

THE IDEAL OF COMMUNITY IN THE WORK OF THE PRESIDENT'S COMMISSION

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INTRODUCTION

Perhaps the appointed function of a Presidential Commission is to reassure people and not to disturb them. But I am disturbed by the tone of reassurance that blankets the Commission's report on Deciding to Forego Life-Sustaining Treatment.¹ I hope I am wrong, but I am convinced that we are about to enter an era of medical practices that will push retarded, elderly, and gravely ill people toward hastened deaths. The President's Commission did not intend to endorse such practices; many of its specific proposals are obviously formulated to avoid these results. But its strictures are too mild, its sense of alarm too muted.

To explain the basis of my alarm, I will focus specifically on the Commission's proposals regarding withholding treatment from impaired newborns, though at the end of this Article I will point to similar problems in the Commission's consideration of other proposals. The starting point for my analysis, and the core of my concern, is not the Commission's specific proposals but rather the vision of social community that underlies those proposals and the results that may flow from that vision.

In the last few decades, extraordinary advances in technology have permitted the survival of infants whose serious disabilities would previously have assured their death. This lifesaving technology, however, presented this problem: Many of the "rescued" infants had suffered such severe brain damage or other disability that their survival appeared pointless and perhaps even cruel. Accordingly, many infants were allowed to die, both by physicians working in concert with parents and by physicians acting alone.

The question of withholding treatment from gravely ill and retarded infants is not new, however. It has virtually always been an open secret, at least within the medical profession, that treatment was frequently, even routinely, withheld from many impaired newborns.

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¹ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions* (1983) [hereinafter cited as *President's Commission*].

During the past decade, however, as this "secret" has been breached with increasing frequency, both physicians and parents have begun to seek public validation of the moral and legal propriety of withholding treatment.² Physicians continued this practice, but until 1983 none was successfully prosecuted³ and no other legal sanctions were imposed. By the time the President's Commission addressed this issue, however, the 1983 *Baby Doe* decision had changed the public context of the issue by finding that parents had a right to withhold lifesaving surgery from their impaired newborn.⁴

Baby Doe was a Downs Syndrome boy born with a closure in his digestive system that was certain to cause him to starve to death without surgical correction. His parents decided against the surgery and the treating obstetrician agreed. Other hospital staff, however, opposed their decision and brought suit in the Indiana courts to compel the surgery. In a closed proceeding, the trial judge ruled that the parents had a constitutional right to deny lifesaving treatment to their child. On emergency appeal, the Indiana Supreme Court affirmed. The child died six days after his birth while the state prosecutor was seeking immediate review in the United States Supreme Court.

The Commission explicitly condemned this decision,⁵ but its criticism effectively amounted to an endorsement of the decision's most novel, most radical, element. The truly novel aspect of *Baby Doe* was not in its particular application of the "best interest of the child" standard, but that the court was prepared to identify *any* circumstance when parents had a right to withhold lifesaving treatment from their child. In criticizing the decision, the Report stated that treatment should be withheld only if an impaired newborn's handicaps "are so

² The first printed breach of this "open secret" occurred in a 1973 issue of the *New England Journal of Medicine* in which two faculty members at the Yale Medical School documented their hospital's practice of withholding lifesaving treatment from seriously impaired newborns. Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 *New Eng. J. Med.* 890 (1973). If this practice was "in violation of the law," they said, then "the law should be changed." *Id.* at 894.

³ See *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983), where a California appellate court issued a writ of prohibition against the prosecution of two physicians on murder charges for discontinuing life-sustaining treatment for their deeply comatose patient. The court went to great lengths to validate the treating physicians' discretion to terminate treatment for a patient with an "extremely poor" prognosis for recovery, and where they acted in accordance with the expressed wishes of the patient's family. *Id.* at 1010-11, 195 Cal. Rptr. at 486.

⁴ *In re Infant Doe*, No. GU 8204-004A (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), writ of mandamus dismissed sub nom. *Infant Doe v. Baker*, No. 482-S-140 (Sup. Ct. Ind. May 27, 1982) (unpublished and sealed decisions); see *The Story of Baby Doe*, 309 *New Eng. J. Med.* 664 (1983) (letter to the Editor by Dr. John E. Pless).

⁵ President's Commission, *supra* note 1, at 218-19.

severe that continued existence would not be a net benefit" to him or her,⁶ and, therefore, because Downs Syndrome is not such a severe impairment, the *Baby Doe* case was wrongly decided. Although the Commission differed as to the substantive content of that right, it endorsed the general proposition that there was such a right—though limited, of course, to "appropriate" circumstances.⁷

I do not want to debate the Commission or the courts about whether such a parental right exists as a matter of constitutional law. For present purposes, I want only to identify the novelty of the claim: As recently as fifteen years ago, it would have been absurd, unthinkable, and offensive to suggest the existence of such a right. This does not mean that there is no adequate contemporary claim for such a right; the jurisprudential question of the source of new or new-seeming rights is complicated.⁸ Nor does this mean that fifteen years ago no parents had ever withheld treatment from their impaired or retarded child, or that formal legal processes had punished every parent who engaged in such conduct. There was, however, a powerful social attitude that stood both against the public recognition that such practices took place (either among parents or physicians) and against the possibility of any public approval for such practices.⁹

⁶ *Id.* at 218.

⁷ *Id.* at 227.

⁸ The doctrinal basis for finding a parental right to withhold treatment stems from two converging lines of Supreme Court cases. One line holds that parents must be free from state interference in making basic decisions about their child's welfare. See, e.g., *Parham v. J.R.*, 442 U.S. 584 (1979); *Wisconsin v. Yoder*, 406 U.S. 205 (1972). The other set holds that adults have a constitutional "right to privacy" in making decisions about their own medical treatment and that children have a similar right, which their parents may exercise as surrogates for them. See, e.g., *Roe v. Wade*, 410 U.S. 113 (1973); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976). Neither set of cases necessarily compels the conclusion that parents have a constitutional right to withhold lifesaving medical treatment. These cases all insist that the state retains authority to protect children from parental abuse or neglect. As the Court stated in *Yoder*, "the power of the parent . . . may be subject to limitation . . . if it appears that parental decisions will jeopardize the health or safety of the child, or have a potential for significant social burdens." 406 U.S. at 233-34.

⁹ For example, the opinion by Judge Learned Hand in *Repouille v. United States*, 165 F.2d 152 (2d Cir. 1947), mirrored the conventional treatment of retarded people at that time: killing them could not be openly avowed or morally justified, but American society was prepared to look away, and let them disappear cloaked by the passage of time and distance. The specific question in that case was whether Louis Repouille, a recent immigrant, was entitled to United States citizenship. In 1939, Repouille had killed his severely disabled son after caring for him at home for 13 years. Judge Hand described the boy as "blind, mute, and deformed. He had to be fed; the movements of his bladder and bowels were involuntary, and his entire life was spent in a small crib." *Id.* at 152. While Repouille had been criminally prosecuted for manslaughter in the first degree, the jury showed its sympathy by finding him guilty of manslaughter in the second degree and recommending "utmost clemency." Repouille was sentenced to probation without imprisonment. *Id.* at 153.

Judge Hand ruled that Repouille's petition must be denied because the statute required

This social attitude has obviously changed in our time. The public avowals by physicians, the *Baby Doe* decision, and the proposals by the President's Commission are evidence of this change. But there is a deeper question that must be asked, a question about the larger social meaning and consequence of this change. If indeed we are in the midst of changing moral attitudes on this subject, if a new conception of parental rights has emerged in our jurisprudence, then this change is more significant than a changing fashion regarding taste in clothing, for example. Men's neckties can go from wide to narrow to wide again; even a prolonged period of abandonment for bow-ties or turtle-necks has no necessary long term implications. This is not so for moral attitudes. When the issue is important, when it reaches deep into the structure of our conceptions of ourselves, then a change in one aspect brings consequential change in other aspects and, in time, change becomes so pervasive and so interlocked that return to earlier moral visions is simply impossible, if not inconceivable. Changing moral attitudes toward withholding care from impaired children is such an issue.

I. THE PARENT/CHILD RELATIONSHIP

Consider the implications of this issue on our conception of the forces that truly bind parent and child. A series of California court decisions beginning in 1977 address the question whether a "true" parent would choose to withhold life-prolonging medical care from a retarded child. At its outset, *In re Phillip B.*¹⁰ resembled *Baby Doe*. Phillip Becker was a Downs Syndrome child who had been institutionalized shortly after birth by his parents. When he was six years old, physicians diagnosed a heart defect, which, they said, could be surgically corrected but otherwise would lead to his early death. Phillip's parents refused to permit the surgery and, after several years of desultory discussions, the physicians brought suit against the parents to compel surgery. The California courts decided that Phillip's parents had a right to refuse this surgery. That seemed the end of the matter (and, in due course, of Phillip).

But the case then took an extraordinary turn. Mr. and Mrs. Herbert Heath, volunteer workers in the retardation institution, had be-

"good moral conduct" and Repouille's action could not be so construed. Nonetheless, Hand continued, the statutory requirement applied only for the five years preceding naturalization, so that if Repouille were to renew his petition after five years of the date of his son's death, it "would not be open to . . . objection; and . . . the pitiable event, now long passed, [would] not prevent Repouille from taking his place among us as a citizen." *Id.* at 153-54.

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

come emotionally attached to Phillip and had spent considerable time with him both in the institution and during numerous visits to their home. They now brought suit alleging that the mutual emotional attachment between themselves and the child, entitled them to be considered his parents, at least for purposes of authorizing the surgical treatment that could save his life. After extensive hearings and appeals, the California courts effectively reversed their first decision and ruled that the Heaths could authorize the surgery for Phillip.¹¹

In this case the very basis of parenthood was transformed from a biological to a psychological one by the claim that Phillip's "original" parents had forfeited their parental status by deciding against providing lifesaving treatment for their retarded child.¹² Beneath the ultimate court decision in this case is a powerful ideal of parenthood—that a "true" parent always saves life, always provides care, no matter how undeserving his child might seem. This, after all, was the basis on which Solomon identified the true mother between the rival claimants: a true mother would save her child's life no matter what sacrifice was involved. This ideal of parenthood was challenged by the first round of court decisions in Phillip's case. But in the second round, the Heaths prevailed in their effort to save Phillip's life by invoking this underlying public ideal of the "true" parent and transforming themselves, in the court's eyes, into Phillip's parents.

The *Phillip B.* case does not conclusively demonstrate, however, that this ideal has triumphed over the proposition that parents can choose death as the best care possible for their gravely impaired children. The Heaths' longstanding relationship with Phillip may distinguish this situation from that of newborns like Baby Doe, where the Indiana courts disregarded the presence of several prospective adoptive parents and deferred to the biological parents' decision. The result of the *Phillip B.* case may thus only be a momentary interruption in the advance of a new cultural norm. The question for us, then—the question for the President's Commission—is whether we, as a society, should accept or resist the advance of this new norm.

The President's Commission did not address the implications of

¹¹ The unpublished court opinions are reproduced in W. Wadlington, C. Whitbread & S. David, *Children in the Legal System* 921-23 (1983).

¹² For the tension between the claims of "biological" and "psychological" parents, and reasons for preferring the latter claims in some contexts, see J. Goldstein, A. Freud & A. Solnit, *Beyond the Best Interests of the Child* (1973). In a subsequent book, however, these authors disregard the potential relevance of this tension by opting, without qualification, for the psychological parents' right to withhold lifesaving treatment. J. Goldstein, A. Freud & A. Solnit, *Before the Best Interests of the Child* 91-109 (1979) [hereinafter cited as *Before the Best Interests*].

its proposals for this public ideal of parenthood. To be sure, the Commission left room for public reversal of parents' decisions to withhold treatment by specifying that internal hospital review boards should scrutinize all such decisions and should refer "appropriate" cases to public agencies where the parents' decisions would not result in a "net benefit" for the child. But the Commission did not address the question in the specific context presented by the *Phillip B.* case—the Solomonic context of rivals for the status of parent—although there were realistic, practical reasons for the Commission to have done so.

Adoption of impaired infants has become an increasingly common practice since various social trends, including ready access to abortions, have reduced the numbers of healthy babies available for adoption.¹³ Moreover, the public furor accompanying the *Baby Doe* decision, and the intense involvement of "Right to Life" lobbying groups in that furor,¹⁴ are likely to give considerable impetus to the creation of organized mechanisms for finding adoptive parents for impaired newborns whose biological parents decide against treatment. The Commission could have promoted those efforts in its Report. It could have specifically urged internal hospital review panels to stimulate the creation of local adoption placement mechanisms or at least to ensure that biological parents know that adoptive parents may be found for their impaired child. But the Commission virtually ignored these issues. It implicitly assumed that the biological parents' decision to withhold treatment did not forfeit—or even presumptively forfeit—their status as "true" parents.

This is, I submit, a remarkably thoughtless stance. It is as if King Solomon were prepared to award the baby to one claimant without acknowledging that a rival claimant sat outside the closed doors to his court. As a matter of formal legal precedent, of course, the Commission was not obliged to recognize the claims of potential adoptive parents. Potential adoptive parents are strangers to an impaired newborn and, in many ways, the biological parents are also strangers to this child, unexpectedly confronted as they are with its unwanted, disturbing and grief-provoking abnormalities. The *Phillip*

¹³ See Note, Black-Market Adoptions, 22 Cath. Law. 48, 48–49 & n.6 (1976).

¹⁴ A storm of protest erupted against the Indiana Supreme Court's apparent endorsement of the proposition that withholding lifesaving treatment from a retarded infant could not be legally prohibited because parents had a constitutional right to make such a decision. "Right to life" groups expressed outrage that any lifesaving treatment should be refused to any infant no matter how severe his disability. They argued that the Indiana court's decision was the predictable consequence of the holding in *Roe v. Wade*, 410 U.S. 113 (1973), that fetal life can be aborted. See K. Luker, *Abortion and the Politics of Motherhood* 154–56, 207–08 (1984). For the response of the federal government to this protest, see *infra* note 20.

B. case is distinguishable as a proposition of law, however. Phillip and the Heaths were not strangers, they had already formed a mutual emotional bond when the Beckers refused to permit heart surgery for him.

No court decision required the Commission to acknowledge these propositions. But if the Commission had been attentive to the full moral implications of the new social visibility of a parent's right to withhold treatment from an impaired child, it would have grasped the challenge implicit in this claim to the traditional definition of "true" parenthood. Inadvertently, the Commission added its weight to the social forces that are working toward a redefinition of parenthood by which a "true" parent does not always give care without question and a "true" child is not always cared for unstintingly.

II. THE PHYSICIAN/PATIENT RELATIONSHIP

In the same inadvertent way, the Commission supported comparable changes in the definition of what it means to be a physician. There is a powerful tradition in our society that a "true" physician (like a "true" parent) always gives care, always saves lives, and that prospective patients can unquestioningly rely on that caretaking. This ethos has been attacked with good reason in recent decades for leading physicians to impose medical treatment on patients without regard for their wishes.¹⁵ This ethos, moreover, is not always put into practice, as medical care is routinely withheld from poor people, old people, racial minorities, and other vulnerable, disadvantaged groups.¹⁶ These refusals of medical care do not, however, challenge the ethical ideal. Indeed, the ideal is regularly invoked to condemn the practices (just as widespread practices of child abuse are regularly condemned by invocation of the ideal conception of parent caretaking). But here too, as with the ideal of parenting, the Commission embraced a conception of physicianhood that is antithetical to this traditional ideal, and yet, did not acknowledge this implication.

The contravention of the traditional ideal is perhaps clearest in the Commission's proposal for internal hospital review panels to "confirm the propriety of a decision" by parents and physicians to withhold medical treatment.¹⁷ In their composition and in the character of their deliberations, the proposed panels would closely resemble the committee, convened some twenty years ago in Seattle,

¹⁵ See J. Katz, *The Silent World of Doctor and Patient* 104-06 (1984).

¹⁶ See Hilfiker, *Allowing the Debilitated to Die: Facing Our Ethical Choices*, 308 *New Eng. J. Med.* 716 (1983).

¹⁷ President's Commission, *supra* note 1, at 227.

Washington, to decide who could have access to limited lifesaving renal dialysis resources.

Seattle physicians convened a committee of clergymen, lawyers, and nonprofessional "citizens" to predict the benefits of dialysis for the competing candidates, comparing factors such as general health and life expectancy with the utility of the treatment, the strength of their family and community ties, and their intellectual and emotional capacity or self-care and compliance with medical directives.¹⁸ This committee (popularly, and perjoratively, known as the God committee) provoked considerable public opposition. Its creation was a seemingly reasonable response to a practical problem: there were, in the early 1960's, more candidates for dialysis than available equipment and allocations accordingly had to be made on some basis. But this committee, with the high visibility of its decisions regarding who should live and who should die, was morally intolerable in our society at that time. In particular, the committee's very existence offended the social ideal that a physician's role was to save life, rather than to decide who deserved to live and limit treatment on that basis.¹⁹

The Commission's proposal for a formalized committee to affirm treatment refusals regarding impaired newborns also arises from a seemingly reasonable appreciation of a practical problem. But the Commission was nonetheless inattentive to the similarities between its own proposal and the God committee mechanism. The Commission did not discuss, and perhaps did not even consider, how change in society's moral sense since the 1960's might have made these death-dispensing committees acceptable. More important, the Commission did not address the question whether, even if such a mechanism were widely acceptable today, this is a change in moral sensibility that should be opposed rather than accomodated.

I don't know whether we have come to a different moral climate on this issue from the 1960's.²⁰ But I do believe that if there has been a change, at the very least the change should be identified and its

¹⁸ R. Fox & J. Swazey, *The Courage to Fail: A Social View of Organ Transplants and Dialysis* 244-46 (1974).

¹⁹ *Id.* at 246-49, 252-53, 267-68.

²⁰ The current existence of an intense moral struggle is revealed in the differing responses of the three branches of the federal government to the *Baby Doe* decision. First, in 1982, the executive branch found authority, in a congressional act forbidding "discrimination" against handicapped people, Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982), to prohibit any federally funded hospital from withholding care from an impaired newborn. To implement this prohibition, the executive established so-called Baby Doe squads to investigate any allegations of such hospital conduct. In 1984, the Second Circuit ruled that there was no statutory authority for this prohibition, sustaining a challenge to the government's demand for hospital records where parents of a spina bifida newborn (known as Baby Jane Doe) allegedly decided

significance explored. For myself, I would go further: the change, if it has happened, should be opposed. The reasons for my opposition come from my beliefs about the likely social significance of this change.

III. THE INCLUSIVE COMMUNAL IDEAL IN AMERICAN LIFE

The likely significance of the present shift in moral climate can be explored by considering the resolution of the controversy that raged around the Seattle God committee in the 1960's. The practical impetus for this committee was the limited availability of resources for renal dialysis. In 1972, Congress made an open ended commitment of public funds for anyone in need of dialysis, thus ending the moral dilemma with a wave of its fiscal wand.²¹ In making a financial commitment for this purpose, Congress seemed to be acting on the basis of two factual assumptions, one of which was obviously false and the other was soon to be proven false. The obvious falsehood was that this society could devote sufficient resources to medical care to save every life that might technologically be saved in any circumstance. The second falsity, as it turned out, was that the cost to meet everyone's need for renal dialysis was relatively modest. Within five years, federal expenditures had risen to some \$600 million annually for the care of some 25,000 patients, and the annual expense surpassed one billion dollars shortly thereafter.²²

But what led Congress into this incautious, extravagant commitment in 1972? It was clear from the floor debates and earlier legislative hearings that members of Congress could not tolerate the moral implications of the God committee and its underlying operating

to withhold life-prolonging care from her. *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984).

Congress then quickly enacted the Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121(3)(A), 1984 U.S. Code Cong. & Ad. News (98 Stat.) 1749, 1752 (to be codified at 42 U.S.C. § 5102), which provide that state child protective agencies receiving federal funds must themselves police hospitals to ensure that lifesaving treatment is not withheld from an infant unless, in effect, the child is already inevitably dying or is "chronically and irreversibly comatose." 131 Cong. Rec. H9805 (daily ed. Sept. 19, 1984) (statement of Rep. Hawkins).

The last official word on this controversy has not yet been spoken. It is conceivable that the federal courts could invalidate this invocation of the federal spending power on the ground that it trespasses on protected state autonomy in such traditional matters as operation of state hospitals, regulation of medical practice in private hospitals, and governance of family relations. See *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1, 17 n.13 (1981) ("[t]here are limits on the power of Congress to impose conditions on the States pursuant to its spending power").

²¹ See Rettig, *The Policy Debate on Patient Care Financing for Victims of End-Stage Renal Disease*, 40 *Law & Contemp. Probs.*, Autumn 1976, at 196.

²² *Id.* at 200-01.

premise that lifesaving medical care could be explicitly withheld from a needy, helpless person.²³ Beneath this moral revulsion was an image, an ideal, a mythic vision of a community. This communal ideal was a homespun, uniquely American product. It is the ideal encribed, among other places, at the foot of the Statue of Liberty: that no suffering person will ever be turned away from this place, that our community is open and generous and rich enough to care for everyone in need, "give me your tired, your poor . . ." It is the American version of the new Jerusalem, the universal human community welcoming all strangers in need, turning away no one.

To be sure, we have never had the full resources to honor this commitment, we have never committed all possible resources available for this purpose, and at various times in our history we have even explicitly repudiated this commitment. But Congress reaffirmed this commitment in 1972 to people who would otherwise die from kidney failure. These people were not a powerful political lobby in any ordinary sense; there were, after all, only 25,000 of them in 1977 and even with their families and friends, few members of Congress need have feared their retaliatory wrath at the polls. Their force arose simply because their neediness and suffering had become so publicly visible by the very creation of the Seattle God committee.²⁴ To permit their deaths in this circumstance was clearly to repudiate the inclusive communal ideal in American life. Congress' commitment to save them became an occasion for reaffirmation of this central ideal.

There may be some significant differences between the Commission's proposal for internal hospital review panels and the Seattle God committee. Impaired newborns may be viewed more as individuals than as competitors for scarce medical resources, and dialysis seems to promise full restoration of health as opposed to the permanent disabilities that loom for impaired newborns. Yet these differences can be exaggerated: dialysis carries unavoidable physical and psychological burdens for its recipients,²⁵ and resource availability is a central determinant of the ultimate extent of physical and mental disability for many seriously impaired newborns.²⁶

²³ *Id.* at 223-24.

²⁴ See G. Calabresi & P. Bobbit, *Tragic Choices* 22-27 (1978).

²⁵ See R. Fox & J. Swazey, *supra* note 18, at 275-78; Evans, Manninen, Garrison, Hart, Blagg, Gutman, Hull, & Lowrie, *The Quality of Life of Patients with End-Stage Renal Disease*, 312 *New Eng. J. Med.* 533 (1985).

²⁶ Goldstein, Freud and Solnit explicitly link resource availability and provision of lifesaving treatment in this way:

parental autonomy is not accorded recognition and if society insists through law that such children, indeed any children, receive medical treatment rejected by their parents, the state must take upon itself the burden of providing the special finan-

But whatever the magnitude of these differences, they do not diminish the fundamental parallel: in both cases, formal social authority would be granted to one person or group to withhold lifesaving treatment from another. While the specific rationales for withholding treatment might differ, explicit social legitimation of such withholding generally could lead to the repudiation of the inclusive communal ideal.

The embrace of this ideal in 1972 had consequences beyond the fact that some kidney patients' lives were saved, and its repudiation today would have consequences beyond the death of some impaired newborns. One such early consequence, I believe, was the congressional enactment of the 1975 Education for All Handicapped Children Act,²⁷ which effectively repudiated state laws that had excluded such children from public schools (thus banishing them to geographically hidden residential institutions), and which made a considerable commitment of federal funds to assist states in educating these children.²⁸ This legislation was the "consequence" of the earlier action regarding renal dialysis in the sense that the same vision underlay both—that of an inclusive community, rejecting no one and making a special effort to include those with special vulnerabilities.

This vision, moreover, was not limited to people with special health disabilities. There was a similar connection between the 1972 legislation for kidney patients, the 1975 legislation for handicapped children, and the 1968 Fair Housing Act,²⁹ which prohibited race discrimination in the sale or rental of homes throughout the nation. This communal commitment, in turn, came from the moral force, the inclusive communal vision, of the Supreme Court's decision in *Brown v. Board of Education*.³⁰ All of these actions shared the same underlying moral vision, each having a consequential relationship with the other.

There was no necessary causal connection among them, however: one act made it easier for the next—easier but not inevitable. And the converse is also true—that a refusal to acknowledge an inclusive communal relation with one group makes it easier to ignore the claims of another, to repudiate any communal relation with another.

cial, physical, and psychological resources essential to making real the value it prefers for the child it "saves." . . . Minimally, it should fully finance their special-care requirements.

Before the Best Interests, *supra* note 12, at 97.

²⁷ 20 U.S.C. §§ 1400–1420 (1982).

²⁸ *Id.*; see also S. Rep. No. 94-168, 1st Sess. 8, reprinted in 1975 U.S. Code Cong. & Ad. News 1425, 1432.

²⁹ 42 U.S.C. §§ 3601–3619 (1982).

³⁰ 347 U.S. 483 (1954).

The underlying stubborn reality is that each act of communal inclusion and affirmation has been met with resistance, has been and remains filled with difficulty. The reality is that communal bonds are fragile, difficult to enforce or to sustain, easily obstructed or repudiated. These bonds are never more than tenuous linkages built against powerful psychological and social forces that drive us apart, that lead us toward hostile competition for inevitably limited resources, that make us fearful strangers to one another.

If I am right in all of this, then the Commission's proposal to approve the denial of lifesaving treatment to impaired infants is socially reckless. Formal legitimation of authority to withhold treatment would give impetus to these divisive forces. However cautious the Commission seemed in recognizing only a qualified "parental right," however guarded it was in proposing internal hospital review committees that would in "appropriate" cases be required to report to public agencies, the Commission did not understand the potentially widespread implications of its position. I do not claim that the Commission's proposals will lead this country to repudiate communal relations between blacks and whites (though I do believe that its proposals are related to the same social forces that are pressing, with considerable strength, toward that repudiation in many contexts). But in the specific context of the rights of handicapped people and the protection of those who need special medical care that the Commission does overtly address, I believe that direct and harmful consequences would come from the repudiation of an inclusive communal relationship with impaired infants.

IV. THE PAST BECKONS

The Commission proposals come, after all, at a specific historical moment. It is always difficult to draw precise historic parallels, to recognize the trends at work in our own time by analogizing to some past time. But I believe that we have been here before, that we stood earlier at this historical crossroad and took a shameful path. A hundred years ago, the question was the communal status of blacks. In the preceding fifty years, around 1830, this country had moved from public approval of slavery—an uneasy approval, but approval nonetheless—to a growing revulsion, then to emancipation, and then to an effective repudiation of that emancipation, and virtually avowed reenslavement. The dispositive shifts in attitude occurred in the space of just one generation, from 1860 to the 1880s.

At the same time that an inclusive communal relationship with blacks was repudiated, a similar social attitude was turned toward

retarded people. The end of the nineteenth century witnessed the creation of monstrous residential institutions that embodied the exclusion of retarded people from our communal life.³¹ As noted earlier, withholding lifesaving treatment from impaired infants—a purposeful infliction of death—has never been an openly avowed and approved public policy in this country.³² The avowed policy was, however, not benign. We did not kill retarded children. We buried them alive in hidden public residential institutions.

A generation ago, during the 1950's and '60's, we reopened the question of our communal race relations. And once again, with a similarly brief time lag, social attention focused on the communal status of retarded people. The existence of, and true conditions in, retardation institutions were widely admitted in public forums during the 1960's³³—the moment of emancipation. A public commitment was made to open community-based facilities for retarded people, to acknowledge a communal caretaking obligation and caring relationship with them—the promise of reconstruction. Now, however, we seem poised at the moment of reenslavement—not, perhaps, by returning to the old practice of live burials, but by bestowing approval on the real thing, the purposeful infliction of death.

V. CONSEQUENCES OF THE COMMISSION'S REPORT (FROM A RIGHT TO A DUTY TO WITHHOLD TREATMENT)

The formal announcement of this new policy of legitimizing the withholding of lifesaving treatment from impaired newborns can be seen in the *Baby Doe* decision by the Indiana courts and the first *Philip B.* decision, never explicitly repudiated by the California courts. While the President's Commission criticized these specific decisions,³⁴ its proposal inadvertently adds to their underlying social momentum. The most likely immediate consequence would be evident in parents' attitudes toward their impaired newborns and their perceptions of social expectations for them. This momentum, however, does more than give approval to parents and physicians who want to withhold medical treatment from Downs Syndrome or other anomalous children. It will press parents beyond the right to withhold lifesaving treatment toward the belief that they have a "duty" to withhold this

³¹ See P. Tyor, *Segregation or Surgery: The Mentally Retarded in America, 1850-1920* (1972).

³² See *supra* note 9 and accompanying text.

³³ See President's Special Message to the Congress on Education, Pub. Papers 105, 113 (Jan. 29, 1963).

³⁴ President's Commission, *supra* note 1, at 218-19.

treatment because our society has clearly signalled both its unwillingness to extend a communal relationship to these children and a consequent inhospitality—an intolerance, perhaps—for their very existence.

A. *The Child and Society (The "Net Benefit" Standard and Altruism)*

The President's Commission explicitly formulated its proposals to avoid the creation of a duty to withhold treatment. But in condemning the *Baby Doe* decision, the Commission paradoxically relied on the underlying moral premises that themselves give social momentum to these pernicious, unintended results.

The Commission acknowledged the problem of social prejudice toward, and the consequent vulnerability of, handicapped people. In formulating a substantive standard that would authorize withholding treatment from such children, the Commission tried to provide protection against this vulnerability: The Commission stated that treatment should be withheld only if the child's handicaps "are so severe that continued existence would not be a net benefit" to him or her.³⁵ It concluded that by this "net benefit" criterion, treatment clearly should have been provided for Baby Doe.³⁶ But the contradictory impulse in the Commission's formulation is revealed in its specifications regarding the content of this "net benefit" criterion. The Commission stated that whoever applied this "net benefit" standard—whether parent, physician, or public official—must "exclude[] consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society."³⁷ The decisionmaker, so the Commission enjoins, "is obligated to try to evaluate benefits and burdens from the infants's own perspective," excluding these other possible competing perspectives.³⁸

There is an internal logical tension in this formulation that contains paradoxically destructive implications. The tension is this: If I imagine myself to be a seriously impaired infant and, as that infant, ask myself whether I get more benefit than burden from continued life, does it necessarily follow that I must ignore the burdens created by my impairments on my parents, my brothers and sisters, and the society of which I am a member? What if I, as that impaired infant, want to save these others from suffering on my account? What if I

³⁵ *Id.* at 218.

³⁶ *Id.* at 219.

³⁷ *Id.*

³⁸ *Id.*

want to define my self-interest in a way that gives substantial weight to alleviating the suffering of others, even greater weight than I give to alleviating my own suffering? Am I forbidden to act on altruistic motives, am I necessarily restricted only to act on the most narrowly conceived, selfishly grasping motives? The Commission's formulation seems to bar any ascription of such altruistic, self-denying motives to an impaired infant.³⁹

But then, we will ask, why should the rest of us behave altruistically toward this selfish, grasping, unreciprocating person? If this infant is truly a member of our community, then why shouldn't he be expected to give at least some weight to others' interests? But if he is exempt from this communal obligation why, then, are the rest of us obliged to weigh only his interests and none of our own in making decisions that obviously affect us both?

There is more than a formal logical bind here. This internal tension in the Commission's formulation highlights the basic underlying social force that is likely to defeat the Commission's avowed protective purposes toward impaired infants. The Commission's proposed standard relies on the rejection of any social commitment to give substantial weight to others' interests, the very rejection of a communal caretaking obligation that in itself jeopardizes the communal status of impaired children. The Commission's proposed standard on behalf of the impaired child elevates selfishness to a high moral plane. It thus inadvertently endorses the anticommunitarian ethos that is an increasingly pervasive characteristic of our time. The Commission implicitly relies on an understanding that an impaired infant would be and should be as narrowly self-centered in his calculation of net benefits and burdens as the rest of us.

But here is the central problem: There is no room for severely impaired children or adults in a society where it is permissible for others always to behave in a narrowly self-interested way, always to deny any moral imperative for self-sacrifice in the service of others, always to prefer self-serving actions at the expense of communal bonds. Severely impaired children and adults cannot thrive, indeed they can hardly live, unless others are prepared to prize a communal relationship with them and to place loyalty to that communal bond above their own narrowly conceived self-interests. These infants and adults depend on others' willingness to care for them.

To be sure, many of these infants and adults are not inevitably helpless; many have potential for substantial or even complete self-

³⁹ See R. Burt, *Taking Care of Strangers* 151-52 (1979).

sufficiency. But considerable support, both emotional and financial, is required from others for the ultimate realization of their potential capacities. A society gripped by the ideology of extreme individualism cannot generate this kind of support. There is an insufficient sense of connection, the bonds of community are too attenuated in such a society to sustain the social and individual efforts required to provide adequately nurturant care and support to impaired children and adults.

In such a society, moreover, not only strangers, but also parents of impaired children, are implicitly encouraged to deny the existence of caretaking obligations and communal bonds toward such children. This encouragement is the route that leads parents from the proposition that they have a *right* to deny care to their impaired children to the conviction that they have a *duty* to deny care. This sense of duty arises because the dominant ideology, the moral image that the society maintains of itself, posits that each individual must stand alone (or at least must have the readily achievable capacity for independent autonomy). This ideology dictates that no one is entitled to depend indefinitely on others for support and caretaking. It thus excludes those in need of such caretaking as a moral imperative, as a duty that requires the social exclusion of the impaired individual. This was the moral premise on which the isolating, monstrous residential institutions for retarded were created around the turn of the century. This is the moral premise that will lead parents (as well as physicians and judges) to exclude impaired children by withholding treatment from them.

B. *The Parent and Society (Responsibility and Isolation)*

For parents, in particular, this impetus will gather momentum from the special circumstances at the birth of their impaired child. Typically, healthy and able-bodied parents hoping for a "normal," perhaps even a "perfect," child are suddenly thrust into a position of responsibility for an abnormal infant. However fully parents might grow to treasure their abnormal child, and to reformulate their own identities as "normal people," this response does not arise easily and immediately at the first moments of their new and unexpected relationship.⁴⁰

Understandably, these special difficulties may affect parents' atti-

⁴⁰ See Solnit & Stark, *Mourning and the Birth of a Defective Child*, 16 *Psychoanalytic Study of the Child* 523 (1961); Drotar, Baskiewicz, Irvin, Kennell, & Klaus, *The Adaptation of Parents to the Birth of an Infant With a Congenital Malformation: A Hypothetical Model*, 56 *Pediatrics*, Nov. 1975, at 710 (based on interviews of the parents of 20 children over a period of nearly two months commencing from one week after child's birth).

tudes when, shortly after the child's birth, they are asked to decide whether he or she should live or die. Parents are the obvious candidates to make this decision because their lives will be most directly affected and because the child's welfare depends principally on their continued involvement. Yet implicit in this "parental right" is not only the proposition that parents alone have this right to decide but that they are alone in making this decision.

This implication can readily be magnified by the parents' perceived isolation from their prior inclusion in the community of "normal people." Whether or not they are conscious of this impulse, it is temptingly easy for them to reenter the "normal community" by exercising their recognized right to let their impaired child die.

Many parents would recoil—just as the Commission did—from even a whispered invocation of this kind of self-interest. Even so, this perceived isolation readily translates itself into the proposition that the child's own interest is best served by death; these parents are forced by their social isolation to conclude that no one will help them and their child, and that all assistance for their impaired child must come from their own limited and generally insufficient resources. Unless these parents possess a heroic vision of their own nurturing capabilities, this isolation will ultimately lead to a decision in favor of the child's death.

The implication of a parent's isolated authority to determine the survival of an impaired child may lead to negative societal consequences of a more general nature. Should this parental right be clearly established, then the *survival* of an impaired infant would connote that his parents not only wanted this result but could have decided otherwise. From this connotation, it is only a short step to conclude that the parents alone bear the responsibility of satisfying the child's full needs from their own resources—that it is their "private problem," as the child's survival was an exercise of their "private authority." Consequently, this "family privacy" right would foster the erosion of an already tenuous communal commitment, and would feed the natural impulse among "normal people" to deny assistance to disabled people.

For all these reasons, the formal recognition of a parental right to withhold treatment would tend to press toward its exercise. The "right" would not remain a neutral construct, available merely for those who choose to use it. The right would feed itself, and would magnify the belief that death best serves everyone's interests, including the impaired child's.

CONCLUSION

I do not claim that death is *never* preferable for any impaired child. In many circumstances, death can be the most humane, even loving care a parent can provide. But this reality does not necessarily demand the formal legitimation of such a parental right. Establishing a formal social regime to give prior explicit authorization for death has, for the reasons I have indicated, an intrinsic momentum that inflicts terrible suffering on many people, even though continued treatment might also inflict suffering on many impaired children and their families. This is the pervasive tragedy in these cases: that suffering cannot be averted, no matter what individual or general social decisions might be made regarding seriously impaired infants.

I am not suggesting that the Commission simply made a drafting error in the formulation of its proposal and that socially vulnerable infants could have been more reliably protected if the Commission had drafted a different verbal formula to govern decisions about withholding medical treatment. My point is that the Commission's formulation reveals an underlying ideology in our society that itself jeopardizes the protective goal that the Commission set for itself. The Commission should have identified the expansive implications of this individualistic ideology in any proposal to legitimize the withholding of care from impaired infants, no matter how such a proposal might be drafted. The Commission should have warned that the claims for parental "privacy rights" in withholding care have an inevitable public significance, should have warned that formal social legitimation of these actions transforms private conduct into public performance, approves and invites imitation. The Commission should have warned that this formal legitimation erodes the inevitably fragile public connection between an impaired child, and his parents and their community, upon which any child's welfare, upon which his very life, inevitably depends.

If the Commission had understood these potentialities, it might also have seen the same forces at work in other contexts where the withholding of lifesaving medical treatment was at issue, and might have seen how these same forces could similarly undermine its avowed protective purposes in those other contexts. Consider, for example, the Commission's general approbation of the principle that since autonomous individuals have a right to determine their own medical treatment, a competent individual has a correlative right to decline lifesaving treatment.⁴¹ As a general proposition I have no

⁴¹ President's Commission, *supra* note 1, at 45.

quarrel with this. But there is a considerable social danger lurking in this seemingly self-evident formulation, for the individualistic ideology that lies beneath this formulation, giving it contemporary moral force, also implies that there is no public commitment, no communally acknowledged obligation, to sustain and nurture burdensomely sick people. This implication may only be implicit, it may be glimpsed only as if "through a glass, darkly"; but if a gravely ill person, if a sick old person, sees this message embedded in the contemporary social ideology, then he will construe his individualistic "right to die" in a different light. Then he will see this right as something more, as a "duty to die" because no one wants him to act differently, because no one will sustain him in adversity, and because then even he will refuse this caretaking sustenance to himself.

The Commission did not intend this result any more than it intended to require parents of impaired newborns to withhold treatment from them. But the Commission did not acknowledge, perhaps it did not even understand, the potential power of the underlying social forces at work in the context of withholding lifesaving treatment, and how readily these social forces might find ideological expression by transforming rights into duties to die or to inflict death.

Even if the Commission had acknowledged all of this, it might still have offered the same proposals. It might still have concluded that treatment must be withheld from some gravely ill newborns and that explicit social validation of this withholding is necessary to achieve this result or that seriously ill adults must be free, and formally acknowledged as free, to reject lifesaving treatment. There are authentic problems that these proposals address and, in their own terms, would solve. On balance, perhaps the Commission's proposals are reasonable, sensible, practical. But the Commission's presentation of these proposals lacks balance. There are serious social risks in these proposals, risks that the Commission was not prepared to admit.

Perhaps the Commission thought its public function was to reassure rather than disturb people. But I for one am disturbed. I fear that fifty years from now we will see these matters in retrospect, not "through a glass, darkly, but then face to face." I fear we will be appalled and ashamed at what we see then in our communal treatment of retarded people, of physically disabled people, of sick and old people—just as we were horrified when, in the 1960's, we looked inside our public retardation institutions as if for the first time "face to face." And I hear us asking fifty years from now, as we asked twenty years ago, "How did this happen? Men and women of good will and good intentions set the forces in motion that led to this result. How

did this happen? And how can we protect ourselves against this happening, once again?"