory language, although its terms importantly frame decisions with a focus on futility and inhumanity.

In interpreting these concerns, the Department of Health and Human Services issued regulations under the amendments that acknowledge the Congressional commitment to balance "the need for an effective program and the need to prevent unreasonable governmental intervention." 50 Fed. Reg. 14,880 (1985). The Department's interpretive guidelines, not intended to be binding rules, id., eliminate the language of a proposed interpretation that referred "to situations where death is imminent and treatment will do no more than postpone the act of dying." Id. at 14,890. The Department explained that it still interprets the futility or "merely prolong dying" exception to the child abuse amendment's requirements not to apply to instances "where treatment will not totally correct a medical condition but will give a patient many years of life." Id. at 14,891. In other words, the Department interprets the federal definition of child abuse and neglect to encompass the withholding of medical treatment from handicapped newborns who could gain many years of life from the medical treatment, even if that treatment would not totally correct the medical condition. This gives more scope to the futility exception than at least some interpretations of the proposed regulations. There remains considerable ambiguity in the final interpretation, which places renewed importance on the judgments of medical professionals about "the degree of inevitability of death, the probable effect of any potential treatments, the projected time period within which death will probably occur, and other pertinent factors." Id. The meaning of "reasonable medical judgment" in this context is the same in the amendments as in the regulation, see id. at 14,882, 14,888 (defining term to mean "a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved."). But this term, and the meaning of "treatment," will be subject to continuing debate. See id. at 14,890 (reviewing contrasting interpretations of treatment and reasonable medical judgment). The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recently acknowledged the lack of both certainty and knowledge within the medical profession about infants born prematurely, and/or with congenital defects and handicaps. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 198, 220 (1983).

78. See Longino, Withholding Treatment from Defective Newborns: Who Decides, and on What Criteria?, 31 U. KAN. L. REV. 377, 398-99 (1983) (arguing that the medical feasibility approach denies treatment where death is imminent even with treatment, or when treatment cannot restore consciousness); cf. R. Weir, supra note 61, at 146 (es-
to a low-birth weight, premature infant who cannot breathe or pump her own blood without assistance? Pulmonary and circulatory devices temporarily perform these functions for her, but no prospect of future independence from the machines exists for the infant. Using the machines may prolong her life for days or even weeks. Add to this situation the risk that the infant's undeveloped lungs and heart cannot long sustain life functions even with assistance, and indeed may rupture with the exertion. If the right to life principle requires treatment at this point, the meaning of the term "life" may be at issue, not the meaning of futility. If the principle does not direct unquestioning use of all medical devices, then a line-drawing problem must arise under this principle as well as under the quality of life principle. Indeed, the two principles merge in this respect, even though advocates of each may see only antagonism.

Similarly, the right to life principle has been used in efforts to prevent discrimination on the basis of handicap; yet the results preserve rather than resolve the issue of when treatment must be authorized for the disabled infant. As Norman Fost analyzed the situation, "[w]e withhold dialysis from an anencephalic infant girl precisely because she is so handicapped that she cannot experience any benefit from the treatment." Here the handicap itself supplies the reason for discriminatory nontreatment (posing a position favoring treatment of all "nondying" infants).

79. See R. Weir, supra note 61, at 52 (case study); id. at 140 (discussing Custody of a Minor, 385 Mass. 697, 714, 434 N.E.2d 601, 610 (1982) and issue of prolonged or increased suffering—competing with sheer life as value); for different estimates by different people of same situation, see Tedeschi, supra note 60, contesting characterization of Baby Jane Doe's medical situation.

80. In addition, the right to life position contains no intrinsic reason to value human life over other forms of life. See generally Singer, Ten Years of Animal Liberation, N.Y. Rev. of Books, Jan. 17, 1985, at 46 (reviewing emerging theories of equal rights for animals based on inherent value or equal interests of all living creatures).


ment. In this instance, an assessment of futility stems from the fact of the handicap, making a rule against discrimination on the basis of handicap less than useful as a guide for treatment decisions.

Problems beset the quality of life position as well. Most importantly, it affords at best an uncertain guide about what constitutes a quality of life worth preserving. The quality of life position corresponds to arguments favoring euthanasia, sought by people who anticipate their own degenerative prognosis and desire to end their lives as their lives become, in their own eyes, no longer worth living. In instances where the patient has already become comatose or otherwise incapable of deciding his or her own treatment, family members may choose euthanasia based on what they know about the patient’s desires and values. Adherence to the values of the patient continues to guide the medical treatment even in such circumstances. The self-determination theme of this euthanasia position obviously cannot govern cases involving a disabled newborn. Other people’s assessments of that infant’s potential quality of life will always control. Other people may crudely misjudge the effect of handicaps and grossly undervalue the life of a handicapped person. Or they may romanticize life and underestimate the deprivations imposed by the handicap as experienced by the handicapped infant. Even if some agreement could be reached regarding what quality of life should mean, most imaginable meanings—some measure of consciousness, ability to communicate, or to experience joy or relatedness—involve the internal world of the infant and of the ma-

85. See supra note 68 and accompanying text.
87. Sondra Diamond, who has cerebral palsy, attended college, despite the prediction by doctors that there was little or no hope she would achieve meaningful humanhood; she had to fight for medical treatment when she suffered burns in her twenties because doctors believed treatment was not worthwhile as she could not lead a normal life. She herself concluded, “I do not believe that any human being does not deserve the opportunity to live.” “I Am Not What You See” A Film Dialogue Between Sondra Diamond and Roy Bonisteel, reprinted in J. Areen, P. King, S. Goldberg & A. Capron, Law, Science and Medicine 1199, 1202 (1984); Hentoff, The Awful Privacy of Baby Doe, supra note 4, at 57-58. See generally Riga, Privacy and the Right to Die, 26 Cath. L. Rev. 113-15 (1981) (noting undervaluation of life and conflicts of interests in proxy decisions); Robertson, Involuntary Euthanasia of Defective Newborns: A Legal Analysis, 27 Stan. L. Rev. 213, 254 (1975) (“Life, and life alone, whatever its limitations, might be sufficient worth” to a disabled child).
ture person that infant will become, an internal world that others cannot know.

Additional ambiguities arise over whether parents should prolong an infant's life if some possibility exists for achieving the requisite quality of life in the future. Such ambiguities acquire considerable importance in light of historical discrimination against and underestimation of disabled people. Reform efforts and increasing medical knowledge have in the past changed the social meaning of disabilities. Notably, Down's syndrome once spelled institutionalization based on very low estimates of mental and self-care capabilities, while more recent assessments of Down's syndrome urge community care and predict varying degrees of self-sufficiency. Today, society widely believes that a Down's syndrome individual can experience and generate considerable love and joy. This transformation reflects both medical advances and advocacy activity designed to change public attitudes.

Future political and scientific efforts might elevate the quality of life assessments for people now considered severely disabled. Changes in community attitudes and activities themselves could markedly affect the quality of life for the disabled person. The quality of life for a wheelchair-bound person, for example, depends greatly on how disabling the social and physical environment makes that person. As Norman Fost has written, "if buildings had ramps, if colleges would not exclude them from dormitories . . . and if airlines would not require them to be accompanied by adult companions, many such individuals would not see themselves as significantly handicapped." If changes in the physical environment can bring about such significant changes in the social meaning of handicaps, the handicap itself does not reside solely in the handicapped person, but instead in the relationships between that person and the community. These relationships can change, and also can change to some ex-

88. See generally Smith, Notes on the History of Childhood, HARV. MAG., July-Aug. 1984, at 64A, 64B-64C (describing the historical destruction of sick and crippled children).

89. AN ALTERNATIVE TEXTBOOK IN SPECIAL EDUCATION (1977) (describing research and political action to challenge socially constructed category of mental retardation); cf. M. MACDONALD, MYSTICAL BEDLAM: MADNESS, ANXIETY AND HEALING IN SEVENTEENTH-CENTURY ENGLAND (1981) (examining shifting conceptions of mental illness).

90. Fost, How Decisions are Made: A Physician's View, in SWINYARD, supra note 67, at 224. How the handicapped individuals see themselves is interdependent with how others see them, and how others construct their shared environment. See Minow, Bilingual and Special Education: The Dilemma of Difference, 48 LAW & CONTEMP. PROBS. 157, 204-06 (1985).
tent the effect of that handicap in the handicapped person's daily life. This understanding itself depends on a conception of the meaning of the handicap as an issue for people other than the handicapped person. If we conceive of the mobility problem for someone in a wheelchair as not simply her problem, but as a problem for others who may be deprived of her presence, we could find it important to devise new options, like equipping buildings with ramps and developing buses that can accommodate her. Her quality of life, in this sense, is mutable because it depends in significant ways on her relationships with others, and those relationships can change when others see her quality of life as an issue for them. Being bound to a wheelchair may seem less disabling than some other handicaps, like mental deficiencies. But recognizing the way social attitudes construct the meaning of disabilities holds promise for possible changes in the quality of daily life for mentally disabled persons as well as for the physically disabled.

In the meantime, this mutability of the meaning of particular handicaps offers reason to doubt assertions that disabled people inevitably suffer from a lesser quality of life and greater unhappiness. Indeed, asserted concern for the quality of life may be used to justify confining handicapped persons to a stigmatized status and depriving them of opportunities to become more than others expected. The quality of life position thus runs great risks of preserving old assumptions about the meaning of various disabilities. Parents or doctors who act on outdated assumptions about the meanings of particular disabilities should be challenged, and yet there remains no guarantee that the child-protective agencies or courts presiding over such challenges have any more reliable assumptions to guide their decisions. Continual process of research and advocacy could challenge old assumptions and also guard against idealized misconceptions over-

91. See Zachary, The Neonatal Surgeon, 2 Brr. Med. J. 869 (1976) (“extreme disability is not synonymous with unhappiness, and we are only at the beginning of finding ways of developing the capabilities of these patients to the maximum”).

92. Taking this point a step further, nothing within the quality of life position offers a line against unlimited, indiscriminate termination of the lives of nonperfect infants. R. Weir, supra note 61, at 181. For this reason, Weir recommends objective standards for the treatment decision that use diagnostic categories, relative to the status of medical technology available at a particular time and place. Id. at 240-41. A drawback to this approach is its tendency to rigidify the treatment decision based on existing practices, prevailing conceptions of given disabilities, and available technology, rather than subjecting these very conventions to criticism. Perhaps the risks of perpetuating stereotypes and underassessments of the quality of life ahead for infants with a range of disabilities could be reduced by making such diagnostic categories an issue for public debate. See infra text accompanying notes 185-87.
estimating the life chances for particular severely disabled newborns. In what could well be painful confrontations, parents and their doctors could be challenged with the best available information about the meaning of the particular disabilities or deformities manifested in their child. Hospitals could help the broader medical community and advocacy groups to disseminate new information about the meaning and potential meanings of varied medical prognoses. With new information, predictions about future medical advances could push a quality of life assessment toward a more positive assessment and support more efforts to preserve a severely disabled infant’s life even under a quality of life principle. A commitment to guard against mistaken underestimations of the potential life experiences for handicapped persons would also move the quality of life assessment toward more aggressive medical treatment. As a result, decisions under this principle may well come to resemble decisions made according to the right to life view.

The quality of life assessment would increasingly find value where it had been underestimated, even where prevalent assumptions deem the disabilities so severe that the fact of life alone supplies the core meaning to its “quality.” Similarly, desires to avoid futile treatments could make the right to life position converge with the quality of life view. Efforts to weigh the benefits and costs of treatment will occupy the assessment of futility, much as they would in an analysis of the individual’s potential quality of life. Nonetheless, neither position would dictate a result in any difficult case, so ambiguity and controversy remain trapped within each position.

Further, the quality of life position blurs the question of whose life is relevant to the medical care determination: the infant’s or other members of the family? The quality of a family’s life may directly or indirectly enter into the calculus of the quality of the child’s life. Moreover, the potential quality of life for

93. It is undoubtedly with this in mind that Surgeon General Koop has called for the creation of comprehensive information services to make available to parents of handicapped newborns (1) information about competent diagnostic services; (2) a list of governmental and private agencies able to help parent and child; and (3) names of parents “with similar situations who have managed the problem successfully.” Koop, The Handicapped Child and His Family, 48 LINACRE Q., Feb. 1981, at 23, 29, quoted in R. WEIR, supra note 61, at 83. Given his commitment to the right to life position, however, Koop does not include in this proposal information about parents who have chosen not to authorize aggressive medical treatment, or who have not been pleased with the results of such treatment. A full exchange of information should include these sources as well.

94. See also Longino, supra note 78, at 389 (noting that the family’s interests are seldom discussed expressly but courts may tacitly rely on them). Compare R. WEIR, supra note 61, at 78 (discussing Raymond Duff, who notes that “families need to be
the child may turn largely upon the opportunities that the parents or custodians grant to that child in terms of the quality of care and quality of love that they offer. The quality of life position obscures how much the infant’s relationships to others enter into the calculus; yet the relevance of those others to the decision itself deserves debate. Should the child’s medical treatment turn on the willingness or unwillingness of her or his parents to provide ongoing care and love? Such a result seems to burden the child with an accident of birth beyond the disability. The potential availability of foster or adoptive parents, willing to care for a disabled child, could alter a quality of life assessment made with the initial assumption that the biological parents or institutions constitute the only relevant caretakers. The quality of life position thus becomes more complicated and more contestable upon exposing its assumptions concerning the range of possible caretakers for the child.

Both the right to life and quality of life positions rely on established legal doctrines and yet both also give rise to conceptual and practical problems. The apparent certainty of the right to life position gives way under scrutiny to a more difficult set of assessments about the exact duties of parents and doctors in particular circumstances, and about the meanings of futility, dying, and life for specific infants born with severe disabilities. The quality of life position initially seems to offer protection for autonomous choice-making, but who should be that decisionmaker where the medical choice concerns a disabled newborn poses a problem unanswered by the quality of life position itself. Moreover, the interdependence between any infant and the adults in his or her life significantly affects the quality of each of their lives. This interdependence is, if anything, even more pronounced with a handicapped person whose relationships with other people critically affect the opportunities and experiences that will or will not become available. The quality of life principle spared the chronic sorrow of caring for infants with little or no possibility for meaningful lives with id. at 81 (Surgeon General Koop “thinks that physicians who engage in selective nontreatment of infants often do so primarily to prevent parents from having burdens they do not want to bear”).

95. Shaw, Conditions in Newborns that Pose Special Problems, 11 CONTEMP. SURGERY, Oct. 1977, at 51 (arguing that assessment of the potential quality of life of an infant with Down’s syndrome depends on home life with parents as well as the child’s mental and physical abilities).

96. In contrast, if the child’s likely destination is a state institution, the quality of life would be predictably low—and yet this has less to do with the child than with the resources society is unwilling to devote to him or her. See infra text accompanying note 170 (discussing institutions like Willowbrook).
ple is not only highly ambiguous, it also obscures the centrality of other questions about who will become involved with the disabled infant, and how.

Both the right to life and quality of life principles also share the tendency of legal and philosophical reasoning to approach difficult problems with abstract standards, and to couch actual conflicts in terms of conflicting rights. The right to life position on its face fits this description. It translates these highly complicated, emotionally charged medical care determinations as a conflict between the right to life and other rights, like parental rights. And it resolves this conflict with reference to an explicit hierarchy of rights: the right to life supersedes all others. The quality of life position is quite similar in its reliance on abstractions translating the complicated real situation into an ideal, claimed to trump others. A serious drawback to approaching problems in the world with abstract principles is their tendency to obscure the very ambiguity of those problems, and the complex human relationships implicated in both the problems and their solutions. The abstract principles carry an illusion of uncontroverted answers and empower their advocates to treat opponents as wrong, even though aspects of different positions may be simultaneously powerful and compelling.

Perhaps a more serious difficulty arises when competing, abstract standards become platforms for lofty and impassioned argument, removed from the particular case and invigorated by emotional commitments symbolized by the abstract standards themselves. Poised on their separate platforms, contending debators are unlikely to persuade each other or glimpse how much they have in common. This description may fit the emerging debate between advocates of the right to life and of quality of life in controversies like Baby Jane Doe's. This pattern already fits the debate in the related area of abortion; examining that area could shed light on the handicapped newborn issues for the future.

3. The right to life principle and the quality of life principle in the abortion controversy— The right to life and quality of life positions share historic roles in the related, yet distinct controversy over abortion. The dichotomous quality of the two positions appears even more stark there. The abortion debate

97. One aim of this analysis is to show how seemingly dichotomous conceptions, such as the right to life versus the quality of life and state intervention versus nonintervention, obscure how each side of the dichotomy merges into the other, through shared assumptions or shared problems. Once a focus for political debate, the dichotomous conception remains rigid as a vehicle for expression of opposing groups and avenues for
also exposes the problems with each principle while suggesting how the appeal of the two principles varies according to the type of dispute in which the principles clash. As in the handicapped infant context, the “right to life” argument raised in the abortion context stakes out an absolute position on life and leaves to opponents the more uncertain and controverted claims about quality of life. The quality of life argument, couched as the “right to choose” claim about abortion, stakes out an absolute position on private freedom that leaves the more uncertain claims about state intervention for its opponents. The quality of life position in both contexts expresses belief in the capacity and right of people to plan their lives.

rapprochement diminish, as the abortion debate exemplifies. Each side stereotypes the other, and also forces disagreements into crude oppositions. Geertz, Distinguished Lecture: Anti Anti-Relativism, 86 AM. ANTHROPOLOGIST 263, 263-64 (1984) (criticizing view that anti-anti-abortion means pro-abortion rather than pro-choice).

98. The Supreme Court’s decisions on the subject of abortion have struck uneasy compromises, first by according different decisional power to the pregnant woman and her doctor in relation to the stage of pregnancy and notions of fetal viability, see Roe v. Wade, 410 U.S. 113 (1973), and next by according the power to choose an abortion only to women who can afford it without state assistance, Harris v. McRae, 448 U.S. 297 (1980); Maher v. Roe, 432 U.S. 464 (1977). These compromises grow increasingly unstable as new technologies alter the timing and meaning of fetal viability; see King, The Juridical Status of the Fetus: A Proposal for Legal Protection of the Unborn, 77 MICH. L. REV. 1647 (1979); R. ARDITT, R. KLEIN & S. MINDEN, TEST-TUBE WOMEN: WHAT FUTURE FOR MOTHERHOOD? (1984) (estimating effects of new reproductive technologies), and as the economic discrimination in Maher undergoes criticism; see L. TRIBE, AMERICAN CONSTITUTIONAL LAW 933-34 n.77 (1978). The abortion controversy in the future may well emerge in a new form, connecting the issues of new reproductive technologies, like artificial wombs, women’s freedom from unwanted pregnancies, and the demand for babies by parents unable to bear their own. These new options may allow the legal issues to shake loose from unstable compromises between dichotomous right to life/right to choose debates. The legal debate could focus instead on (1) the rights a woman would have to avoid carrying a fetus for nine months by giving it over to a substitute mother—real or artificial; (2) the rights the future child would have to a loving home if someone decides to complete its fetal development outside its mother’s womb; and (3) the rights of adults who want to be parents to have children produced through new reproductive technologies. See HEW Support of Human In Vitro Fertilization and Embryo Transfer, 44 Fed. Reg. 35,055 (1979) (responding to fears about effects of in vitro technology on family rights and privacy); King, supra (discussing embryo transfer).

99. The “right to life” and “right to choose” positions rest on different conceptions of the problem, and perhaps different world views altogether. See K. LUKER, supra note 40, at 158-91 (describing world-views of activists on both sides of abortion debate). But see Addelson, Baby-Killers and Fetus Fetishists: Review of Abortion and the Politics of Motherhood, 2 WOMEN’S REV. BOOKS, Nov. 1984, at 14, 15 (arguing that Luker fails to uncover the complexity of coalitions within each side of abortion debate, and offering the fact that “each side includes some supporters who are closer to the other side’s supporters on nearly every issue but that of abortion”).

The Baby Jane Doe case draws the crossfire in the battle already raging on abortion. Many “right to life” activists spoke out for state intervention to help Baby Doe, and the lawyer who initiated the lawsuit against the infant’s parents had previously initiated legal action on behalf of fetuses to halt abortions. See supra note 9. In addition, the Doe
Despite apparent symmetry in the arguments available in the two contexts, the quality of life and right to life positions take on different casts with the different applications. The quality of life principle emphasizes free choice in the abortion context for the woman who seeks control over her life while the quality of life concern focuses on the life of the handicapped newborn in the medical treatment context. Although both versions express the belief that people can and should plan and control what happens in their lives, the argument for the pregnant woman's right to choose an abortion draws importantly on claims that women have not in the past had power over important decisions in their lives, and especially deserve power over decisions affecting their own bodies. The analogous claim in the medical treatment context urges autonomy for parents, who historically have had power over important decisions, and may even be suspected of abusing that power. At the same time, analogies to euthanasia for dying adults may support a parental decision to refuse medical treatment for a severely disabled newborn in a way that pro-choice defenses of abortion cannot maintain.

The right to life argument in the abortion context pits the rights of a fetus against the rights of a woman to control her own body while the right to life argument in the medical treatment context raises the rights of an infant against the rights of parents whose burdens, however serious, are not the same as the bodily burden for the woman facing pregnancy. Thus, the very question of whose individual rights and whose quality of life are in jeopardy is put to a contest in the debates over medical treatment for disabled newborns and abortion. Who should be allowed to exercise power over important choices arises as a cen-

---

100. It is also possible that the notion of parental power is founded on illusory historical notions of a golden age of family autonomy and stability, but judicial power has often been used to reinforce parental authority, for whatever reason. Burt, supra note 45, at 331, 333-36.


102. But see C. Gilligan, In a Different Voice 70-104 (1982) (noting that women characterize the abortion decision as a conflict between responsibilities rather than a conflict of rights; a conflict between responsibilities to care for the child and to care for the self). See generally infra text accompanying notes 169-75 (discussing responsibilities of caring for handicapped child).
tral question under both the right to life and quality of life principles, and the contrast between the situation of the pregnant woman and the situation of the parents of the handicapped newborn strikes different people differently. The rhetorical force of the right to life position may appeal to new constituencies in the medical treatment context, such as handicapped rights groups. The powerlessness of the infant may move people who are less moved by the powerlessness of the fetus, in part due to the significance people attribute to the moment of birth in moral status, and in part due to the contrast between the positions of the pregnant woman and the parents of a child who is already born. The abstract principles alone do not determine the line-up in political debates even though they may define the battle lines.

In the context of handicapped newborns, the two substantive positions appear less polarized and rigidly positioned than they do in the abortion debate. Perhaps this reflects the relative length of time occupied by the two policy problems in the crucible of public debate. Rather than following the path of the abortion debate, I suggest that we resist the tendency to polarize the infant care debate into dichotomous substantive positions much as I urge rejection of the polarized version of the state intervention debate. This polarization may be tempting precisely at the moment of a tough decision, when the decisionmaker may feel both moved and repelled by the plight of the infant. Instead we should acknowledge the problems inherent in each side. Yet the substantive debate represents only half of another dichotomous treatment of the problem: the separation between substantive and procedural choices. As the convention goes, when substance confounds, procedure beckons. No panacea, however, lies there either.

B. Procedural Choices

Distinguishing between substance and procedure is a classic

103. See Feldman & Murray, supra note 38 (discussing starvation of Indiana Baby Doe); Mnookin, supra note 67, at 675 (discussing political groups' responses to Baby Doe controversy); cf. R. BURT, TAKING CARE OF STRANGERS 19-20, 46-48 (1979) (describing the power of the powerless in compelling the attitudes and actions of others). The experience of being moved by the infant's powerlessness may, however, engender ambivalence by exposing the adult's power to influence both the quality and the fact of the infant's life. The substantive debate contrasting right to life with quality of life positions fails to expose to view just this problem, which will be explored in section III infra.
legal concern. This dichotomy makes procedure important precisely when the more obviously important substance hits a logjam. When we cannot agree about what to do, it becomes urgent to know—and to control—who will have the final say. Not only will this procedural choice control the outcome of the substantive debate, it may also yield the independently desirable feature of some conclusive decision, or some apparent resolution, whatever its content. Thus, deciding who will decide shifts the debate from ambiguous substantive questions onto a procedural question that one can specifically answer.

For example, the state may grant the infant’s parents an absolute or a qualified power to decide the medical treatment issue, give doctors and hospitals power to make or review the decision, accord public officials, judges, or court-appointed guardians the power to decide, or transfer the authority to treatment committees composed of lay and medical personnel. No neutral resting place exists on the issue of who should decide. One way or another, the state approves or selects the decisionmaker, whether it cedes choice to parents or establishes countervailing decisionmakers and processes for decision. And the state decides whether that decisionmaker’s choice will constitute a final decision or will remain subject to review. If the decision remains subject to review, the state determines who will conduct the review.

This inevitability of public choice imbues a case like Baby Jane Doe’s with the dimensions of classic drama that have long captured public attention: inevitable suffering combined with the possibility that human will may avert disaster.104 Like Greek tragedy, the Baby Jane Doe case presents human suffering to an

104. See W. KAUFMANN, TRAGEDY AND PHILOSOPHY 360-71, 373-76 (1968) (noting that elements of tragedy include great suffering, moral conflict, human intention to reduce suffering but guilt in continuing to inflict it); cf. Cavell, The Avoidance of Love: A Reading of King Lear, in DO WE MEAN WHAT WE SAY 267, 309-10, 317-18 (1976) (discussing the tragic theme of judging a world where good is doomed and injustice may flourish; and human responsibility includes responsibility for fate). Cavell powerfully evokes the experience of a member of the audience who wants to alter what happens on stage but must learn he can do nothing to alter the choices the actors themselves must make: “There is nothing and we know there is nothing we can do. Tragedy is meant to make sense of that condition.” Id. at 330. In a sense, public preoccupation with cases of medical care decisions for handicapped newborns enacts such a drama, where the observer can do nothing and must learn to deal with this without at the same time converting the agonizing choices of the actors into mere entertainment for the audience. See id. at 348; see also infra text accompanying notes 136-44 (discussing legal standing for strangers). Yet, in another sense, the tragedy arises because the very meaning of the handicap could be changed, in some measure, if the observer overcame paralysis and revulsion and treated the handicapped person differently.
audience and suggests that at least one aspect of existence is agony that humans must live through rather than avoid. Rather than turning heated debates into technical ones, the transition from substance to procedure preserves the difficulties in cases like Baby Jane Doe's. This Section explores the state's dilemmas in determining who decides, whether the initial decision is reviewable, and who conducts that review.

1. Who decides?

   a. The distinction between substance and procedure—The move from substance to procedure recapitulates rather than bypasses the inevitability of choice. Moreover, in choosing who should choose, the state must address the difficulties behind both the state intervention debate and the debate between right to life and quality of life advocates. The substantive choice between the child's right to life and the parent's right to choose incorporates a choice between decisionmakers. The state either lets the parents choose, or supervises the parents' choice and supplants it if necessary to attain the desired result, whether drawn from the right to life position or the quality of life position.

   b. Self-determination or proxy decision making—The state's choice from among these alternatives draws back into dis-

105. See W. KAUFMANN, supra note 104, at 373. Guido Calabresi and Philip Bobbitt explore the tragic dimension of social allocation of scarce resources, like artificial kidneys, in G. CALABRESI & P. BOBBITT, TRAGIC CHOICES 21 (1978). In their analysis, the sense of powerlessness to remedy massive problems may be translated into societal support for extraordinary efforts to respond to limited crises. "[T]he United States will spend a million dollars to rescue a single, downed balloonist but will not appropriate a similar sum to provide shore patrols." Id. In the area of medical treatment for handicapped newborns, a similar dynamic could be at work. People feel powerless to solve the general problem of handicaps, and indeed, the problem of assuring every child opportunities for a full and happy life. This sense of powerlessness may translate into pressure for extraordinary measures in a few, widely publicized cases where individual, disabled newborns face medical treatment decisions.

George Eliot's conception of tragedy as the human struggle in spite of grand submission identifies the heroic dimension in choosing resignation before the inevitable; she also links this attitude with a sense of connection with other people. Thus, she reasoned that the individual faces common misfortune best through acceptance, and "imagination actively interested in the lot of mankind generally." 3 GEORGE ELIOT'S LIFE AS RELATED IN HER LETTERS AND JOURNALS 33-34 (1885), quoted in S. GRAVER, GEORGE ELIOT AND COMMUNITY: A STUDY IN SOCIAL THEORY AND FICTIONAL FORM 195 (1984). Here, then, is a conception of tragedy as deepening the sense of human connection rather than human isolation.

106. The current argument includes no one urging state supervision of parental decisions to authorize medical treatment; only decisions declining treatment trigger the demand for state review, even though the opposite is theoretically as plausible. This lack of symmetry in the actual debate strikingly reveals assumptions that parents rather than the state will be inclined to err on the side of nontreatment; it also reveals the political stance of the pro-interventionists as generally aligned with the right to life position.
pute the conceptions of family and state. If controversy arises over which decisionmakers can best approximate self-determination for the infant, the competing pictures of the oppressive family and the oppressive state underlie contrasting preferences for parents or other decisionmakers, just as these competing pictures underlie discussions of state intervention. For instance, a parental decision to forego surgery for the child appears unproblematic if one views the family as a source of love and selflessness. In contrast, if one distrusts the parents, a stranger's decision approved by the state appears more promising as an approximation of the child's self-determination.

But these contrasting conceptions of the family and the state should not obscure the problematic nature of the very notion of a "proxy" decisionmaker. The term "proxy" implies someone who knows the affected person's interests and indeed received decisional power directly from that person, as with proxy voting for corporate shareholders. Yet even in the corporate context, reasons exist to doubt that a shareholder knowingly assigns his voting interest and that the proxy assignment advances the shareholder's interest. In the medical care context, proxy decision making produces several more complications. The term refers to decisions that someone other than the affected party makes under one of two approaches: best interests analysis and substituted judgment. Under substituted judgment, the decisionmaker inquires into what the affected person would choose if he or she could choose. Evidence about the person's prior wants and express or implied direction inform the decisionmaker's judgment.\textsuperscript{107} This effort is fraught with guesswork. The substituted judgment approach claims to operate objectively through efforts to find evidence of the wants and concerns of the patient, but it also searches for the subjectivity of the patient by inquiring into what the patient personally would want, which in turn

\textsuperscript{107.}

In trying to make a decision for a patient who can't decide for himself about lifesustaining treatment, we're after moral informed consent ... It requires the surrogate decision-maker to try to determine what decisions the patient would make if he were able to at the time. This requires intense effort by the surrogate, and the health care team to find out what the patient may have communicated on the subject.

Boisen, Mds, Lawyers Probe Ethical, Legal Issues in Ending Treatment, Am. Med. News, Apr. 6, 1984, at 17, 17 (quoting Frank Marsh); see also City Bank Farmers Trust Co. v. McGowan, 323 U.S. 594, 599 (1945) (substituted judgment should be made acting "upon the same motives and considerations as would have moved" the incompetent). See generally Baron, Medicine and Human Rights: Emerging Substantive Standards and Procedural Protections for Medical Decision-Making within the American Family, in \textit{The Resolution of Family Conflict} 575 (1985).
depends upon who the patient is. It relies on the imaginative effort of the decisionmaker to construct what the patient would want, given what the surrogate knows. At its best, the substituted judgment approach may express concerns and sympathy for the patient, rather than actually divining that person's unknown wishes. Yet whatever the success of efforts by family and friends to imagine the past wants of a now comatose eighty-year old, substituted judgment makes little sense for a newborn who has no history nor prior expressions of wants.

Under the alternative form of proxy decision making—best interests analysis—the decisionmaker determines from an external stance the needs, risks, and benefits to the affected person. This approach also appeals to objectivity, rationality, and consensual assessments of the benefits and detriments of the proposed medical treatment. Best interests analysis addresses the interests, not the desires, of the patient. This decision making about the child's interests must treat the situation hypothetically and removed from the particular circumstances and identity of the infant, although best interests analysis is intended to make that infant's interests paramount over all other interests. Subjective elements may emerge, however, as the particular views of the proxy decisionmaker enter into the best interests calculus.

More importantly, assessment of the child's best interests is also problematic because no one can be certain of another's interests. The Western liberal commitment to individual auton-
omy and self-determination relies on a view that only the self can have the self's interests at heart.¹¹⁶ No way exists to achieve self-determination when one person makes decisions for another; this axiom holds true whether parents or others direct medical treatment or withhold it. Therefore, even a proxy decision grounded in an assessment of the child's best interests disguises any decisionmaker's inability to know what a self-determining infant would choose.¹¹⁷ The best interests analysis remains as problematic as it was before being draped within the folds of a proxy decision.

c. Closeness or distance— No decisionmaker for the infant can act in accord with an infant's self-determination; yet notions of proximity and distance from the infant's self affect the appeal of alternative decisionmakers. Parents appear to have the advantage of closeness, commitment to the child, and perhaps love and attachment through the parent-child relationship. From these sources, the parents may bring persistence and hope to the medical treatment decision, and work to preserve the child's life—or end it, if the child's suffering seems too great. From this

¹¹⁶. See, e.g., J. Rawls, supra note 52, at 136, 142. Individual autonomy, even under this tradition, must be fitted into the social and natural worlds that set some boundaries on individual power, and the very concept of autonomy incorporates these implicit limits. See generally Benjamin, The Oedipal Riddle: Authority, Autonomy, and the New Narcissism, in Authority in America 195, 199-205 (1981) (arguing that autonomy is developed in relation to authority and internalized norms). Thus, autonomy "can refer either to the capacity to govern oneself, which of course is a matter of degree, or (on the analogy to a political state) to the sovereign authority to govern oneself, which is absolute within one's own moral boundaries (one's 'territory,' 'realm,' 'sphere,' or 'business.');" Feinberg, supra note 112, at 97, 114; cf. M. Horwitz, The Transformation of American Law 180-88 (1977) (arguing that the rise of the will theory of contract is linked to formalist notions of objectivity and bounded rather than subjective and equitable notions).

Philosophers also debate the certainty with which anyone may know his or her own interests, Feinberg, supra note 108, at 116-19 (arguing that a person's good may not coincide with person's choices or desires; but person's preferences molded by others); others cast doubt on whether anyone may know even his or her own experiences and perceptions. See S. Kripke, supra note 108, at 60-83; H. Putman, Reason, Truth, and History 71-72 (1982). These two forms of skepticism produce some irony; while some philosophers maintain that no one can understand what goes on in another's mind, others maintain that no one can understand what goes on in his or her own mind without reference to communal enterprises like language. These positions are not, however, inconsistent, in the sense that one can believe that one cannot know what another person knows while also believing that human knowledge is located and framed by the society and culture in which it forms—all larger than any given individual. Cf. Quine, Epistemology Naturalized, in Ontological Relativity and Other Essays 68, 89-90 (1969) (arguing that building blocks of perception may be culturally variable).

vantage point, any decisionmaker other than the parents sits too far removed from both the emotional fabric and actual responsibility in the situation for the state to entrust that decisionmaker with the medical treatment decision.118

Yet many observers cite parents' closeness as a disadvantage, a "conflict of interest," because their life-style and commitments depend on the child's future.119 Parents may worry about the economic and emotional costs of raising a handicapped child. Consequently, their closeness to the child may disadvantage them in determining the child's own interests. Alternatively, parents' closeness to the child could disadvantage them because they may care and love the child too much. Their selfless love for the child, rather than their worries about the burden of the child, may lead them to choose medical treatment to prolong the child's life despite the pain or futility of such measures.120 On the other hand, parents may love the child too much to allow extended medical treatment that continues the infant's pain. In either view, problems of bias, subjectivity, or over-involvement persist. By contrast, decisionmakers other than the parents, such as doctors, guardians appointed by a court, or treatment committees, have the advantage of distance and objectivity. Thus, underlying assumptions about the consequences of parental closeness will guide the state's decision to grant or deny deci-

118. Arguments such as these have supported decisions recognizing the right of parents or guardians to refuse treatment on behalf of another. See Superintendent v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1977); Matter of Quinlan, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976). Alternatively, it could be argued that the state's position bears a resemblance to the parents'. The very state which assigns parents the duty to care for children may then conclude that because of this duty, parents have a conflict of interest when facing a medical care decision. Still another approach would claim that if the state is behind the reinforcement of parental duties—and also holds responsibility for the child if the parents default on their duty—then the state itself is not without interests that could conflict with the child's. In terms of ultimate ignorance about the child's interests, and also ultimate responsibility for the child, the parents and the state are rather similarly situated. See infra text accompanying notes 170-75 (proposing an increase in the state's duties to equate their conflicting interests with the parents').

119. See Capron, The Authority of Others to Decide About Biomedical Interventions With Incompetents, in WHO SPEAKS FOR THE CHILD, supra note 110, at 115, 133; see also supra text accompanying notes 94-96 (noting that the quality of life analysis obscures question of whose quality of life is at issue).

Medical personnel fall subject to the same charges of bias through proximity, especially to the extent that the medical personnel defer to the parents as clients whose wishes should govern.

120. Knowing what kind of pain the infant may experience could prove as difficult as knowing what lies at the end of that pain—salvation or nothingness. The parents' views about the possibilities of an afterlife for the child could influence their decision, which could support claims on a freedom of religion theory for their privilege to decide what should happen to their child.
sional authority to parents.

Like the competing conceptions of the nature of the family and the state, these contrasting assessments of closeness and distance underlie arguments about the choice of decisionmakers for the infant’s medical treatment. Each view of parental closeness and subjectivity parallels a view of the virtues or defects of the distance and objectivity manifested by alternative decisionmakers such as state officials, doctors, or treatment committees. Distance disqualifies a decisionmaker if the closeness of the parents signifies greater responsibility and care. The distance of another decisionmaker appears desirable for those who deem parental closeness disqualifying because parents may care more for their own needs than for the child’s. Regardless of one’s views concerning the relative advantages and disadvantages of closeness to and distance from the child, serious doubts persist about whether someone other than the parents can know the child’s interests.

To the extent that parents suffer from the limitation that one can neither know the interests of anyone but oneself nor achieve self-determination for anyone but oneself, so do state officials, doctors, and treatment committees. To the extent that parents’ roles in the child’s life and attitudes toward the child disqualify them as decisionmakers, the other possible decisionmakers suffer from similarly prejudicial roles and attitudes. The very non-involvement and freedom from continuing responsibility that individual state officials, doctors, or treatment committees enjoy influence their assessments of the child’s future. Ultimately, the state, in selecting a decisionmaker, must determine what proximity to the child and amount of continuing responsibility should qualify or disqualify a decisionmaker. The state will in effect select as decisionmaker parents, who will take into account the difficulties of raising a handicapped child, or decisionmakers other than the parents, who either will fail to consider these difficulties because these are not their problems, or will themselves need to determine whether such issues are concerns relevant to the treatment decision. The evaluation of competing decisionmakers turns, then, on assumptions about the effects of varied relationships to the child, and how these relationships influence perceptions of the child’s interests. These assumptions, in turn, reflect the knotty substantive issues about the medical treatment decision that make procedural solutions appear more feasible. Procedure provides no escape.

In sum, the three sets of dualistic concepts for analyzing “who decides” initially offer structure to the procedural analysis, but
that structure fades under scrutiny. The distinction between process and substance blurs as each procedural option exposes the ongoing substantive dilemmas. The contrast between self-determination and determination by others recurs in formulations of “proxy” decision-making notions even where the patient is incapable of self-determination. And worries about different decisionmaker's closeness to and distance from the child combine with desires for subjectivity and objectivity even while echoing opposing notions of trust in family and state. Little resolution emerges by picking one side of any of these dichotomies. Focusing on a procedural choice revives substantive disputes. Conceding that the patient cannot make the treatment decision leaves the search for the infant's interests untethered; appeals to the infant's expected desires or his or her family's desires are not compelling. Yet seizing on the closeness of the parents as a basis for allowing them to decide for the child can provoke challenges that the parents fear or love too much.

It is possible that each successive characterization may alter the seeming appeal of the opposing sides. An argument cast in terms of process may divert attention from substance, and tap into independent hopes for a legal regime that assures the freedoms of private persons. An argument cast in terms of proxy decision making, in contrast, may soothe objections to intrusions on such freedoms. The proxy notion implies such close connections between the decisionmaker and the person affected by the decision that this exception to the self-determination principle appears relatively unproblematic—even though there is no possible chance of self-determination by the handicapped newborn. And the third formulation, contrasting the closeness and distance of a range of possible substitute decisionmakers, could alter yet again the appeal of competing arguments. Here, suspicions of parents could well become heightened, because parents' proximity to the situation may smack of bias, conflicting interests, and subjectivity, in contrast to the seeming objectivity of the more distant alternative decisionmakers. The alternative formulations of the problem, then, may draw on images and ideas that influence the appeal of one outcome rather than another, even though the same problem could be tackled through each of the other formulations. The sheer choice of characterizations of the problem could then influence the likely result.

Yet the failures of these alternative, dichotomous formulations stem not simply from their conceptual indeterminacy nor from their almost arbitrary influence on the appeal of contrasting outcomes. The more serious defect is that these formulations ob-
secure the ways in which any decision about the child will grow from and express relationships marked by ambivalence. It is not just the parents, but also the doctors and state officials, who have relationships with the infant and who may experience conflicting desires to help and to flee, to identify with the infant and to avoid identification. What happens, then, when decisionmakers turn to resolve particular cases with these less than helpful, dualistic categories of analysis? A case examined in the next Section suggests that the dualities, contrasting objectivity and subjectivity, and procedural and substantive issues, do not yield closure, and that an unusual judge may break their mold and acknowledge his own relationship to the child.

2. Applying dichotomous concepts to procedural choices: the case of Phillip Becker— Each of the tensions described in the last Section appears in another case in which adults contested both the medical care alternatives for a child and the selection of a decisionmaker. Like Baby Jane Doe, Phillip Becker's case also captured public attention. Shortly after his birth, his parents discovered that Phillip had Down's Syndrome and institutionalized him. Phillip was also born with a heart defect. His institutional caretakers and doctors repeatedly sought, without success, consent from his parents for medical procedures to assess and repair the heart defect. Another family, the Heaths, then sought guardianship and court authorization to consent to the medical treatment. The Heath's guardianship petition requested authority to make the medical care decision, but also requested rights to custody and care for Phillip. Unlike the stranger who initiated court action in the case of Baby


122. He was born with a ventricular septal defect, a hole between his right and left ventricles, that produces greater strain on the heart, and ultimately leads to death. In re Phillip B., 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), cert. denied, 445 U.S. 946 (1980). This decision affirmed a trial court's refusal to find the child a dependent of the court due to deprivation of the necessities of life. Evidence at trial suggested that surgery to correct the heart defect could be more risky for a person like Phillip who has Down's syndrome and with pulmonary vascular changes. Id.; see also Annas, Denying the Rights of the Retarded: The Phillip Becker Case, HASTINGS CENTER REP., Dec. 1979, at 18, 19 (criticizing court for approving nontreatment of handicapped child due to slightly greater health risks and presumptively lesser quality of life).

123. A critical problem was the effect of delay which made medical procedures more risky as time passed. Guardianship of Phillip Becker, Order re Final Findings of Fact and Conclusions of Law, 75, 78, 82, No. 101981 (Super. Ct. Santa Clara).

Jane Doe, the Heaths had befriended Phillip, worked with him at the institution through a volunteer program, and over the course of several years, brought him into their own family's life through overnight visits, holidays, and close relationships. After an extended trial, the trial court concluded that the Heaths had become Phillip's psychological parents. The court awarded guardianship to the Heaths and permitted them to authorize medical treatment. The court also authorized a medical procedure to determine the feasibility of surgery on the heart defect.

Although the court started with the procedural choice, substantive choices preoccupied its opinion. The court began with the question, "Who speaks for the child?," but soon turned to evaluate the quality of parental care offered Phillip by the Heaths and by his biological parents, and the conceptions each set of parents had of Phillip and his quality of life. According to the court, Phillip's parents maintained a conception of an unskilled and devalued person, incapable of love, based on the initial advice of doctors that Phillip belonged in an institution. Phillip's parents clung to the assessment offered by doctors at the time of his birth while the Heaths acted on a changing conception of Down's syndrome. The Heaths pictured Phillip as an educable and valuable person capable of love. In a sense, this case vividly presents how different understandings of a disability can have major consequences for the actual quality of life available to the disabled person. And the court treated these comparative assessments of Phillip's quality of life as central evidence concerning both the procedural question of who should make the medical treatment decision, and the substantive issue of whether treatment of the heart condition should go forward. The choice of decisionmakers thus marked a choice in conceptions of the child's quality of life and in the substantive choices the decisionmakers would reach about the medical treatment the child deserved. The court found the Heaths' conception—and their

125. See supra text accompanying note 9.
126. Guardianship of Phillip Becker, No. 101981 (Super. Ct. Cal. 1981). The trial court did not, however, terminate the parental rights of the Beckers. The appellate court affirmed; it emphasized that the fact of detriment to Phillip was established not by his parents' decision to institutionalize him, but by their decision to remain emotionally and physically detached. Herbert & Patsy H. v. Warren B., 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983). After this decision, the parties reached a settlement, and successful heart surgery was performed on Phillip. J. AREEN, FAMILY LAW: CASES AND MATERIALS (2d ed. 1985). The Heaths established a financial trust to assist Phillip. They believe he will be able to work in a semi-sheltered environment with other handicapped people. Id.
claim for guardianship—more persuasive, and likely to offer the least detrimental alternative for Phillip: a life worth living.

Still, the procedural question of who should decide what should happen to Phillip remained for the court. Here the court sought some way to catch a glimpse of the choice Phillip himself would make; self-determination of some sort seemed more preferable than arrogation of the decision by the court. The self-determination cast to a quality of life principle thus guided the judge to search for some way to couch a decision about Phillip as a decision he wanted. Acknowledging that the state provided no method for a mentally retarded child to state a preference, the court adapted the substituted judgment notion from other jurisdictions. The court then applied an unprecedented approach to this substituted judgment method: a “[P]latonic dialogue with the court posing the choices to Phillip and Phillip’s preference being ascertained from the more logical choice.” Through its Platonic dialogue the court turned the procedural problem of who should decide what should happen to Phillip back to the substantive choices of the care alternatives and quality of life estimates offered by the competing sets of parents. The court used the self-determination mode invited by the imagined dialogue with Phillip to frame the court’s determination of the child’s interest. And the competing conceptions of Phillip’s abilities, held by the Heaths and the Beckers, figured prominently in the court’s evaluation of what Phillip would want.

The court did not discuss expressly whether closeness qualified or disqualified either set of parents for decision making, although it acknowledged the biological tie between Phillip and his parents, and refrained from terminating that relationship.

128. The court announced that substituted judgment entailed discerning “as nearly as possible the incompetent person’s ‘actual interests and preferences,’ ” and that other courts had found this method consistent with the best interests doctrine. Id. at 15-16.

129. Id. at 16-17.

130. “Phillip’s case may pave the way for recognition of a developmentally disabled child’s right to choose his fate or destiny by the substituted judgment approach, or by the type of legal proceedings we are presently engaged in.” Id. at 17. Yet self-determination for the child is to be secured by decision making by the court.

131. The court thus permitted the Heaths to act as guardians without terminating the parental rights of the Beckers. See Guardianship of Phillip B., 139 Cal. App. 3d 407, 412, 188 Cal. Rptr. 781, 783-84 (1983). This amounted to an unusual decision to maintain through law multiple ties between the child and the two sets of parents. The traditional legal approach rests on the contrasting assumption that only one set of parents can have legal rights and responsibilities regarding a given child. Recent scholarship challenging this assumption has offered recommendations for facilitating through law several simultaneous adult relationships with a child. See Bartlett, Rethinking Parenthood as an Exclusive Status: The Need for Legal Alternatives when the Premise of the Nuclear Family has Failed, 70 Va. L. Rev. 879, 886-89, 944-61 (1984) (exploring traditional notion of
The court also credited the psychological closeness between Phillip and the Heaths\textsuperscript{132} and did not suggest that the Heaths' closeness to Phillip caused them to act in their own rather than in his interests. Instead, the opinion registered considerable sensitivity to the multiple relationships in the child's life, relationships where neither closeness nor distance could direct who should decide the medical treatment.

Nevertheless, an extraordinary expression of concern about closeness and distance, and objectivity and subjectivity appears in the judge's statements about himself. Judge Fernandez included personal statements of great emotion and reflection.\textsuperscript{133} The judge asserted that while this court has tried to remain objective,

\begin{quote}
[j]udges are humans and not machines. From my point of view I believe that we prefer to be judged by a real person with emotions and common sense, and all those other important characteristics of a Homo sapien . . . . As I read his file and I could see that this little boy was beginning on his trip towards death, and that he realized it, I was stricken with anguish and parental grief . . . . It may be argued that I used the footnotes too much to philosophize and state some personal views, experiences, and anecdotes. My defense is that in a case like ours which is so fundamental and basic to life, people should know how some of their 'governors' think and have their opportunity to judge the judgment of the judge.\textsuperscript{134}
\end{quote}

exclusive parenthood, challenges in current patterns of divorce and child custody, and alternatives to exclusive parenthood); Garrison, \textit{Why Terminate Parental Rights?}, 35 \textit{STAN. L. REV.} 423, 439-48, 474-89 (1983) (discussing alternatives to permanency policy in foster care system and reviewing psychological evidence about children's needs). The lawyers for the Heaths constructed a theory of the case that transformed the medical treatment decision into a custody context—and then into an innovative arrangement shifting limited custody to the Heaths. The Beckers challenged this shift and lost. 139 Cal. App. 3d 407, 188 Cal. Rptr. 781.

\textsuperscript{132} The court did, in context, expressly chastise Phillip's parents for clinging to the assessment they formed of him at birth. \textit{Id.} at 19 & n.69. It is important to note that the court's gesture of care and compassion towards the child may well punish others, like parents who have chosen a different position on the medical treatment issue. Parents may well experience a decision overruling their judgment as a serious rejection or even humiliation, yet these experiences are inevitable when their decision fails to meet a standard of care that legal authorities will enforce.

\textsuperscript{133} \textit{See id.} at 18-19 & nn.68, 68a, 70 (discussing how the case haunted the judge, brought to the judge's mind the treatment of disabled people in other cultures, in literature, and in the judge's neighborhood).

\textsuperscript{134} \textit{Id.} at 23 n.70 (emphasis added). Note how the judge placed himself within the case—"in a case like ours." \textit{Id.} It is a moving opinion, and one that pierces the usual grey prose of official state documents. It gives both an encouraging sense of a real human
Thus, Judge Fernandez revealed his relationship to the child by breaking through the usual conventions of distance and anonymity to share with the public his personal moral struggle between respecting and rejecting the parents’ choice. In so doing, he exposed the decisional process as he experienced it: it implicated his relationships to the child, to the two sets of parents, and to the general public as well.

It is an unusual opinion, in an unusual case. For the usual frameworks for analysis that divide self-determination and proxy determination, procedure and substance, and objectivity and subjectivity, all appear in the opinion, and yet the opinion itself challenges these dualities, and reaches resolution outside their confines. Self-determination and proxy determination would both be problematic, given the child’s mental retardation but also his evident personality and attachments to people. For Judge Fernandez, Phillip’s own views could no more be ignored than they could themselves be determinative. Instead, the judge constructed a dialogue form in which the judge could combine what he had learned about the child with his best effort to imagine what the child would want, in relation to how the judge himself saw the situation. Similarly, for Judge Fernandez, the substance of the medical treatment decision could not be separated from who should decide, nor indeed from questions about what kind of life Phillip would face in relation to people who had contrasting conceptions of who he was. These issues appeared inextricably connected in the judge’s opinion, for the kind of life open to the child seemed to depend on which relationships he could maintain.

Acknowledging the central importance of relationships, the judge also acknowledged his own relationship to the child. He made it clear that he, Judge Fernandez, was undertaking some large share of the decisions for the child, even though the “who decides” question allows a judge to hide behind presumptions, precedent, and professional role. His personal involvement, and his honesty about it exposed the limits of the standard tensions between self-determination and determination by others, procedure and substance, and objectivity and subjectivity.

Other cases routinely express medical treatment decisions through these dichotomies, but imply that these somehow help being struggling with moral issues and a disturbing sense of how thin is the veneer of laws on a justice system of men. Compare B. Brecht, The Caucasian Chalk Circle (presenting a judge abandoning commitment to laws in favor of revealing personal dimension of justice) with R. Cover, Justice Accused (1975) (exploring how and why anti-slavery judges enforced slave laws despite personal commitments to the contrary).
resolve the problem. Yet these dichotomies afford no basis for gaining insight into fears and hopes about the child, and no guidance for viewing how the child’s relationships affect the opportunities that lie ahead. Nor do the dichotomies offer a way for the reviewing judge to recognize his or her involvement in and distance from the case—or the similar mix of involvement and distance for the watching public. A series of additional procedural choices surrounding judicial review also invoke the standard dichotomies without illuminating these complicated patterns of relationships and ambivalence that surround the medical treatment decision for a severely handicapped child. These procedures may effectively allocate power or uncertainty in ways that in effect produce resolutions in particular cases, but they still fail to unearth, much less address, the deeper conflicts about relationships between handicapped persons and others that animate controversies over these cases. An examination of review procedure, burdens of proof and presumptions thus can reveal the persistence of the familiar dichotomies—and the persistent patterns of distrust that remain to divide people over these controversies.

3. Review procedures—The state makes additional procedural choices in determining the methods of review available if someone wants to challenge a parental decision, and in assigning burdens of proof and presumptions in cases involving such challenges. Real consequences flow from these procedural choices in terms of the duration and costs of the medical care decision, and also in terms of the ultimate allocation of decisional power.

First, the state establishes the availability of review of a parental decision concerning the medical care of their child. Should the state permit some other relatives, hospital personnel, or strangers to challenge that decision? Should the state encourage or require such challenges, by establishing a board to


136. The state should decline to recognize challenges brought by persons unrelated by family or professional contact to the instant case; although doctrines of standing permit variable recognition by the judiciary of claims, C. Wright, The Law of Federal Courts 59-74 (1983); one generally cannot assert the rights of another, id. at 73. If the rights of the infant are at stake, the state itself should represent them. See supra text accompanying note 15.
review whatever decision the parents make? Answers to these questions have made consultation with a medical ethics committee routine in some states.\textsuperscript{137}

Federal regulations have also stimulated the use of hospital ethics committees.\textsuperscript{138} Such committees initially gather information about the particular health of and treatment options for the infant, and then draw upon the interdisciplinary knowledge of the doctors, nurses, theologians, philosophers, social workers, and lay people on the committee to decide the proper medical care for the infant.\textsuperscript{139} An advantage of such committees is their collaborative structure, in contrast to the adversarial format of a judicial proceeding. A disadvantage—shared by judicial review—is the time the committee process may take, forcing in-

\textsuperscript{137} Bolen, \textit{supra} note 107, at 17. In the Quinlan case, the court required use of the hospital ethics committee as a check on the doctors' assessment that there was no reasonable chance of the patient's recovery. \textit{In re Quinlan}, 70 N.J. 10, 355 A.2d 647, \textit{cert. denied}, 429 U.S. 922 (1976). Other courts have similarly relied on—and thereby encouraged the use of—ethics committees. \textit{E.g.}, \textit{In re Torres}, 357 N.W.2d 332 (Minn. 1984); \textit{see} L'\textsc{ongino}, \textit{supra} note 78, at 402-03 (discussing ethics committees).

\textsuperscript{138} \textit{See} Bolen, \textit{supra} note 107, at 19. The American Academy of Pediatrics supported the use of such committees in response to the proposed Baby Doe regulations. The proposed regulations provided guidelines for Infant Care Review Committees (ICRCs) to:

- develop policies and guidelines for the treatment of such infants; act as a resource to hospital personnel and families of disabled infants to provide current and complete information concerning medical treatment, procedures and resources as well as community resources; and review decisions made in individual cases to assure that appropriate treatment is provided. Where medically indicated treatment is not being provided, the ICRC will report such a case to the \[state child protective service\] agency for immediate legal intervention.

\textit{45 C.F.R. \textsection 1340.14.} The final regulation clarified that the guidelines concerning these committees are purely advisory and no federal carrots or sticks would induce their adoption. 50 Fed. Reg. 14,880, 14,896. Nonetheless, these advisory guidelines continue to provide a detailed model for such committees that combines information, resource, and referral with mechanisms to report cases to court or state child protective services. \textit{Id.} at 14,896. And the Department of Health and Human Services encourages the formation of such committees. \textit{Id. at} 14,893. Although no particular substantive effect need follow from the use of such committees, the federal policy statement regarding the committees reaffirms the commitment of the Department of Health and Human Services to promote institutional practices with a guiding principle “to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.” \textit{Id.} at 14,898.

\textsuperscript{139} Procedural ambiguity arises over who should sit on the committee, when and at whose instigation cases should be sent to the committee, and how weighty a committee decision should be. \textit{See} Robertson, \textit{supra} note 87. The advisory guidelines issued by the federal government recommend inclusion of: a practicing physician, a practicing nurse, a hospital administrator, a social worker, a representative of a disability group, a lay community member, and a member of the facility's medical staff. 50 Fed. Reg. 14,893-94. The guidelines also recommend procedures for review of specific cases, including appointment of a member of the committee as an advocate for the infant, and procedures for referring a case to court or to state child protective services. \textit{Id.} at 14,896. Each of these features recapitulates issues about who should decide the merits and how.
terim treatment decisions and prolonging parents’ agony. Indeed, prolonging the decision may force one decision over another in many cases. For example, time delays may require treatment to preserve the infant’s life pending a committee review, or postpone treatment pending an appeal of a committee’s decision reversing parental choice.

Substantively, rationales for committees’ judgments are as problematic as for parents’ judgments. No societal consensus exists about these issues; the lack of consensus explains why these cases reach ethics committees. Additionally, no consensus exists about what ethical principles should guide the committees’ decisions. Committees may simply approve the decision reached by parents and doctors, which makes the committee process seem redundant. Indeed if this is the result, the committee structure may simply provide a procedural evasion of the substantive issues. The procedural decision to create a committee itself represents a choice to disturb the traditional legal arrangement that allocates power to parents, subject to the review only by a state social service agency or court. The committee process injects a new set of decisionmakers as a seeming answer to the troubling procedural problem of who should decide these cases. It only seems an answer because if committees reverse the parents’ and doctors’ decisions, these people may pursue judicial review, thereby further extending the decisional process, and reopening the question of who should decide. The reviewing court then would have to consider whether the parents’ proximity to the problem disqualifies them from judgment, or instead privileges their position. Similarly, the court could consider who can provide the most reliable proxy decision, given the impossibility of self-determination for the disabled infant. Whatever substantive decision produced by the committee process and judicial review, the review committees do not provide any way for parents or the larger community to develop understandings about types

140. See R. Veatch, Case Studies in Medical Ethics 40-41 (1977) (noting that clergyman, judge, utilitarian, formalist each have special expertise). Veatch maintains that in an egalitarian society, debates about right and wrong in such situations express the values and epistemology of democracy. Id. Deciding whose values should prevail in medical ethics, then, raises the same problems as debates over values in the larger society: problems for debate, not deference to higher authority or special expertise.

141. The state also could use the threat of malpractice charges should doctors fail to pursue medical treatment and thus encourage the doctors to seek state approval if they accede in a parental decision to forego treatment. Such a risk of malpractice charges would draw doctors into a search for administrative or judicial review. Both the ultimate decision by the committee and the standards for malpractice for the medical personnel directly draw the process back into the substantive debate over treatment. Rather than bypassing substance, these procedural choices depend on it.
of handicaps and treatment options, or about how parents and the community itself are implicated in the meaning of the infant's disability and opportunities in the future. Instead, the committee process could play into tendencies to distrust the parents, and to force decisions into an adversarial mode.

One procedural alternative to the current review process would assign to committees the task of developing working guidelines for treatment based on diagnostic categories. This alternative would address the confusion, inconsistency, and secrecy of treatment decisions by giving guidelines to parents and doctors, without exacerbating the difficult decisional process at the moment that they must make a treatment decision for a particular infant. Another alternative would place the parents on the review committee rather than treat them as witnesses or parties before it. This would give others a chance to talk with the parents in a context where the parents do not turn into defendants but also do not remain inviolate decisionmakers. Finally, a third alternative would modify the methods of ethics committees. Ethics professionals would not make or review the treatment decision but would help the parents and doctors make that decision in light of the range of concerns that an ethics committee would deem important. Such an approach could challenge parents' overestimations or underestimations of the infant's quality of life, while also helping parents clarify their assessments of the relationship between their interests and the child's interests.

Adopting any of these alternatives, however, involves a judgment to assign the treatment decision, as a rule, to the parents in consultation with their doctors, rather than to the committee itself. This central judgment returns to the "who decides" ques-

---

142. Cf. R. Weir, supra note 61, at 210-11 (recommending treatment decisions based on diagnostic categories); see also Hentoff, The Awful Privacy of Baby Doe, supra note 4, at 54-55 (distinguishing treatment options by diagnostic category). See infra text accompanying notes 185-88 (proposing procedures to develop guidelines outside of the context of any pending case).

143. This alternative might be impractical for decisions that must be made shortly after the child's birth, when both mother and father may be physically and emotionally incapacitated. Yet even at this point, greater access to good information about the child's condition and prospects could help the parents and the decisions they and/or the doctors make. See infra text accompanying notes 176-83 (proposing nonadversarial exchange of information).

144. Malcolm, Medicine, Law and the American Way of Death, N.Y. Times, Dec. 30, 1984, § 4, at 7, col. 2, (hospital ethics committees that "don't actually make life-and-death decisions" but "dispatch individual members to meet with doctors, patients and family to insure specific treatment decisions are made in an ethical context" for chronically ill patients).
tion, and the state's task in resolving this question remains difficult, given reasons to distrust all available decisionmakers. Indeed, the issue of parental bias due to their closeness to the situation is a major basis for the committee review process. If the committee is created to alter the usual allocation of power between parents and state, it leaves judicial review as the avenue for parents to reassert their view—to reopen the questions of who should decide, and what should be decided.

Issues about who should decide centrally recur in the state's procedural choices of burdens of proof and presumptions, with or without a review committee. For instance, should the law assign a presumption in favor of any parental decision and impose a burden of proof on the state or any challengers to rebut this presumption?\textsuperscript{145} These procedural choices determine the routine handling of cases, and also what will happen in an unusual case, given doubt about the merits. The usual rule grants a presumption that parents act in their children's interests.\textsuperscript{146} A legal framework in which parents are presumptive caretakers for their children casts any person who would challenge the parents' decision in the role of the accuser, and the parents in the role of defendants charged with violating the trust bestowed upon them by the state. Frequent challenges in practice, and institutional procedures like ethics review committees that second-guess the parents' decisions, erode a presumption for the parents simply by subjecting their decisions to review.\textsuperscript{147}

The state's choices about review procedures, burdens of proof, and presumptions also revive substantive issues and debates concerning self-determination versus proxy decision making, closeness, and distance. Given the impossibility of self-determination by the handicapped infant, the state's choice of the proper nature and standard of review reflects trust and distrust of the family and the state. The conception of the family as an

\textsuperscript{145} Variations in the formulation of the presumption are also possible. Compare \textit{In re Barry}, 445 So. 2d 365 (Fla. 1984) (requiring clear and convincing evidence that child suffers from irreversible defect in order to sustain parental decision to withhold treatment) with \textit{In re Becker}, 92 Cal. App. 3d 796, 801-02, 156 Cal. Rptr. 48, 51 (1978) (declaring that the state has serious burden to overcome presumption of parental autonomy), \textit{cert. denied}, 445 U.S. 946 (1980).


\textsuperscript{147} Of course, the presumption may serve the additional purpose of tilting the case toward the parents' decision once review is underway, but even this function of the presumption may be undermined if review committees structure their process routinely as evaluating anew the parents' medical treatment decision.
enclave of love and selflessness removed from the untrustworthy power of the state supports arguments for allowing parents to make the medical care decision and for restricting the kinds and numbers of challenges and review by others. The contrasting conception of the family as a dangerous, unbridled area of discretion and the state as the source of law and justice supports substitute decisionmakers and vigorous review by the state. Each version expresses distrust of one set of authority figures and greater trust for another.

Debates over cases like Baby Jane Doe's embroil the affected family and the watching community in a drama of blame and defense. The frameworks for analysis, cast in terms of substantive versus procedural choices, and state intervention versus nonintervention, merely permit people to enact their distrust rather than to acknowledge it. When abstract principles and dichotomous concepts structure debate, impassioned, rigid and polarized stances can emerge, as in the abortion debate. Such debates obscure the complexity of the connections between state and family, between the value of life and the relationships that give it value, and between procedural and substantive decisions on these matters. Abstract and dichotomous debate also occludes the ambivalence and distrust that can fuel controversy. Especially when forged in the crucible of adversarial processes, debates over medical treatment for handicapped newborns actually impede our recognition of and confrontation with the sources of emotional conflict that animate public fascination with the state's decisions in cases like that of Baby Jane Doe. This article has suggested thus far, in marginal ways, how this fascination may be linked to people's conflicting experiences of being moved and repelled by the plight of the infant, just as it has suggested how the meaning of life for a handicapped person—or, indeed, any person—depends importantly on the relationships others are willing to undertake. Unusual moments—like Judge Fernandez's decision in the case of Phillip Becker—offer profound insights into this deeper level of understanding. There a judge was able to acknowledge the real difference particular relationships could make in the child's life, and the judge also acknowledged the complexity of his own relationship with the child before the court. Yet these powerful effects of interpersonal relationships, and the significant role of emotional conflict, barely surface for express acknowledgment in the usual legal and policy debates over individual cases or the issue in general.

Rather than confining these matters to the corners of concern,
the next Section of this article proposes to address these issues directly. I will start with the theme of distrust, as a thread interwoven in public debates that hints at deeper conflicts, usually obscured by those very debates. The next Section thus asks, what conditions give rise to this distrust?

III. CONDITIONS OF DISTRUST AND CONDITIONS FOR TRUST

Distrust reverberates in the state intervention debate and in tensions between both substantive and procedural options concerning medical care for disabled infants. Arguments over the merits of state intervention in the family in part express competing views about whether the state or the family is more trustworthy in caring for handicapped newborns. Similar conceptions animate debates concerning who should serve as the presumptive decisionmaker and whose interests do not conflict with the interests of the infant. Yet explaining distrust by reference to these conceptions affords little insight or suggestion for change.

To understand the sources of distrust, analysis must plunge deeper than these debates. These debates depend upon abstract conceptions of the state and the family. And these abstractions oversimplify what is at stake while tapping deep sources of distrust.

Use of the "state" as a concept in the debate over intervention oversimplifies, because the state is not one entity but instead sets of institutions, employees, and rules subject to interpretation. The "state intervention" in the Baby Jane Doe case involved half a dozen judges, many administrators and investigators, and several hundred legislators. Each of these individuals had a different relationship to the situation, a point obscured in the press and public debate by general expressions of trust or distrust of state action.148 Similarly, the "family" is not one entity but a multitude of unique interpersonal relationships bound by complicated mixtures of biology, culture, love, and dependence, and threatened by complicated internal and external pressures. It is too crude to assign genuine feelings of trust or distrust to the abstracted concept of "family."

Yet the attribution of serious concerns to abstract concepts typifies legal and policy analysis. The tendency to translate com-

148. There may be a basis to distrust the state due to the very numbers of persons involved when the state acts. This marks a different point from a general statement of distrust of the state, compared with the family.
plicated emotional dimensions of the medical care decision into the choice between oversimplified, competing concepts recurs when observers box the medical care decision into procedural and substantive categories, and the substance of the decision into the extreme alternatives of right to life and quality of life assessments. Such alternatives provide a rhetorical structure for debating what should happen, but it is a thin and limited rhetoric that obscures the ambiguity and line-drawing problems that arise with each substantive alternative. Similarly, casting procedural choices among decisionmakers, review mechanisms, and burdens of proof provides outlets for debate but offers little insight into continuing disagreements.

A. Distrust and Identification

I propose to examine deeper sources of disagreement than the abstract alternatives of state versus family, right to life versus quality of life, and procedure versus substance. This inquiry may help uncover what rivets public attention to cases like that of Baby Jane Doe, and also may open a new and more promising arena for attention. Informed by work in psychology and philosophy, this inquiry will consider: (1) how might experiences of identification with Baby Doe, her parents, and others explain people's responses to the case; (2) how might the mass media coverage and the adversary system contribute to ambivalent and yet condemnatory responses to aspects of the case; and (3) how might psychological theories about the self illuminate sources of distrust in debates about the case.

1. Objects of identification—The Baby Jane Doe case and similar tragedies capture the attention of the general public because almost all members of society can identify with one or more of the principal figures in such cases.149 This identification occurs on three levels.

First, people may identify with the vulnerable infant. Every-

149. For discussions of the psychological concept of identification, see J. Greenberg & S. Mitchell, Object Relations in Psychoanalytic Theory 70-72, 160-61, 171, 331 (1983) (discussing internalization of aspects of others as developmental dimension; the authors are object-relations theorists); J. Kagan, The Nature of the Child 139-43 (1984) (discussing the process by which a child develops identification with distinctive qualities of others, and constructs standards of behavior on the basis of this identification). I am using the term more generally to apply to the self-recognition adults as well as children may feel in perceiving the roles and attitudes of others; I mean to refer to the psychological notion that the individual's self-conception and repressed internalization of others is implicated by experiences of identification.
one has been an infant once, and everyone in that capacity has dealt from a position of vulnerability with powerful adults who make decisions for the child. Identification with the infant may exist unconsciously and subtly; it may also be intense and disturbing. It may be intense because childhood vulnerability may undergird adult memory and identity. \textsuperscript{150} It may be disturbing because identification with the vulnerable infant does not itself help an adult know which choice about medical care to prefer even though the identification makes the choice itself seem terribly important.

Identification with the infant may support aggressive medical care and elaborate methods to preserve or prolong life, but it may also encourage more conservative treatment. An adult identifying with the disabled infant may imagine desires on the part of the child to live, to receive all possible care, and to gain assurances of attention and comfort. Yet an adult identifying with the infant might as easily prefer suicide to extensive medical treatment that cannot ameliorate the underlying handicapping conditions. Or such an adult may imagine wanting to relieve family members from the burden of caring for a severely disabled child. The adult may also imagine living inert and unloved in an institution, which might produce strong desires for treatment, but also strong desires for nontreatment. Indeed, whether the competing choices about medical treatment seem in equipoise or yield a preference, an adult identifying with an infant may well distrust anyone else to know and understand what the infant needs. \textsuperscript{151}

At the same time, an adult can also identify with the parents of a handicapped infant. This identification may horrify the adult, for it can involve feeling both revulsion at having given

\textsuperscript{150} Many theorists assert that the child's early life may be characterized by vulnerability and helplessness, see J. Goldstein, A. Freud & A. Solnit, supra note 43, at 7-10, and that these experiences remain in the individual's psychic world even during adulthood; H. Fingarette, The Self in Transformation: Psychoanalysis, Philosophy and the Life of the Spirit 59 (1963); M. Seligman, Helplessness: On Depression, Development, and Death 104-05, 150 (1975). \textit{See generally} J. Greenberg & S. Mitchell, supra note 149, at 373 (discussing Joseph Sandler's theory of internalized representations compounding past experiences and perceptions that allow the individual to locate the present).

\textsuperscript{151} \textit{See} A. Miller, The Drama of the Gifted Child (1983) (describing parents imposing their desires on children); A. Miller, Thou Shalt Not Be Aware 7-8, 31-36 (1984) (adults and psychoanalysis denying abuse of children by parents, ignoring patients' signals); \textit{see also} R. Burt, supra note 103, at 13-44 (1979) (reporting that reasons to distrust both patient and doctors grow from their mutual impact on each other, stemming from basic psychological construction of self and others).
birth to a handicapped newborn and revulsion at this revulsion. An adult identifying with the parents of Baby Jane Doe may discover both an inclination to abandon the child and disgust with that inclination. The identifying adult may also feel drawn by a moral view of duty to resolve this emotional turmoil by renouncing instinct in favor of conscience.152

Just as the emotional response may be deeply ambivalent, any duty the adult constructs from identification with the infant’s parents may support opposite courses of action. For example, a duty of care, extrapolated from the role of parent, may command consent to all measures to preserve or prolong the child’s life. Yet that same duty may also direct attention to the dignity of that child, including an entitlement to die with dignity. Identification with the parents’ emotional ambivalence and role obligations provides bases for distrusting those parents, because the identifying adult discovers through his or her identification a basis to distrust himself or herself.153

Finally, some people may also identify with the medical and legal personnel and this too may produce ambivalence. They may feel drawn by medical personnel’s commitment to preserve life. On the other hand, people may imagine and resent medical professionals’ technological fix154 or tendency to use all new


153. Moreover, observers may identify with both infant and adult and experience a conflict like the tension between the quality of life position and the right to life position. Advocates of a quality of life standard may focus on the risks of imposing pain or joyless existence on the helpless infant. They fear that someday the child they save will wish not to be alive, or will be incapable of expressing or even formulating that wish. They may also worry about the burdens to the family—the marriage, the other children—who will have to care for this infant with little or no financial or emotional assistance from the state. The right to life advocates in contrast fear that attempts to draw lines between different qualities of life devalue life, and start down a slippery slope where no one’s life is assured value and protection. Some ignore or deem irrelevant the burdens to the family from raising a severely disabled child, some assume institutional care will be available, and a few argue for societal commitments to assist the family by improving the services for and social status of disabled people. See supra text accompanying notes 61-62 and infra text accompanying note 171.

154. See Bolsen, supra note 107, at 17 (reporting hospitals’ bias toward technological intervention); see also R. Wein, supra note 61, at 30 (describing neonatal intensive care centers and technological sophistication of tertiary care hospitals). The fact that tertiary care hospitals are not the only place where babies are born poses problems of inequitable access to resources, which also influence the range of treatment options for infants. Thus, using “all available” methods means something different in different institutions.
techniques available to save life rather than estimate the sense or value of the procedure. People may identify with a judge and feel the isolation of that role.

Furthermore, people who identify with the adult actors in the case have reason to distrust them, because they have reasons to distrust themselves. And people who identify in any way with the infant have reasons to distrust others, because they have memories of learning that no one could know their needs completely. However these feelings of trust and distrust arise, and however people deal with these feelings, a story like the case of Baby Jane Doe engages individuals' own senses of vulnerability, self-loathing, and aspirations for wisdom—much as medieval morality plays engaged their audiences. The case of Baby Jane Doe may thus expose people's fears about their own vulnerability to the power of others. The case may also invoke fears about betraying a sense of duty with emotional responses, and also fears about cutting off emotional impulses with a sense of duty.

The case may at the same time nurture hopes for resolution of these fears. People may view the parents as good or evil, and similarly evaluate the state. But in any case, the story itself may capture their own self-distrust and distrust of others, while offering an occasion for judgment. In judging parents, doctors, and other decisionmakers in this context, a watching public audience risks projecting self-distrust onto any of these actors. Observers may also project onto others one side of their ambivalent feelings, such as the fear of emotional impulses, while waiting ready to condemn those others based on the contrasting side of ambivalence, such as the fear of cutting off emotional impulses through a sense of duty. One observer may blame parents for underestimating the value of the life of the severely disabled child; another may blame the parents for clutching at technology

155. The practice of "defensive" medicine, in the face of malpractice risks or other worries, may lead medical personnel to use whatever techniques are available. See R. Weir, supra note 61, at 138. But see Longino, supra note 78, at 401-02 (describing physicians torn between their own moral judgments and desires to remove burden from parents).

156. See F. Artz, The Mind of the Middle Ages 359-60 (rev. 3d ed. 1980) (reporting that medieval morality plays used actors to represent virtues and vices and other abstractions; usual theme had evil forces pursue Everyman and Wisdom rescue him); see also M. Ball, The Promise of American Law: A Theological Humanistic View of Legal Process 42-59 (1981) (contrasting law's and theatre's techniques for redirecting passion and comparing trials and morality plays).

157. Cf. R. Burt, supra note 103, at 55, 65, 134 (arguing that interaction between patient and doctors reveals power and powerlessness of both, and opportunity for continuing struggle for choice making).
only to prolong the process of the child’s death. Both the adversarial structure of legal proceedings, and the media’s tendency to cast news events as moral tales with good and evil figures exacerbate this risk of mutual blame and projected self-distrust, and deserve fuller consideration.

2. **Fomenting distrust**—The media news coverage gives the story of decisions about medical treatment for a handicapped newborn a sense of crisis even as it may prolong, through each daily update, the ambivalence and conflict people may feel about each alternative. Nonetheless, mass media attention has severe limitations as a vehicle to resolve or accommodate these fears. Media coverage focuses longstanding emotions on a crisis, and plays into desires for ad hoc judgments rather than for working solutions amid acknowledged complexity. A dramatic presentation of legal and medical debate does not address the relationships where vulnerability arises but merely attracts the feelings those relationships generate. Distrust relates to fears about how people treat others who are vulnerable. The media portrays the treatment of the vulnerable but does not elevate to express discussion the feelings this treatment may arouse. Moreover, the media presentation fails to emphasize the relationship between the witnesses and the witnessed. The presentation fails to reveal that the future meaning of the life of the handicapped person depends in part on the meaning the watching society gives to the handicap—that the offering or withholding of help expresses as much about the helper as it does about the helped.

The public audience in these cases, then, in a real sense, are related to and involved in the drama. Perhaps because the drama involves the universally familiar subject of family life—and the double vulnerability of a handicapped child—the audience identifies even more powerfully than they do in other public dramas, like those involving terrorists or trapped coal miners. In addition, there may be a special fascination with the communities’ own power and powerlessness to alter the meaning of disabilities. Our attitudes about particular handicaps, about parents of handicapped children, and our priorities for medical expenditure construct the moral and social universe in which handicapped infants and their parents live.

Yet these dimensions of interrelationship remain obscured by

---

158. In a sense, readers of the unfolding news story are like the audience watching tragic drama. As Stanley Cavell describes, tragedy occurs in a continuous present demanding attention and immobilizing the audience which can do nothing but witness. Cavell, *supra* note 104, at 314, 322, 329-30.
the adversarial character of the legal drama that the media publicizes. Adversarial decision making may heighten the conflict over a case like Baby Jane Doe's, and feed rather than resolve the sources of distrust. Indeed, administrative and judicial review of parental medical care decisions for handicapped newborns may reenact and refuel exchanges of distrust. Hospital review committees, even with their internal collaborative structure, may establish adversarial relations between hospital and parents, and parents and child. The media's tendency to cast villains and heros, combined with the adversarial posture of legal and administrative decision making, conveys the ways the players are opponents and strangers, and submerges the ways in which they—and we—are connected to one another.

3. The relationship between self and other—Each of these dimensions—the adversarial structure, the public audience observing a distant but enthralling media drama, the possible identification by many people with the relationships between vulnerable infants and more powerful adults—exposes a psychological issue about the relationship between self and other. Is the self separate from others—free from their power, abandoned to care for itself? Or is the self connected to others—receiving care but also subjected to oppression? Some elements of the debate reflect the first view, some the second. The notion of the separate and isolated self underlies adversarial problem-solving, where opponents perceive each other as separate and antagonistic. Similarly, the sense of an audience removed from the actors in a drama, and the infant with interests at odds with her parents, depends upon the view of the self as separate and open to harm from others. Each of these conceptions has an either/or structure, dichotomous like the duality of self and other. To some extent, psychologists offer support for this view of the self. They


tell us that the child develops a sense of self by seeing parents, and all others, as separate.\(^\text{161}\)

Yet these theorists also emphasize that even this development of a separate self depends on the child's relationships with others to discover and delineate a boundary between self and other.\(^\text{162}\) Moreover, some theorists maintain that the individual self is more than a bounded separate identity. Instead, the person continually negotiates an identity in relationship with others, with varying degrees of dependence and interdependence, distance and closeness.\(^\text{163}\) These theorists suggest that the individual depends on others in the very creation of a sense of self, and this dependence persists even in the process of separating, emotionally and cognitively, from others. The development of a sense of personal boundaries—where the self ends—in this sense is entwined with continuing awareness of where others begin. Finally, the self may continue to depend on experiences with others that become internalized as part of the individual's sense of self. These notions of the self, forged in ongoing relationships, support a view of inevitable, interpersonal connection, attended by risks of domination but also opportunities for mutual care.

This excursion into psychology suggests that debates over the medical treatment of an infant like Baby Jane Doe may raise intense and complicated psychological aspects of the relationship between the self and others. A limited notion of self as separate may underlie and animate the issues of trust and distrust as expressed in the varied dichotomous debates over state intervention, substance and procedure, quality of life and right to life. A richer sense of the interdependent self may highlight ways in which these dichotomies are misleading—for a right to life depends on relationships that can give it meaning, procedure and substance intertwine, and the state cannot avoid intervening in the family it defines and regulates—just as the self depends

\(^{161}\) See J. Greenberg & S. Mitchell, supra note 149, at 274-81, 345-46 (describing Margaret Mahler's and Edith Jacobson's theories of individuation and self).

\(^{162}\) Id.; see also N. Chodorow, The Reproduction of Mothering (1978) (reports that male and female children both construct gender identity in relationship to mother); D.W. Winnicott, Mirror-Role of Mother and Family in Child Development, in Child, Playing and Reality 30-138 (1971) (reporting that the child needs to see mother seeing him to develop sense of self).

on others in establishing boundaries, integrity, and internalized identity. At the same time, knowing that the self depends on others even in its separateness and that another may betray you out of care as well as out of unconcern, a healthy individual may experience conflicting desires for both separation and interdependence. People may distrust both state officials and parents as "others" adverse to the child's interests, and yet appreciate both as the sources of support. From this complicated posture it is easy to find grounds to distrust anyone's claim to be acting in the interests of the child. Efforts to acknowledge the relationship between the adults and the child—and the interaction between their interests—may eliminate fears of undisclosed conflict, but only by disclosing the possibility of actual conflict.footnote{164}

Thinking about problems in either/or terms fits neatly into the psychological problem of constructing a self in relationship to others; and yet the either/or terms may hide the very bases of relationships between the alternatives, and among those affected.footnote{165} Thus, the adversary structure may overemphasize sep-

---

footnote{164} Reasoning with a focus on relationships between individuals has been a concern for feminist theorists. See C. Gilligan, supra note 160; N. Noddings, supra note 163. An interesting parallel occurs in the approach advanced by pragmatists like William James, whose thinking, according to Jacques Barzun, is:

held fast by as many demands and duties as the moral agent can think of. His relativism relates, which means many links to fixed points . . . . In thus relating one's decision or conduct to several needs and ideals, one gives the observer as many chances to criticize, whereas the absolutist relates his act to only one thing: the fine abstraction that his God or his grandfather once uttered emphatically.


The temptation to adhere to sharply-defined categories is understandable. Judges generalize, they articulate concepts, they enunciate such things as four-factor frameworks, three-pronged tests, and two-tiered analyses in an effort, laudable by and large, to bring order to a universe of unruly happenings and to give guidance for the future to themselves and others. But it is certain that life will bring up cases whose facts simply cannot be handled by purely verbal for-
aration and antagonism while obscuring commonality and mutual need. The public drama may exaggerate the separation of the audience from the anguish of the actors. Conceptions of the vulnerable infant may underestimate the vulnerability of the adults to the infant, and the interdependence of interests. The conception of decision making as a task to be completed alone may exaggerate a need for separation and undervalue a need for consultation. And the tendency to carve problems into rigid dichotomies between the self and others, substance and procedure, intervention and nonintervention, may emerge from psychic preoccupations only partially understood.

I offer these views in the belief that greater efforts to understand such psychic preoccupations can free us from simply enacting them. Where those preoccupations give rise to distrust in matters of public policy, such efforts at understanding may be the only way to escape polarized, rigid debates. Distrust, unexamined, cannot be cabined. Attributing it to an abstraction, like the family or state, simply preserves it; assuaging it with procedural solutions leaves its sources unexplored. An alternative approach to a case like that of Baby Jane Doe would break out of the ill-fitting dichotomies of state and family, objective and subjective, substance and procedure, and instead work for conditions of trust. The principal premise behind this approach would assert that trust cannot be announced, but must be achieved. Just as the self develops through struggles with others for both separation and connection, the foundations for trust must grow through human encounters and public struggles over the meaning we give to the fact of our shared humanity. Pursuing conditions for trust, I offer the following suggestions to attend to disputes in cases like Baby Jane Doe.

B. Conditions for Trust

Media and legal attention to cases like Baby Jane Doe will probably continue for some time, given these conditions of un-


mulas, or at least not handled with any sophistication and feeling for the underlying values at stake. When such a case appears and a court attempts nevertheless to force the old construct upon the new situation, the result is mechanical jurisprudence.
certainty and distrust, and little said in this article or elsewhere can change these conditions. No new substantive rule, procedural technique, or new position on the state intervention debate will promote trust between people concerning this subject that so invokes personal vulnerabilities. New medical knowledge and changes in the social meaning of various handicapping conditions may partially address the current uncertainty that undermines settled expectations. Over time new rules may well secure public confidence through new routines that recede into the background of settled expectations much like the old routines, where parents or doctors quietly made decisions about infant medical treatment with the tacit or express endorsement of legal and community authority.\textsuperscript{167} Such developments seem distant now, however, largely because distrust and controversy in this area are increasing, not abating. The debates over state intervention, right to life versus quality of life, and procedural alternatives themselves express dimensions of distrust between people—distrust that runs deeper than the particular medical treatment decisions at issue. Addressing the conditions of distrust themselves may open the way for new routines to gain wide acceptability for dealing with medical treatment decisions for handicapped newborns. Because sharp disagreements are bound to persist, these routines will chiefly involve ways of channeling disagreement away from simplistic, adversarial alternatives, and toward contextual discussions that address what really could and should happen in the lives of disabled newborns. Such discussions require at minimum the kind of trusting relations that allow people to move beyond polarized, rigid positions, and simplistic conceptions of their opponent’s positions. Achieving this kind of trust will require encounters, conversations, and confrontations between people in ways that will make vivid the shared condition of humanness and vulnerability.\textsuperscript{168}

\textsuperscript{167.} See infra note 182 and text accompanying note 184. New routines could—and should—involve careful and difficult efforts to think through individual cases not general rules. See R. Weir, supra note 61, at 139.

\textsuperscript{168.} Sociologists and anthropologists who study the conditions of trust in varied societies emphasize the role of exchange in the development of interpersonal relations. See S. Eisenstadt & L. Roniger, Patrons, Clients and Friends: Interpersonal Relations and the Structure of Trust in Society 29-42 (1984) (discussing work of John Bowlby, George Homans, Peter Blau, Claude Levi-Strauss, Emile Durkheim, and Michael Mauss). One variant on exchange as a basis for trust is conversation—the exchange of words—as a basis for trust. In contemporary scholarship, the prevalence of “conversation” and “dialogue” as models for moral and political discourse is striking, especially because these models are adopted by authors who represent a range of views on other matters; see also T. Todorov, Mikhail Bakhtin: The Dialogical Principle 60-74 (W. Godzich trans. 1984) (theorizing that every utterance is related to every other utterance;
The first step in building conditions for trust occurs simply by asking what state decisions about medical care for handicapped infants would promote trust in the processes and results. How can a decision about the medical treatment of a handicapped newborn avoid the assignment of blame by people who disagree with the decision? How can parents, medical personnel, and others appreciate the great degree to which they share the problem, and ambivalences about it, rather than only the degree to which they desire different medical care for the infant? How can each of these actors note how each has a relationship with the infant, and how these relationships will deeply influence whatever future awaits the child? These questions differ from the usual frameworks for debating medical care for handicapped newborns by rejecting questions that ask for either/or answers and by expressly addressing the objective of acknowledging ambivalence while promoting actual care for the child, whatever the medical treatment decision. Asking such questions represents a gesture toward commonality and an effort to resist antagonistic problem solving. Asking such questions embraces the paradox that opponents share their controversy, and the fearful self shares with other persons the psychic construction of self and other. Embarking on this inquiry expresses a small act of trust and permits a glimpse of how the problem would change if we viewed all the actors involved, the parents, the infant, the medical personnel, and the legal officials, as standing on the same side rather than on opposing sides. Posing trust as part of the agenda will not cause it to emerge. But turning public attention requiring study of dialogical relations in all texts). Compare Habermas, Toward a Theory of Communicative Competence, 2 Recent Soc. 134, 146 (H. Dreitzel ed. 1970) with B. Ackerman, Reconstructing American Law 4, 10 (1984). The Supreme Court itself has expressed a notion of due process as a conversation—and both as representing fairness. In Goss v. Lopez, 419 U.S. 565 (1975), the Court ruled that due process requires an informal hearing in the form of a conversation before suspending a student from public schools. The Court reasoned that this requirement is, "if anything, less than a fairminded school principal would impose upon himself in order to avoid unfair suspensions"—and the Court concluded that the procedural requirement would permit the student to give his version of the facts and allow the school official to respond.

A commitment to conversation—or any participatory process resembling it—is not a neutral stance, at least from the vantage point of anyone who would rather not participate. Cf. W. Arney, Power and the Profession of Obstetrics 240-42 (1982) (noting that the one freedom currently unavailable to pregnant women is the freedom to remain unseen, unmonitored by the obstetrical system). Yet in a democracy, public knowledge of important decisions is central to the commitment to decentralized power. See Bazelon, Coping with Technology Through the Legal Process, 62 Cornell L. Rev. 817, 823-25, 824-32 (1977). Acknowledging that the commitment to conversation embraced in this article is not neutral, I support it in part as a way to check the power of parents, doctors, and the state officials who make treatment decisions for handicapped newborns.
to this issue could help establish a context in which the needs of the infant and the family involved can be addressed rather than deployed in a public drama of blame and controversy.

1. Addressing the relationship between treatment decisions and care-taking responsibilities—Several elements of public debate cast distrust on the parents as ultimate decisionmakers for their child. The conception of the family as a center of lawless oppression and domination of the powerless by the powerful depicts the parents as untrustworthy. Similarly, quality of life arguments raise suspicions about the parents who may have their own quality of life at heart rather than the child’s when they make their treatment decision. Grounds for distrust may increase with the claim that the parents’ own stance toward the child deeply affects that child’s potential quality of life because that quality depends on the quality of interpersonal interactions. Further, the premise that the parents have a conflict of interest because they are too close to the child implies that those who will bear the burden and benefits of caring for the child should be disqualified from making the medical treatment decision. Parents might want to avoid the financial and emotional burdens of caring for a disabled child and therefore their possible opposition to aggressive medical treatment could be distrusted as self-interested.

These kinds of claims in the public debate play into the adversarial mode of problem solving by suggesting grounds to distrust parental decisions and grounds for state supervision of medical treatment for disabled infants.¹⁶⁹ This line of thought fails to disclose analogous reasons for distrusting the state. The state, as well as the family, runs the risk of insensitivity to the needs of the child, and also risks underestimating the quality of the child’s life. A serious form of state insensitivity appears in the unrealistic and abstract legal analysis that addresses the medical treatment decision disconnected from other issues about the child’s future. State decisionmakers, or hospital review committees permitted by the state to second-guess parental choices, may assume that the parents will continue to care for the infant at home, while the parents may assume that they will ultimately send the child to an institution. Whether the parents or the state have the final word on the medical treatment decision, and whether or not that decision directs treatment, the severely

¹⁶⁹. These sources of distrust seem to lie behind the movement for hospital ethics committees to review infant care decisions. Such committees could serve more constructive roles in sharing information with parents, rather than judging parental decisions.
handicapped child faces a possible destiny in a poorly main-
tained and staffed institution. These issues—and the child’s
ultimate destination—are obscured by the usual frameworks of
analysis because the questions about state intervention, right to
life versus quality of life, and who should decide, all neglect the
relationships between the infant and those who will care for him
or her. The usual analysis fails to address this matter of care
even when the state itself may become the caretaker with its
own conflicting interests. The state’s own goals include protect­
ing life and reducing budgets. These goals pose a conflict that
makes the state no less free from bias and conflicting interests
than the parents. Analysis that focuses chiefly on reasons to dis­
trust the parents’ medical treatment decision fails to expose
similar reasons to distrust the state.

Policy makers committed to building trust rather than dis­
trust should strive for an understanding that both the parents
and the state can inspire distrust, and both share responsibility
for the child that can be abused. Acknowledgment of the respon­
sibilities both parents and the state have for children in need
could usefully focus public debate on the relationship between
the medical treatment decision and the ongoing caretaking the
child requires, whatever medical steps are pursued. Rather than
disqualifying parents from the decisional process because they
bear the burden of caring for the child, we should develop deci­
sional processes that emphasize the state’s obligations for the
child’s future care. Although state officials and members of hos­
pital ethics review committees may not personally feel responsi­
bility for the child’s future care, they should feel responsibility
for that child’s future if they exercise institutional power to af­
fect that future. To make these institutional responsibilities pal­
pable, treatment decisions made by actors other than the par­
ents should carry with them the financial support to pay for that
medical treatment, and to assist the parents or others who end
up caring for the child. This approach resembles the proposal
that the state should not conclude a medical care decision for a
child while refusing to assume responsibility for the subsequent

ing scandal-ridden institution for the mentally retarded).

171. This solution might mean that the state would undertake a cost/benefit analysis,
and decide to discontinue treatment because of cost reasons. Yet the same risk currently
arises in less explicit ways when the state countenances cost/benefit decisions made by
parents or hospitals. Making the basis of the decision more explicit will enable broader
public debate, and improve chances that solutions will be chosen rather than merely
tacitly accepted. But see G. Calabresi, Tragic Choices (1978) (noting the use of subter­
fuge to allow society to accept painful cost/benefit decisions).
costs of the child's medical care. The joint responsibility suggested here builds on this proposal by connecting decisional authority with subsequent responsibilities for the child, and by directing the state to alleviate the financial and emotional burdens on the parents that may bias their decision. The parents' conflict of interest then will present no greater problem than the conflict for the state or the ethics committee, because each decisionmaker will have future caretaking responsibilities.

This approach calls for identifying the large problem that the parents, the state, the public, and the disabled infant share: how can the patterns of relationships and care among all these actors acknowledge the infant as someone deserving to live and die with dignity? This is a problem that is larger than the medical treatment decision alone. The problem reaches the treatment of handicapped people in a society not constructed with them in mind. For example, child-care and job arrangements make caring for a severely handicapped child a difficult task for parents.

172. See, e.g., Goldstein, Medical Care for the Child at Risk, in WHO SPEAKS FOR THE CHILD (1982) at 169:
If society insists through law that such children, indeed any children, receive medical treatment rejected by the parents, the state should provide the special financial, physical, and psychological resources essential to making real for the child it 'saves' the value it prefers. The state should become fully responsible for making 'unwanted' children 'wanted' ones.

173. The parents' financial burden, for example, could be extreme when medical and legal costs are both involved. See Rankin, The Staggering Cost of Baby Fae, N.Y. Times, Dec. 9, 1984, at F11, col. 1 (discussing costs not covered by insurance).

174. Determining exactly what rules should govern the availability of state financial support for the medical treatment and care of a disabled child poses a complicated task. If the state reimbursement is available only when the state supersedes a parental decision to forego medical treatment for the child, there is a risk that parents will deliberately refuse treatment in the belief that the state will displace their judgment and then pay the costs. Cf. DONZELOT, THE POLICING OF FAMILIES (1979). Taking seriously the risk of a perverse incentive means attributing considerable instrumental thought to parents at the moment of a significant and often urgent decision about their child, and yet such consequences of governmental rules should not be overlooked. At the same time, developing some contrasting set of criteria for state reimbursement will be difficult. Should state payment apply to treatment for all disabled newborns, or only treatments that would not be futile or inhumane, or only treatments that meet some state-defined requisite standard? The reimbursement program will expose once again the tensions behind the treatment decision itself. In addition, equity problems arise given the large numbers of persons in other age groups who face considerable medical costs. The elderly are an obvious group with analogous needs. Perhaps the state should promote the development of private insurance programs to cover the medical costs for disabled newborns as a way of avoiding some of the equity problems that accompany a program of direct state subsidies. Here another problem arises: third-party reimbursement will require yet another set of criteria for eligibility, and may also pose cost containment issues for the medical system generally. All of these problems require serious study and debate. Yet they remain hidden from view as long as the medical treatment decision alone remains as the focus for debate.
The problem also includes the state and private institutions that at best offer less to the child than a home with individuals who love the child, and at worst offer neglect and degradation. This large problem is the proper framework for the issues of state intervention, right to life versus quality of life, and procedures for medical treatment decision making, for it connects the treatment decision with the issues of care for the handicapped infant. Within this framework, other alternatives could appear such as state-provided homemaker support for the parents, or state-facilitated adoption connecting the child with a family willing to provide care in their home for someone with severe handicaps. Developing such options would engage state and private actors in comprehensive planning and struggles to reallocate funds to address this large problem.

Within the institutional structures currently in place, no single set of decisionmakers may feel able to engage in such comprehensive planning and resource allocation. In part, then, I offer this analysis as a way to highlight how limited the medical treatment decision is, given the range of issues implicated in it. Greater humility about the scope of issues left unresolved after the medical treatment decision is made might help alleviate the blaming and defensiveness that accompany review of parents' decisions by hospital review committees or courts. In addition, more modest activities could contribute to larger reforms. For example, people who wish to improve the parents' decision and help them better provide care for their child could develop and distribute information to parents about the next or final destination of the child and about the full array of alternatives for caring for the child.171 This call for information relates to a second suggestion for structuring conditions for trust, the sharing of information among actors involved in the medical treatment decision for disabled infants.

2. Sharing information—Parents, doctors, and representatives of the state should have opportunities to exchange information and to discover in nonadversarial settings whether competing sets of information support or challenge assumptions about the infant's prognosis, the risks of various decisions, and the trustworthiness of potential decisionmakers.176 Intense de-
bate in the Baby Jane Doe case—and in the Phillip Becker case— concentrated in part on clashing estimates of the meaning of the child's medical condition both in terms of quality of life and proximity to death. Conflicting estimates of the child's medical condition became entrenched by the time the parents, the doctors, and state decisionmakers assumed formal roles and defended their positions in a context of distrust. Shared information may have alleviated some needless confrontation.

Although gathering information may pose difficulties for the parents immediately after the child's birth, the hospital or state could operate a clearinghouse and channel information from medical associations, organizations for the rights of the handicapped, and groups committed to research and support for spina bifida, Down's syndrome, and other disabling conditions to parents and their doctors. The specific means for exchange are less important than the practice of exchanging information in a nonadversarial context, free from assigned blame or judgment against alternatives to be considered by the parents and doctors.

Educational programs to improve services to disabled infants with life-threatening conditions. See H.R. Rep. No. 1038, 98th Cong., 2d Sess. 21 (1984), reprinted in 1984 U.S. Code Cong. & Ad. News 2947, 2951. The advisory rules issued by the Department of Health and Human Services under the amendments elaborate model guidelines for infant review committees that would provide for this information exchange. 50 Fed. Reg. 14,893-94 (1985). But since these model guidelines also direct the same committees to develop treatment policies, id., to work to facilitate coordination with the law enforcement activities of the state child protective service system, id. at 14,895, and to review specific cases and refer some to court or to the state child protective services agency, id. at 14,895-96, this model undermines the chances for nonadversarial exchanges of information for families facing a medical treatment decision. I propose instead a separation of these functions, as described infra note 179 and accompanying text.

177. See supra text accompanying notes 7-8 and 126-28.

178. See Baer, supra note 7, at 35-38 (describing conflicting estimates of baby's disabilities and suffering). Yet as adversarial decision making occurs, individuals may be unable psychologically to reevaluate their assessment of the child. The Beckers may have felt a need to defend the position they had taken at the time of Phillip's birth and as a result they may have been unable to conceive of the child differently from their first impression. See Becker & Becker, Mourning the Loss of a Son, Newsweek, May 30, 1983, at 17 (defending their position in the case and objecting to the state's involvement).

179. The role for Infant Care Review Committees contemplated by the federal regulations suggests a problem in this respect. The committees are to be entrusted with both the task of gathering and sharing information with parents, and the job of reporting cases to state child protective agencies for legal action. See supra note 176. This enforcement function means that such committees would become unlikely settings for parental trust. The committee's role in sharing information could be problematic because there may simply be no time; the parents may face an immediate medical care decision at the moment of birth. Yet even in these situations, decision points down the line would look different to parents who have access to a richer array of information, especially information from parents who have undergone similar experiences. As an alternative to the com-
Exchanged information should address the medical treatment options and the range of possible capacities and abilities that the child could develop. Information about the child's potential personal development could challenge parental and medical attitudes about handicaps and also disclose how contingent the child's quality of life may be in relation to the opportunities parents and society provide. Information of this sort exchanged before the parents reach their decision could make a difference, unlike the effect of information exchanged in an adversarial setting. The adversarial posture rests on and promotes distrust. Others have extolled the value of the adversary process to prevent indecision, to require public decision, and to promote consistent decisions. I suggest that these concerns are less important values than working to promote trust in disputes regarding the care and treatment of disabled infants. Parties must earn one another's trust; and it is more likely earned in settings where parties can safely share information. Ethics review panels and courts may still review a decision reached by the parents and their doctors, but the review may accord greater trust to initial decisionmakers who have extensive information prior to such review.

3. Drawing public attention to rule making— Over time, rules and routines, like common law developments, emerge from crisis decisions with case-by-case review. To facilitate this

mittees described in the regulations, states could have parents consult with professionals who could help the parents make their own decision, based on a broad range of information and serious moral inquiry. This alternative could help parents deal with the problem in response to social concerns without altering the usual presumption of parental choice. See supra text accompanying note 144.


181. See supra text accompanying note 159; see also Nader & Todd, Jr., Introduction, in THE DISPUTING PROCESS: LAW IN TEN SOCIETIES 1, 17-40 (1978) (noting that strangers who have disputes typically have imbalance of power, exacerbated by professionals, and distance of law from community culture).


183. Counselors trained to help parents deal with their feelings while sorting through the information would also improve the decisional process.

184. See supra text accompanying notes 167-68. This notion is the familiar explanation of legal change that displaced an earlier notion that the law consisted of eternal and unchanging principles from which just applications could be deduced. See B. Cardozo, supra note 165, at 23-28, 99; G. Gilmore, THE DEATH OF CONTRACT 97-103 (1974); C. Rembar, THE LAW OF THE LAND: THE EVOLUTION OF OUR LEGAL SYSTEM 43-48 (1980). At work in this currently dominant idea of legal change is a conception of authoritative
process, and to draw public attention away from private family pain, hospitals and states could engage in a form of rule making to set temporary and mutable treatment guidelines based on diagnostic categories.\footnote{185} As medical knowledge and social attitudes constructing the meaning of a given handicap change—and change more quickly in some communities than others—public debate about prospective treatment decisions could accomplish the purposes of education and participatory decision making. The social meaning of Down’s syndrome, for example, has changed over the past several decades.\footnote{186} Consequently, states could develop guidelines stipulating that the deprivation of medical treatment solely because an individual has Down’s syndrome is an action triggering judicial review.

Any general rules would incorporate values and social attitudes as well as medical information. Moreover, medical professionals, political authorities, and lay citizens should share in this rule making process before individual cases capture public attention. Thus, prospective rules and standards should emerge through public debate, whether in reaction to a state rule making process or through a citizens’ advisory review of hospital guidelines. Advocacy groups for people with various handicap-

---

\footnote{185. See R. \textit{Weir}, \textit{supra} note 61, at 210. Ellis proposes legislative guidelines to make the treatment decisions more predictable and in accord with community values. Ellis, \textit{Letting Defective Babies Die: Who Decides?}, 7 \textit{Am. J.L. \\& Med.} 393 (1982). Although I agree with his advocacy of a legislative process to express public values—and his acknowledgment that consensus will be impossible—I find less compelling his emphasis on testimony by medical experts and his concern for the integrity of the medical profession.}

\footnote{186. \textit{See supra} text accompanying notes 126-32 (discussing \textit{In re} Phillip B.).}
ping conditions could use such debates to educate the public. Working guidelines could emerge, but the prospect of ongoing conflict should not be understated. The point of the proposed process for public debate is not that some noncontroversial consensus will emerge, but that a process promoting genuine argument would be better than the current combination of media-hyped morality plays and drawn-out legal proceedings.

Even working guidelines emerging from public debate still would inevitably give rise to conflict, and occasions where parents, physicians, and public observers distrust one another. In areas unresolved by diagnostic and treatment guidelines, hospital review committees could be shaped to provide nonadversarial settings where medical and nonmedical personnel could contribute to the decision. Including parents as participants in the discussions would be a worthwhile experiment, even if they and the other committee members share mutual distrust.

These proposals for public rule making and nonadversarial hospital review committees suggest incremental steps by which methods of problem solving could teach us more about who we are and how and why we mistrust one another. Trust in a democracy comes not through announcement by the powerful but rather through continuing conversations between people who both need and fear each other. In a related context, Dr. Jay Katz has argued that doctors and their patients can remedy their mutual distrust through conversations and sharing of information and decisional authority. He suggests that physicians must first face the limits of their own professional knowledge, and acknowledge their distrust of themselves, in order to learn to trust their patients and share authority with them.

Similarly, medical professionals, legal authorities, media commentators, and parents need to acknowledge their distrust of themselves in order to resist projecting that distrust onto others when difficult decisions arise concerning the medical treatment of a handicapped newborn. As Dr. Katz concludes, such a climate of trusted decision making "cannot be implemented by judicial, legislative, or administrative orders. At best, such outside interventions can prod doctors; at worst they only substitute bureau-

188. See Kann, Consent and Authority in America, in THE PROBLEM OF AUTHORITY IN AMERICA 59, 66-67, 76-79 (1981) (discussing tradition of consent of the governed and shared decision making, jeopardized by centralized power and withheld information).
cratic authority for professional authority." Similarly, neither external authorities nor public enactments of private ambivalence can attend to the sources of distrust that fuel public debate and fascination with medical treatment decisions for severely disabled infants. Instead, a process of education, self-examination, and genuine controversy provides the best hope for building the kind of trusting relations where real disagreements can be acknowledged and worked through.

**CONCLUSION**

Medical treatment decisions for severely handicapped newborns have become public cause célèbres as well as private crises. In an important sense, this article is about the limits of law in dealing with these situations. The problems explored here cannot be resolved by lawsuits, statutes, or regulations, for these legal vehicles replay the ambivalence that underlies our fascination with and perplexity over medical treatment for severely disabled newborns. The public debate has focused on arguments for and against state intervention, with a tendency to treat these alternatives as dichotomous. Similar polarized claims gather under the banners of two substantive principles, the right to life, and the right to make medical choices based on assessments of the quality of life. Adversarial themes permeate disputes over who should decide these cases, who should review such decisions, and what presumptions and burdens of proof should govern. Such disputes carry an intense emotional charge, because almost all members of society can identify with one or more of the principal figures in cases like Baby Jane Doe's. This identification hardly resolves the issues, and instead may occasion the projection onto public debate of deep sources of distrust and self-distrust located within individual psyches. The very pattern

190. *Id.* at 228.

191. Federalizing or constitutionalizing the law in this area seems especially unwise, given these deep-seated feelings on contrasting sides, and given the ambiguous and quickly changing medical understandings about infants with severe deformities or handicaps. See *supra* note 24 (criticizing application of § 504 to these cases). Yet I do not believe that law should—or could—be cordoned off from any involvement here, just as state intervention in the family cannot be avoided once there is a backdrop of state regulation of the family. In this regard, legal settings could strengthen efforts in administrative and counseling settings to confront the ambivalence and interpersonal relationships implicated in these medical treatment decisions. Law in this sense is no special source of answers but neither is it disqualified as one of the possible terrains where enduring human dilemmas can be acknowledged.
of either/or problem-solving that underlies the debates over state intervention, right to life versus quality of life principles, and procedural techniques to give or deny power to parents may be rooted within the psychological development of individual identity where the self stands in contrast to the other.192

This article has argued, however, that the either/or notions in each of these contexts fail to capture the variety and inter-relationships of the concepts and practices they represent. Thus, the article has argued that the debate over state intervention, when couched in either/or terms, neglects both the variety of meanings state intervention has in practice, and the ubiquity of state involvement in family relations. Similarly, the article has argued that the polarized substantive debate between advocates of a right to life principle and advocates of a quality of life principle neglects the line-drawing problems each engage in, and the dependence of both principles on procedural issues. At the same time, this analysis has been influenced by developments in psychological theory that explore the interconnection between the individual’s self and others in the very construction of a sense of personal identity. See supra notes 160-63 and accompanying text. These works reject a simple dichotomy of self and other by showing the interrelation of both, much as other work in psychology explores the relationships between therapist and client through the shared symbolism of language. See M. Edelson, The Idea of a Mental Illness 105-36 (1971); R. Kegan, The Evolving Self 76-110 (1982). This article also draws on emerging work in philosophy, which challenges the traditional Cartesian distinctions between subjectivity and objectivity and explores the relationship between the two through the significance of shared, human enterprises, like language, that have qualities of both. See R. Bernstein, Beyond Objectivism and Relativism: Science, Hermeneutics, and Praxis 71-108 (1983); R. Rorty, Consequences of Pragmatism xiii-xliv, 160-75, 191-208 (1982); see also S. Cavell, The Claim of Reason: Wittgenstein, Skepticism, Morality, and Tragedy (1979) (exploring the meaning of Wittgenstein’s work for philosophic problem of other minds and for moral philosophy); H. Gadamer, Philosophical Hermeneutics (D. Linge trans. 1976) (containing essays exploring the phenomenon of understanding through the conditions that constitute it and lie beyond conscious or obvious meanings). Similar developments in other fields emphasize the process of interpretation that relates the reader to the text rather than other theories of knowledge that separate the knower and the known. See T. Eagleton, Literary Theory: An Introduction (1983) (presenting theories about literature); D. Lacapra, History & Criticism (1985) (presenting intellectual and social history); see also R. Bellah, R. Madsen, W. Sullivan, A. Swindler & S. Tipton, Habits of the Heart: Individualism and Commitment in American Life (1985) (adopting an interpretive approach to social science study of American culture). These efforts in quite varied fields all mark an important challenge to traditional ways of understanding by searching for how our ways of knowing constitute what we know and who we are. Such enterprises can be criticized as self-absorbed and as spending too much time challenging conventions and canons within existing disciplines rather than addressing their supposed subjects. Yet these efforts also hold promise of richer kinds of knowledge that may free us from puzzles and problems that have been a function of the very intellectual approaches to analysis that have been used in the past. See R. Rorty, supra, at xxxvii-xliv. It is in this spirit that this article has tried to probe beneath the prevailing patterns of argument to ask why we talk about problems the way we do, and how focusing on our relationship to these problems may provide a vantage point that breaks free from approaches that have not been especially fruitful in the past.
time, the division of problem solving into substantive and procedural concerns underestimates the interpenetration of these two sets of concerns. Finally, although the very notion of a "self" distinct from an "other" may supply a psychological root for the either/or patterns of problem solving, and trust and distrust, the "self and other" construct should be located within a developmental process in which each individual develops a separate self only in relation to others.

And yet the patterns of either/or problem solving obscure and impede recognition of these very psychological dimensions of public and private responses to the situation of the handicapped newborn. Ambivalence about feeling both moved and repelled by the handicapped newborn propels adversarial debate, and the debate itself fails to help people acknowledge this ambivalence, much less the role of the community in the life opportunities available to any handicapped person. The persistence of the dichotomous formulations of problems cannot be due to difficulties in pointing out how oversimplified and unsophisticated they are. Intellectual assaults on crude absolutist positions can be readily forged, and can handily win superficial victories. In debate over these matters, it is not too difficult to obtain a concession, such as: "state intervention is not a yes or no proposition," or even, "the right to life position at some point has to draw a line." And yet beyond such concessions, there is a structure of talk that sticks. Crude versions of the problem as a contest between either/or alternatives remain and largely frame the debate among key public officials as well as in the media and popular discussion.

These debates express genuine differences between those who prefer to emphasize the right to life without regard to quality or cost and those who in contrast focus on quality and cost questions. Similarly, some people express strong commitments to combating anything that looks like state imposed restrictions on parental decision making, and others as adamantly call for aggressive state activity to review or challenge what parents decide about treatment for a severely handicapped child facing serious medical problems. Further, people who feel strongly on both sides of these issues have seized the instruments and categories of legal analysis and taken their disagreements to legislative and judicial forums at both the federal and state level.

Finally, genuine conflict persists in these legal contexts. People still conflict over medical treatment decisions for handicapped newborns and on these occasions they may win or lose. In particular, parents, and those identifying with them, lose if
they choose a position that so underestimates the life chances for the infant that others can demonstrate to the satisfaction of legal authorities that this estimate amounts to illegal neglect. Although this very notion of neglect will remain contestable in many cases, some parents will lose, or feel forced to a position in order to avoid legal battle. The same will hold for doctors and legal decisionmakers. Similarly, strangers to families with severely impaired newborns lose because they cannot gain legal power to stop parents from sometimes making a decision against possible medical treatment; such strangers experience this result as an assault on their deeply held beliefs. Thus, conflicts over where to draw the line between condemnable neglect and acceptable decisions will be fought with real winners and losers.

In this light, it may seem impossible to conceive of parents, doctors, legal decisionmakers, and the severely disabled infant as standing on the same side of the medical treatment problem. Indeed, the debate over medical treatment for disabled newborns risks becoming as polarized and rigid as the debate over abortion. Yet I have suggested that the very pattern of distrust that underlies these debates offers a starting point of commonality for all participants in these debates. Hovering between tragedy, where choice and human will play a role, and pathos, where human pain constitutes the story, everyone who deals with the infant treatment decision shares the inability to remove the infant’s disability along with the power to affect the meaning of disability in this society. And everyone shares the lack of knowledge of the infant’s interests and the risk of distrusting others’ assessments of those interests.

This article has suggested that starting with what we share, even if it is simply our mutual distrust, affords a promising approach to resolving medical treatment problems, or at least engaging in more productive forms of disagreement. Asking what we share can also reveal opportunities for sharing information, sharing responsibility for the meanings society gives to disability, and strengthening the relationships between the infant and those who will care for him or her.

Both as ways to promote these kinds of understandings, and as initial steps we could take based on these insights, this article proposes processes for decision making that (1) underscore the obligations of both state and family in the care for the infant, whether or not medical treatment is authorized; (2) provide for exchanges of information in nonadversarial settings to improve the parents’ and other parties’ understandings of the medical condition and the ways in which the meaning of that condition
can change over time, partly in light of how the child's caretakers respond; and (3) develop settings where guidelines about treatment can be debated, removed from crisis situations, and assisted by the participation of medical professionals, political authorities, and members of the public. Unlike the infant care review committees currently under development, these proposals separate the exchange of information and the development of policy from law enforcement activities against individual parents and from the heat of particular controversies. In addition, these proposals call for building within the decisional processes we use acknowledgment of the ambivalences and tensions aroused by these medical treatment decisions, and recognition of the way these emotional responses express our relationships with one another. Thus, these proposals call for less adversarial and more constructive processes. The proposals also prefer local, contextual approaches in specific cases over abstract debate over principles. At the same time, the article urges serious efforts to devise policies about the continuing needs of handicapped people rather than the largely symbolic struggles over treatment decisions about handicapped newborns. Over specific cases and broader policies, we will still disagree, yet we may learn to understand how our disagreements show what we share. One important basis even opponents share is our complicated relationships to the handicapped person, and indeed, to others engaged in the debate.

The vantage point afforded by our relationships with one another here offers an important corrective to the perspective that focuses on our separateness. Most important, however, are efforts to keep in view both angles of vision, for our ambivalence about wanting to feel connected and also wanting to feel separate is especially pronounced in relation to a severely handicapped person, who can inspire a sense of recognition and connection but also feelings of revulsion and separation. This very focus on our relationship with a handicapped infant may illuminate how our wanting that infant to disappear is part of our relationship with him or her. Yet the relationship also invites care and sense of connection. This article has described the possible forms such ambivalence may take as an effort to acknowledge what underlies legal responses to and public fascination with cases like Baby Jane Doe's. Bringing this ambivalence to the surface as an express subject for public debate will not eliminate it, but neither will ignoring it. Addressing such ambivalence can allow deeper understanding of the shortcomings of prevailing solutions, which often appear to take rigid and polarized alterna-
tives. Talking about the ambivalence behind these alternatives is at least a way to gain freedom from the ignorance about what may propel debate. And acknowledging ambivalence about the severely handicapped child could help people understand why they may oscillate between feeling that this could be my child—and this has nothing to do with me. A similar understanding could emerge about the real possibilities that the meanings of various handicaps can change, given changes in the opportunities and resources society makes available to the handicapped—but also an understanding that actual people with terribly difficult burdens are involved.

Although the steps proposed by this article are small and incremental, they stem from this diagnosis of the deep, psychological sources of debate over cases like Baby Jane Doe’s. Taking steps that incorporate an understanding of the deep sources of dispute will not end the dispute, but may lead to more productive ways of disputing. Embarked on these routes, we may successfully turn our fascination with other people’s tragedies into commitments to share vulnerabilities and strengths.