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The Treatment of Handicapped Newborns: Is There a Role for Law?

Robert A. Burt

We have just recently entered a new phase in the controversy about the medical treatment of seriously impaired newborns. In October 1985 a new federal law went into effect which mandates the provision of treatment to all infants, no matter how seriously ill or impaired, unless they were inevitably and imminently dying or were irreversibly comatose. In one sense, this legal mandate is nothing new. The law in every state has been clear for many years that purposefully withholding medical treatment from newborns was criminal child abuse and probably even homicide. But though this was the "law on the books," it was widely ignored in practice—a fact that was an open secret among members of the medical profession.

Just thirteen years ago, in 1973, prominent members of the medical profession in effect let the public in on the secret. In an article in the New England Journal of Medicine, Drs. Raymond Duff and Ian Campbell—physicians who were members of the Yale Medical School faculty and in charge of the newborn intensive care unit at the Yale-New Haven Hospital—documented the fact that they and their medical colleagues purposefully withheld life-saving treatment from some

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gravely ill infants. The publication of this article was in effect a radical break with past medical practice—for now these physicians, in the prestigious forum of the *New England Journal*, were forcing public knowledge, and demanding explicit public approval, of practices that had previously occurred only behind closed clinical doors. This was the first phase in the current controversy.

The second phase occurred during the succeeding decade after this 1973 revelation. The Duff and Campbell article was met by considerable hostility in some quarters—most notably among right to life advocates who were spending most of their efforts opposing the Supreme Court's decision in the abortion case. This Supreme Court decision also occurred in 1973, and, though Duff and Campbell did not make their public disclosure in direct response to this decision, the same social forces that made it plausible for the Justices to issue their public approbation of abortion as a protected choice by a woman with her physician, also encouraged Duff and Campbell to speak out in behalf of the right of parents and physicians to withhold treatment from seriously impaired newborns. There was, then, passionate opposition to both of these positions. But notwithstanding this opposition regarding the right to choose abortion, the courts were for the most part adamant in upholding the right and striking down restrictive state legislation. At the same time during the decade between 1973 and 1983, there were some indications that courts would also mount the ramparts to defend the claimed right of parents and physicians to withhold medical treatment from impaired newborns.

Three critical court decisions supported such rights during this time—a 1977 California Supreme Court ruling that the parents of a child with Down's syndrome (in this case, not an infant but a ten-year-old boy) had a right to refuse life-prolonging heart surgery for him; then a 1982 Indiana Supreme Court decision refusing to overturn parents' refusal to consent to surgery to correct an esophageal atresia of a newborn infant with Down's syndrome that led to his death by starvation (the so-called Indiana *Baby Doe* case); and in 1983, the *Baby Doe* case.

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Jane Doe case in New York where both an appellate-level state court and a federal district court ruled that parents had the right to refuse life-prolonging surgery for their infant afflicted with spina bifida. All of these decisions, taken together, suggested that the courts were moving toward the result that Duff and Campbell urged in their 1973 article—to approve in principle the withholding of care from impaired newborns.

Two other significant events occurred in 1982 during this second phase of the controversy. A presidential commission on biomedical ethics issued a report criticizing the Indiana Supreme Court decision in the Baby Doe case, but at the same time endorsing the principle that physicians and parents should have a right to withhold treatment in what the Commission regarded as “appropriate” cases. The Commission's criticism of Baby Doe was based on its judgment that Down's syndrome is not in itself a proper basis for withholding treatment but that, in other cases, it could be proper to conclude that a severely impaired infant might be so incapacitated that survival would not be a “net benefit” for the infant. At the same time that this presidential commission was deliberating, the U.S. Department of Health and Human Services (HHS) reacted to the Indiana court decision by establishing so-called “Baby Doe squads” to investigate all cases in federally-funded hospitals where medical treatment might be withheld from newborns. In the 1983 Baby Jane Doe case, a federal court of appeals ruled that HHS had no statutory authority to conduct these investigations.

This, then, brings us to the third phase—the current phase of the controversy. Congress responded to this court of appeals ruling by passing the Child Abuse Amendment of 1984. This new statute does not mean that the federal government now has authority to reinstate the federal investigations. Instead, the statute requires that states themselves create investigative mechanisms, building on the same agencies that now exist in every state to protect children against abuse.

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8PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIO-MEDICAL AND BEHAVIORAL RESEARCH. DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 219, 227 (1983).
9Id. at 218.
10United States v. University Hospital, 729 F.2d 144 (2d Cir. 1984).
11See 130 CONG. REC. 11699 (1984) (quoting a letter from the principal Senate sponsors of the 1984 amendments, “This legislation does not itself authorize direct federal involvement in individual cases.”)
or neglect, to ensure that all newborns receive medical treatment unless they are inevitably dying or are irreversibly comatose—regardless of their parents' or physicians' wishes to the contrary.

This new statute is not necessarily the last word in this controversy. It is conceivable that the courts could invalidate this legislation on the ground that, like the choice for abortion, parents have a constitutional right of "family privacy" to decide for or against treatment of impaired infants. This is conceivable by building on the precedents in California, Indiana and New York, that a court would reach this result. It is unlikely, however, that any court today would reach this result. But it was also unlikely in 1972, when the abortion case was pending before the Supreme Court, that the Court would find a constitutional right to abortion.

The issue, however, is not to predict how courts should respond to this new legislation. It is instead to evaluate the merits of the legislation and thus to consider not only how courts should respond to it but also what the proper role of positive law is in this controversy. In one sense this new legislation means to move us back to the beginning—to reassert the principle that purposeful withholding of treatment is wrong and violates the law in virtually all circumstances. But in another sense, this legislation seems to put more force into this legal command than it previously possessed. This time, the statute seems to say we mean to enforce it.

As a matter of abstract principle, the resolution of this question is puzzling and even deeply troubling. Considered in the abstract, there are three possible resolutions:

1. to insist, as the new law seems to mandate, that virtually every newborn no matter how gravely impaired receive the most aggressive medical treatment available;

2. to give formal recognition to the rights of parents (or parents acting in conjunction with physicians) to withhold treatment whenever they see fit; or

3. to provide a formal mechanism so that parents (and physicians) who want to withhold treatment must go to court where a judge would be authorized in some categorically defined set of "appropriate" cases to give advance approval to this withholding.

As an abstract matter, each of these three alternatives are unsatisfactory. Each is likely to carry substantially undesirable con-

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sequences: aggressive treatment of every newborn, no matter what the consequences, could inflict terrible suffering on too many people (both the newborn and its family); providing formal legal authority to parents (or to parents and physicians) to withhold treatment whenever they chose would ignore the proper role and the need for society to protect vulnerable children against potentially abusive treatment from their caretakers (and, we must note, retarded people have been especially vulnerable to abuse in this society); and giving authority to a judge to decide beforehand whether treatment should be provided or withheld would give only a hollow pretense of independent, publicly accountable review of such decisions (as proven, in part, by the fact judges in the past who have been charged with protecting the interests of retarded people against wrongful sterilization or harmful institutionalization have turned a collective blind eye on terrible abuses).

This conclusion, however, is not very helpful. If all of the possible resolutions to this controversy are unsatisfactory, where then should we turn? Ultimately, while there is no good solution—no one solution that neatly solves all problems without creating other problems—there is nonetheless a least worst solution; a solution, moreover, that is not necessarily correct for all time but is nonetheless the best available for this particular time in our social history. That solution is—for all its difficulties and imperfections—the statute that the Congress has just enacted.

During this past decade, until the enactment of this statute—during the second phase of this controversy—our society has been poised at the edge of embracing a principle that would proclaim the right of parents (or parents and physicians) to withhold treatment from impaired newborns. The consequences of embracing this principle, at this moment in our social life, would be so harmful, so destructive—not only for specific infants whose lives will be ended but more generally, and even more fundamentally, for the ethos of communal caretaking in our society—that we are best advised to reject the principle clearly and forcefully. This forceful rejection is the public significance of the 1984 congressional act.

The ethos of communal caretaking is already stretched thin in our time. This social fact is a fundamental reason that the medical profession generally is viewed these days with suspicion and even hostility that just twenty years ago or even less would have been inconceivable. As much as physicians might see this new congressional act as a further expression of public mistrust, contemporary social acceptance of parental rights or physicians’ discretion to with-
hold newborns' treatment would ultimately increase the erosion of public confidence in the trustworthiness of the medical profession.

There is a deep issue at stake in this controversy; the issue is even more than the ethical principle abstractly stated. It goes to the underlying way that we think about our relations with one another—whether each of us in our social interactions is more to be trusted than feared, whether each of us will truly and unquestioningly care for one another or turn away from neediness. The real question is: when each of us is or becomes needy (as inevitably occurs to everyone at least at the beginning and at the end of life), whether others can be relied upon to help. Though the current controversy about the status of impaired newborns, and the provision of medical services to them, has not been directly considered in these terms, the resolution of this controversy at this moment in our social life will be viewed—implicitly if not explicitly—as an answer to this general question of overriding social significance.

This proposition cannot be proven, but there are several reasons that leads one to believe in its truth. If this proposition is correct or even plausible, then it is imperative for the nurturance of our belief in the caretaking potential of our society that we turn away from embracing any principle that would erode that collective belief.

The first reason supporting this proposition can be drawn from a detailed consideration of the 1977 California court case mentioned earlier. The case involved a boy with Down's Syndrome named Phillip Becker. Phillip was ten years old when the litigation first began in 1977. He had been placed in an institution by his parents soon after his birth; 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 permission for the surgery; after several years of desultory discussions, the physicians brought suit against the parents to compel surgery. The California courts decided, however, that Phillip's parents had a right to refuse this surgery.\footnote{\textit{In re Phillip B.}, 159 Cal. Rptr. 48.} That seemed the end of the matter (and, in due course, of Phillip).

The case then took an extraordinary turn. Mr. and Mrs. Herbert Heath, who were volunteer workers in the retardation institution, had become emotionally attached to Phillip; they had spent considerable time with him both in the institution and on numerous visits in their home. They then brought suit alleging in effect that their involvement with Phillip, and the mutual emotional attachment between them and him, meant that they should be considered his parents at least for purposes of authorizing the surgical treatment that could save his life.
After extensive hearings and drawn-out appeals, the California courts in effect reversed their first decision and ruled that the Heaths could authorize this surgery for Phillip.14

Mr. and Mrs. Becker maintained throughout these proceedings, both in the courtroom and in the popular press which extensively covered the case, that the Heaths were officious intermeddlers, interlopers who were stealing their child and their rights to control their child's fate.15 The California courts, after first ruling that the Beckers as Phillip's parents had a right to refuse treatment for him, then concluded that the Beckers' refusal had effectively forfeited their status as parents. (Though the courts did not explicitly say this, the Beckers themselves acted on this interpretation; after the surgery was successfully performed, they agreed that the Heaths could formally adopt Phillip.)

The Phillip Becker case reveals an underlying, though usually unacknowledged, aspect of the general claim that the parents of seriously impaired newborns have a right to withhold treatment from them. The California courts' ambivalence on this issue was sharply revealed in Phillip's case, and the ambivalence itself indicates that the recognition of such right would transform our deepest conception of what it means to be a parent. Even though a rational case can be made that death is sometimes the best care that can be offered to a suffering person, and even though it is rational to conclude that parents are better situated than anyone else to decide the best care for their child—Phillip Becker's case demonstrates the deep hold on our moral sensibilities of the proposition that a true parent always chooses life for his child and a true parent never willingly accepts the loss of a child. This, after all, was the way that King Solomon determined the true mother between the rival claimants—that the true mother would never countenance the death of her child, no matter how much suffering its continued life would bring to her.

This conception of parenthood—that the true parent always chooses life, no matter what—is not, however, an eternal verity, true for all time or for our society even in the immediate future. It may be that the tragic choices pressed forward by our technological capacities to extend life for gravely impaired newborns will lead us to a new conception of what it means to be a parent. This, however, would be a new conception and this new conception is at sharp odds with our current ideas of true parental caretaking.

This proposition has direct parallels in our society's deepest current views of the proper caretaking role of physicians as well as parents—and accordingly that the claims of some physicians for a right to choose against life-saving treatment is radically inconsistent with the proposition that a true physician, like a true parent, always and unquestioningly saves life. If we abandon it, we must first of all acknowledge—as with the Beckers’ claim of parental rights to withhold treatment—that this is also a new position and that abandoning the old vision of the caretaking role of parents and physicians may entail quite substantial social costs.

The extraordinary cultural authority of the medical profession in this century has rested on a basic social conviction that physicians work unquestioningly and unstintingly to save every life—that true physicians do not judge whether their patients deserve to live or to die. A public acknowledgment then that sometimes physicians do not act in this way will have deeply unsettling implications for medical practice. This acknowledgment could change the definition of what it means to be a physician in this society, and with this change, could come an erosion of trust in physicians’ curative capacities, a trust which has traditionally led patients to look to physicians for help and which has bolstered physicians’ confidence in their capacity to help. This social trust in the medical profession has already suffered considerable erosion in the past twenty years or so; whatever the causes of that erosion, the professional endorsement for withholding life-saving treatment would give further impetus to this trend.

This proposition cannot be proven with scientific certainty. Its social force is illustrated in the same way that the Phillip Becker case showed the California judges initially embracing and then almost instinctively recoiling from the comparable claim by parents. The illustrative instance regarding the medical profession took place in the 1960s and early 1970s—not with newborns but with the question of withholding medical care from patients in acute renal failure. When the technology for renal dialysis was first developed, most notably in Seattle in the early 1960s, a practical problem presented itself. There were simply not enough resources available to provide dialysis for everyone who might need the treatment. Accordingly Seattle physicians created a formally structured committee to choose among competing candidates—necessarily and visibly, therefore, to choose who would live and who would die.¹⁶

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When this committee became widely known through press reports (it was popularly and pejoratively called the Seattle God Committee) there was considerable outcry, notwithstanding the understandable and sensible reasons that brought the committee into existence.\(^\text{17}\) The existence of the committee, in particular, offended the social ideal that the role of physicians was to save life, that they should not decide who deserved to live and limit treatment on that basis.

In 1972 the United States Congress acted to reaffirm this social ideal by making an open-ended commitment of public funds to provide renal dialysis for anyone in need.\(^\text{18}\) With a wave of its fiscal wand, Congress thus ended the practical constraint that had produced the Seattle God Committee. This was, it must be noted, an extravagant and incautious financial commitment. The costs of this program have grown since 1972 to well over one billion dollars each year for the benefit of a limited number of people—twenty-five thousand or so.\(^\text{19}\) This extraordinary commitment seemed based, moreover, on an obvious falsehood—on the false proposition that this society had sufficient resources for medical care in order to save every life that might technologically be saved in any circumstance.

What then led the Congress to take this extraordinary step in 1972? It was clear from the floor debates and earlier legislative hearings that the members of Congress could not tolerate the moral implications of the Seattle God Committee and its underlying operating premise that life-saving medical care could be explicitly withheld from a needy, helpless person. In one sense the Congress acted to reaffirm the norm of the physician as an unquestioning nurturant caretaker. In this same sense, the new congressional legislation requiring the provision of life-saving treatment to all impaired newborns means to reaffirm this same norm.

There is an even deeper moral norm that was visibly at work in the 1972 renal dialysis legislation and is also implicated in the current debate about impaired newborns. In 1972 the Congress found the Seattle God Committee morally intolerable. 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 enscribed, 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

\(^{17}\)Id. at 224.

\(^{18}\)See Rettig, The Policy Debate on Patient Care Financing for Victims of End-Stage Renal Disease, 40 LAW & CONTEMPORARY PROBLEMS 196 (Autumn 1976).

\(^{19}\)Id. at 200–201. See also G. CALABREST & P. BOBBIT, TRAGIC CHOICES 186–89 (1978).
to care for everyone in need, "give me your tired, your poor..." It is, if you will, 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 the 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 some twenty-five thousand of them and even with their families and friends, few congressmen need fear 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. 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 communal ideal.

This reaffirmation had consequences beyond the fact that some kidney patients lives were saved. One such consequence was congressional enactment of the 1975 Education for All Handicapped Children Act which 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 the education of these children.20 This legislation was the consequence of the earlier action regarding renal dialysis since it shared the same vision of an inclusive community, rejecting no one and making special effort to include those with special vulnerabilities.

This pursuit, 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 open housing act which prohibited race discrimination in the sale or rental of homes throughout the nation.21 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.22 All of these actions were of a piece; each shared the same underlying moral vision; each had a consequential relationship with the other. There was no necessary causal connection among

them; one act did not make it inevitable for the other to follow. One act made it easier for the next—easier but not inevitable. The converse is also true—that a refusal to acknowledge an inclusive communal relation with one group makes it easier to ignore the claims, to repudiate any communal relation, with another.

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

The truth in this abstraction only reveals itself in concrete encounters among specific human beings. One such encounter—when the fragility of our common human bonds is most strikingly revealed—is when parents who have expected and hoped for a “normal,” indeed a “perfect,” child are suddenly confronted with a less-than-perfect, a seriously abnormal, infant. At that moment, their capacity to include this unexpected and even unwanted child into their family, into the “family of mankind,” is put to an unexpected test. At that moment of testing, the general ethos of the society, in which these parents live and into which this abnormal infant has been born, will inevitably have considerable impact on the parents’ willingness and capacity to welcome rather than to turn away from this infant.

The question at this moment, moreover, is not simply how the general society treats mentally or physically disabled people. The more basic question is whether the society offers support to all who are in need, or whether the dominant ethos is rigidly competitive and individualistic, or whether the ethos is “every man for himself.” In such a society, parents would know not only that their abnormal child was unwelcome, but that no one would offer assistance to them in their efforts to meet the special needs of this child. In such a society, these parents would know that they too, if they welcomed this child into their immediate family, would be jeopardizing their own welcome as members of the broader society.

This would be the underlying implication if this society were explicitly to recognize that parents have a right to withhold life-saving treatment from their impaired child. Those who argue for such a right rest their case on the norms of “family privacy” and “freedom of choice.” The underlying implication of this position is that the parents’ relationship with their impaired child is indeed a “private affair,” and if the parents choose to accept this child into their family, that is their
private act with no public significance. To put it in the vernacular, "they have made their bed, now they must lie in it," or this child is "nobody's business but their own." In other words, having made this private choice, the parents are obliged to bear the consequences of this choice in private; they can look to no one but themselves and their own resources to support the special and specially demanding needs of this child.

In principle, one might argue that even with this background understanding, the parents' decision whether to accept or reject this child would be an exercise of "freedom of choice," but the common sense of the matter is that few parents would see themselves as truly free agents in making such a choice. Most parents would be strongly influenced by the surrounding social context in which this decision is made. If a child, because of his impairments, will put special strain on their resources, both emotional and financial, and if no one will help bear these burdens, this knowledge must inevitably affect a decision, even if it does not necessarily dictate one clear result over another. If, moreover, the decision belongs to the parents whether to accept this child and its special burdens because our society values "privacy" and "freedom" above all else, how tempting it is for them to embrace one particular version of these values—"privacy" and "freedom" defined as interpersonal distance and disengagement—in order to put distance between the parents and this abnormal and burdensome child: to choose "freedom" by freeing themselves from this child.

In this paradoxical way, the social norm that parents have free choice becomes readily translated into a unilateral mandate to choose death for the child. In this paradoxical way, the parents' supposed choice even becomes effectively transformed into a perceived duty enforced by infliction of a social penalty. The duty is to remove the severely impaired child from the community. The penalty for parents' failure to act on this duty is that they must bear all the special burdens of this child on their own, without support or even sympathy from the "normal" community.

Fortunately, this is not the direction our society has chosen to take. The enactment of the 1984 legislation was a reaffirmation of our vision of ourselves as a nurturant, caretaking community. This is the basic reason for its enactment—not because in every individual case, the statute will lead to the best possible result for the specific newborn infant and his family but because of the social implications of other possible solutions. The formal social recognition of the right of parents or physicians or judges to withhold treatment in specific cases would harm more infants and their families than it might help and would, moreover, have even wider harmful social implications. This formal
recognition would not only depict parents and physicians as less nurturant, less reliable, caretakers than we had previously believed. It would also, for that very reason, undermine any commonly held vision that American society is a place of common concerns and of mutual support and sustenance.

For those who are inclined to see this legislation as a defeat—as an intrusion on the rights of parents or the professional prerogatives of physicians—should reconsider and see this legislation as an essential, though still incomplete, victory for the common aspiration of parents and physicians, to sustain and nurture all, even the seemingly most unworthy individual, in times of affliction and need.