Withholding Treatment from Baby Doe: From Discrimination to Child Abuse

NANCY K. RHODEN and JOHN D. ARRAS

Ohio State University;
Albert Einstein College of Medicine
and *Barnard College, Columbia University*

THE QUESTION OF WHEN, AND WHETHER, LIFE-sustaining treatment can be withheld from infants suffering from birth defects or extreme prematurity has recently received three different answers from three influential quarters. The Reagan administration's Department of Health and Human Services (DHHS) provided a very restrictive answer in its controversial "Infant Doe Rule."[1] The President's Commission for the Study of Ethical Problems in Medicine—an interdisciplinary body of experts initially appointed by President Carter—then issued its own recommendations, which were at points highly critical of the DHHS policy (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 197–229). Following the demise of the "Infant Doe Rule" in the federal courts, a third response to the "Baby Doe question" was formulated in the Congress as an amendment to the Child Abuse Prevention and Treatment Act (*Congressional Record* 1984). The conclusions of these three governmental bodies have differed dramatically, both in their substantive standards and in their procedural mechanisms for decision-making and oversight.

[1] 49 *Fed. Reg.* 1622 (Jan. 12, 1984), amending 45 C.F.R. § 84.

Milbank Memorial Fund Quarterly/*Health and Society*, Vol. 63, No. 1, 1985

Our purpose in this essay is to assess the substantive ethical standards and accompanying procedures proposed by the Reagan administration, the President's Commission, and the sponsors of the amended legislation on child abuse. While we find little merit in the Reagan administration's approach, we shall argue that a sound public policy can be formulated by going one step beyond the President's Commission report. Finally, using this policy recommendation as our normative guide, we find the recent legislation to be excessively restrictive on matters of principle, but capable of effecting a significant improvement in practice over the now-defunct "Infant Doe Rule."

President Reagan's "Infant Doe Rule"

On April 9, 1982, "Infant Doe," a baby boy with Down's syndrome and esophageal atresia, a defect that prevents normal feeding, was born in Bloomington, Indiana. His parents refused consent to surgery to correct the esophageal defect, a series of courts refused to intervene,[2] and Infant Doe died six days later. The Reagan administration responded immediately by informing hospitals that Section 504 of the Rehabilitation Act of 1973,[3] which prevents discrimination against handicapped individuals in programs or activities receiving federal funds, applies to imperiled newborns.[4] It subsequently issued an "Interim Final Regulation"[5] reiterating this nondiscrimination policy and establishing various procedures for implementing it, including the so-called "Baby Doe Hotline"—a toll-free number to be called by anyone suspicious of discriminatory nontreatment of handicapped children—and the so-called "Baby Doe Squads," consisting of DHHS personnel and pediatrician consultants who would investigate such allegations. Although this interim regulation was overturned in federal court, primarily

[2] *In re Infant Doe*, No. GU 8204-00 (Cir. Ct. Monroe County, Indiana, April 12, 1982), writ of mandamus discussed *sub nom. State ex rel. Infant Doe v. Baker*, No. 482 § 140 (Ind. S.Ct., May 27, 1982), cert. denied 52 U.S.L.W. 3369 (U.S. Nov. 8, 1983).
[3] 29 *U.S.C.* § 794 et. seq. (1976).
[4] 47 *Fed. Reg.* 26027 (June 16, 1982).
[5] 48 *Fed. Reg.* 9630 (Mar. 7, 1983).

because of the administration's failure to follow appropriate notice and comment procedures in promulgating it,[6] the administration promptly issued a substantially similar proposed rule.[7]

The proposed rule, still based on Section 504, stated that treatment of a handicapped infant was mandatory unless such treatment was "medically contraindicated." It ruled out quality-of-life considerations, holding that it was unlawful discrimination to deny treatment on the grounds that "a particular infant is potentially mentally impaired, or blind, or deaf, or paralyzed, or lacking limbs."[8] The administration specified, however, that the regulation was not intended to require futile therapies that would only prolong an infant's process of dying. The procedural requirements of the nondiscrimination notice, the hotline, and federal investigatory power remained unchanged.

Although the "pro-life" lobby and handicapped citizens' groups welcomed this stringent regulation, physicians' groups and advocates of parental discretion condemned it as an unwarranted intrusion into the private affairs of doctors and their patients. The procedural requirements were the focus of particularly withering criticism. Doctors and nurses argued that the hotline and the conspicuous poster announcing it would prove to be profoundly disturbing to the already anguished parents of handicapped children. Likewise, the presence of federal investigators in the nursery would be intrusive and would detract from the purpose of providing good medical care. Finally, these critics contended that this adversarial procedure fostered an atmosphere of mutual suspicion and distrust among the staff (American Academy of Pediatrics 1983; Annas 1983, 26). In commenting on the proposed regulation, medical groups sought to convince the administration to modify its policy in its final regulation.

On January 9, 1984, C. Everett Koop, Surgeon General, and Margaret Heckler, Secretary of Health and Human Services, announced the final rule governing the treatment of imperiled newborns.[9] The final rule reflected significant procedural modifications. The wording

---

[6] *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983).
[7] 48 *Fed. Reg.* 30846-30852 (Tuesday, July 5, 1983) [hereinafter "Proposed Rules"].
[8] Ibid. 30852.
[9] 49 *Fed. Reg.* 1622 (Jan. 12, 1984), amending 45 C.F.R. § 84 [hereinafter "Final Rules"].

of the poster announcing the nondiscrimination policy was altered; the size of the poster was reduced; and it was no longer required to be placed in a location visible to parents. Moreover, the final rule called for the voluntary establishment of "infant care review committees" (ICRCs) to review treatment decisions, and encouraged state child protective agencies to consult with such committees when investigating complaints of discrimination.[10] The language of the rule was conciliatory; it spoke of "reasonable medical judgment" and condemned as discriminatory the withholding of treatment only if such treatment would be "medically beneficial" for the infant.[11]

Despite these procedural modifications and the marked change in tone, the substantive standard embodied in the final regulation remained unchanged. The administration adhered to its position that treatment decisions can be made by reference to a principle of nondiscrimination. It likewise continued to insist that the issue here was a purely medical one, i.e., whether the infant can be medically benefited by treatment. If treatment will prove futile, or has an extremely low chance of success, physicians can make the medical judgment that it is not beneficial. But *medical* discretion was the only type of discretion allowed—the rule disallowed judgments based on factors such as anticipated mental or physical impairment.[12] In other words, as with previous versions, all quality-of-life judgments were ruled out (at least in theory) as constituting discrimination against the handicapped.

Of course, the procedural change of delegating at least some degree of review authority to ICRCs was a major one. It may well have resulted in different decisions than with the former procedure, since committees may, at least implicitly, rely on substantive principles that differ from the administration's nondiscrimination principle. However, the final rule made clear that it was the administration's intent that the ICRCs act in the service of its principle, rather than formulating or relying upon their own standards. Thus, we must analyze the desirability of framing this issue in terms of the nondiscrimination principle and disallowing any consideration of degree of future disability.

---

[10] Ibid. 1651.
[11] Ibid. 1654.
[12] Ibid. 1622-25, 1651-52.

The Discrimination Principle

There is no denying that the "Infant Doe Rule" would have achieved correct results in many cases. We must all admit, moreover, that there has been discrimination against handicapped infants—although no one appears to know just how widespread such discrimination has been. Denying life-sustaining treatments to imperiled newborns must be viewed with extreme caution—indeed, with a good measure of suspicion. Nevertheless, the Reagan administration oversimplified an extraordinarily complex moral and factual situation. Adequate social policy needs to be formulated on the basis of a broad understanding of moral and medical realities, not on moral outrage directed, no matter how appropriately, against a few highly publicized cases.

Medical versus Moral. The first problematical oversimplification resided in the administration's rigid dichotomy between "medical" and "quality-of-life" judgments. Take, for instance, the claim that the determination of an infant's status as a "dying patient" is an exclusively *medical* judgment. This might well be the case when the child in question is literally minutes, hours, or (at most) a few days away from succumbing to his or her underlying terminal condition. But what shall we say of the child born with Trisomy 13, who will almost certainly die before her first birthday, or the nearly anencephalic child who will probably die in a matter of weeks or perhaps months (Brackbill 1971, 195), depending upon how aggressively he is fed and treated? Such children cannot literally be said to be imminently dying, so they differ significantly from the child born without a left ventricle, doomed to die in a matter of hours or days; and yet they also differ considerably from a Tay-Sachs baby, who will develop normally for a year or so and then slowly die over a period of years. Are the Trisomy 13 and nearly anencephalic children closer, conceptually speaking, to the child dying for want of a left ventricle or to the Tay-Sachs child? More to the point, what purely medical grounds could be given to defend *either* position? Attempts to label such children as either dying or not-dying will most likely be largely determined by estimates of the child's suspected longevity and the gravity of its physical impairments—in other words, by the same sort of "quality-of-life" judgments that the administration seeks to exclude.

Since we are often not sure *how long* we can maintain many gravely ill babies—although we can be highly confident that many will be

gravely burdened if they survive—this indeterminacy regarding who counts as a dying patient will color a large proportion of the difficult cases. And it is precisely with regard to this range of cases—which includes the extremely low birthweight infants who pose the most recurrent ethical dilemmas for the neonatal staff—that the administration's rigid dichotomy between medical and nonmedical judgments would have proven totally unhelpful.

Medical Complexity. The "Infant Doe Rule" was also premised upon an overly simple picture of the medical context surrounding such cases. By implicitly assuming that all congenital defects are as potentially "benign" as Down's syndrome, and that all contested treatments are as clearly beneficial as the routine repair of an esophageal fistula, the "Infant Doe Rule" accomplished a Herculean feat of oversimplification. The truth of the matter is that there is a vast range of conditions that can imperil a newborn's life and health. Some are relatively benign, like mild Down's syndrome and low-lesion spina bifida, while others are catastrophic in the sense that they portend a very short life span with virtually no cognitive or affective capacities. Matched against this spectrum of illnesses is a highly variegated set of possible treatments, ranging from simple oral feeding to complicated surgery and chronic kidney dialysis. For example, a Trisomy 13 child has microcephaly, an abnormally small brain, indicating a near-total absence of the abilities to think and communicate with other human beings. He will suffer from numerous physical problems and will almost certainly die within a year, even if maximal therapeutic efforts are made on his behalf. Questions involving his care may include: If he develops an infection, should he be treated with antibiotics? If he experiences breathing difficulties, should we assist his breathing or place him (perhaps permanently) on a respirator? Should heart defects be diagnosed through invasive catheterization and repaired by surgery? If the kidneys fail, do we resort to chronic dialysis? Finally, supposing that the child's heart suddenly arrests, should a full-scale attempt be made to resuscitate him?

As this bewildering list of questions indicates, the problem of caring for imperiled newborns is not usually an *all or nothing* dilemma between so-called "customary care" on the one hand, and doing nothing on the other. Rather, and this is especially true for the very low birthweight infants, it is a question of how far we should go, given this infant's

condition, prognosis, and the relative benefits and burdens of the proposed treatment.

The Concept of Discrimination. The third feat of oversimplification wrought by the "Infant Doe Rule" lay in its operative notion of discrimination. Although DHHS presented the rule as "an equal treatment, non-discrimination standard,"[13] and although every well-meaning citizen would no doubt condemn the practice of unjust discrimination against the handicapped, the great difficulty facing us is to determine what constitutes discrimination against gravely ill newborns. The various incarnations of the "Infant Doe Rule" suggested three possible interpretations of this concept:

1. Failure to provide customary care. The first and most problematic gloss of "discriminatory non-treatment" conceived of it as a failure to render so-called "customary care." The poster that DHHS had originally designed for placement in all neonatal units stated in part: "Any person having knowledge that a handicapped infant is being discriminatorily denied food or *customary* [emphasis added] medical care should immediately contact. . . ."[14] This interpretation was quickly recognized as unworkable by Judge Gesell, who invalidated the initial regulation, precisely because there is no such standard of care governing the hard cases.[15] Indeed, were there a customary standard, we would not be debating the issue so strenuously on medical rounds, in the press, and in the courts.
2. Equal results. A second interpretation of discrimination advanced in the explication of the rule was based on the idea of equal treatment. According to this view, a person or institution is guilty of discrimination if a handicapped child is deprived of care that would have been provided to an otherwise normal child in similar circumstances. Significantly, this standard would have worked very well in factual situations closely analogous to the original Bloomington Baby Doe case. That is, when there is no difference between two patients—except for the fact that one will always be retarded, due to Down's syndrome, and the other

[13] Proposed Rules, supra note 8, at 30846.
[14] Ibid. 30851.
[15] *American Academy of Pediatrics et al. v. Heckler*, supra note 7.

is mentally normal—it strikes most people today as unjust to allow the former to die *solely* on the ground of his or her handicap. Mental retardation, we now believe, is not in itself a morally significant difference between the Down's baby and the otherwise normal child. Since the retardation is entirely separate and distinct from the medical problem needing surgery, equal treatment mandates that we exclude the retardation from our consideration.

However, in many cases the handicap and the medical problem requiring treatment are logically and clinically inseparable. For example, although an "otherwise normal" child might well have an esophageal or duodenal atresia, she does not have a meningomyelocele. In such a case, it is meaningless to ask, "Apart from this child's hydrocephalus and possible retardation, would we seal up the spinal column of an 'otherwise normal' baby?" We may certainly wish to close the child's spine, but we cannot exclude the lesion and accompanying difficulties from our consideration. We must recognize that this type of handicap inevitably makes this infant different from a normal child; if we choose to operate, it will be because the surgery is in the baby's best interests, and not because we would perform the same operation on a normal child.

This equal-treatment standard would have foundered more dramatically when confronted by a child burdened with an anomaly or deficiency of such magnitude that comparisons with normal children seem utterly beside the point. We may all agree, for example, that a Down's child born with a cleft palate should have corrective surgery in spite of his retardation. But what if, instead of Down's syndrome, the child was born with holoprosencephaly, a devastating malformation of the brain, with accompanying microcephaly and cebocephaly, a condition entailing the absence of a nasal breathing passage? Given such catastrophic deficits, pediatricians can confidently state that this child lacks the intellectual capacity to communicate with other persons in a meaningful way and, in any case, is doomed to die a premature death. Highly aggressive medical interventions could *possibly,* however, sustain his life for a year or longer.

Surely, if an otherwise normal child were to be born without a nasal passage, no responsible physician or loving parent would

suggest for a moment that the air passage not be surgically created. (This is a life-sustaining procedure because newborns cannot breathe through their mouths.) But this reasoning does not carry over in anything like an automatic or intuitively obvious way to the case of our cebocephalic child. Here it is a difficult and agonizing question whether the child's temporary breathing tube should be replaced by a surgically created nasal passage; but whether we operate or not, the child's holoprosencephaly, microcephaly, and consequent lack of capacity for human interaction all appear to be relevant factors in our decision-making in a way that the other child's Down's syndrome was not. Our point is simply this: If the degree of severity of a child's "handicap" should matter in such cases, then no standard mandating the "evenhanded treatment" of handicapped and otherwise normal infants will prove adequate to the complexity of these extreme and unhappy situations.

3. No quality-of-life judgments. The third interpretation of "discrimination" went to the theoretical core of the "Infant Doe Rule." According to this reading, it would be discriminatory to deny medical benefits to a child "solely on the basis of an infant's present or anticipated mental or physical impairments."[16] In other words, it is discrimination to withhold nutrition or medical care on "quality-of-life" grounds. So long as a child was not in the process of dying, the "Infant Doe Rule" was explicit; all such children had to be treated, no matter how poor their present or future quality of life. So long as the infant would "benefit" from a given treatment—a supposedly "medical" judgment—the Down's baby must receive her thoracic surgery, the spina bifida baby must have her spinal lesion surgically closed, and every child must, a fortiori, be fed and cared for. If one were to seek out a more positive label for this position—and if one did not have to worry about the secular context of the debate—the words "sanctity of life" would perhaps come to mind.

We contend that this philosophical rejection of quality-of-life reasoning, rather than any well-thought-out moral theory of nondiscrimination, constituted the theoretical nerve of the "Infant Doe Rule."

[16] Final Rules, supra note 10, at 1622.

The language of nondiscrimination and the trappings of civil rights law appear merely to have served the administration as convenient vehicles for advancing a "sanctity-of-life" philosophy in this debate. Notwithstanding this possibility that the administration's interest in the concept of discrimination was purely instrumental, we can still profit from a closer look at this problematic concept. Indeed, we shall argue that the administration's nondiscrimination arguments fail for precisely the same reason that any rigid "sanctity-of-life" position will fail—that is, both kinds of argument fail to show why quality-of-life considerations ought to be discounted by the care-givers and parents of severely impaired newborns. In other words, both strategies merely assume their conclusions.

What, then, is discrimination? In its most general sense, to "discriminate" is simply to make distinctions between two or more different things or persons. We say, for example, that a wine connoisseur possesses "discriminating" taste—that is, she knows how to distinguish good wine from bad. Now, if discrimination in this most general sense refers simply to making distinctions, what is it that renders certain discriminations ethically unjust? We can begin by noting that it is *not* the mere fact of unequal treatment. Although morally invidious acts of discrimination will often involve unequal treatment, not all unequal distributions are discriminatory in this sense. The student who is rejected by a law school because he cannot read or write has not been the victim of discrimination. Why? Because such skills as reading and writing are highly *relevant* to the enterprise of selecting students for legal study. However, if a female applicant were refused admission solely on the ground that she is female, we would say that she has indeed been discriminated against, since sex is irrelevant to the business of studying or practicing law. The key to the notion of discrimination in this morally pejorative sense, then, is the relevance or irrelevance of a given characteristic or criterion to the matter at hand. When a distinction is based on a relevant trait, there is no discrimination; but when people are treated differently solely on the basis of irrelevant criteria, then we have genuine discrimination.

The administration's definition of "discrimination" in the neonatal context thus assumes its conclusion that the infant's probable future condition is not a relevant factor to be considered. That this definition of "discrimination" is entirely inappropriate was recognized in the most recent decisions in yet another tragic "Baby Doe" case. Baby

Jane Doe was an infant born with spina bifida, hydrocephalus, microcephaly (a small and abnormal brain), and a malformed brainstem. With surgery to close the lesion, she could possibly survive indefinitely, but would suffer profound retardation, incontinence, and paralysis from the waist down, as well as facing numerous surgical procedures. Without surgery, she would probably die within two years. After much consideration, parents and physician decided against surgery, and their decision was upheld on procedural grounds by the New York Court of Appeals after an unrelated "pro-life" attorney sued to challenge it.[17] Despite this judicial authorization, the Justice Department filed suit for access to Baby Jane Doe's records to determine if she had been the victim of discrimination.

In a decision which can only be read as rejecting the administration's preferred definition of "discrimination," the United States district court denied the Justice Department access to the medical records, characterizing the parents' decision as a "reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child."[18] This statement is remarkable in view of the fact that discrimination, as defined by the administration, had clearly occurred—that is, a procedure that could have provided a *medical* benefit (at least to the infant's spine) and prolonged life for an indeterminate number of additional years was foregone because of the infant's anticipated degree of impairment. Moreover, the Second Circuit Court of Appeals, which upheld this decision on the grounds that Congress never intended Section 504 of the Rehabilitation Act to apply to medical decisions involving defective newborns, emphasized the magnitude of this infant's handicap—the high risk that she "could never interact with her environment or with other people"—and hence recognized that decisions in the difficult cases cannot ignore such handicaps.[19] At least with regard to those cases where we lack anything like a social consensus, we believe this rejection of discrimination law to be unquestionably warranted. The heavy hand of civil rights law—

[17] *Weber v. Stony Brook Hospitals*, 60 N.Y. 2d 208, 456 N.E. 2d 1186 (Ct. App. 1983).

[18] *United States v. University Hospital, State University of New York at Stony Brook*, 575 F. Supp. 607 (E.D.N.Y. 1983), aff'd 729 F.2d 144 (2d Cir. 1984).

[19] *United States v. University Hospital, State Univ. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984).

so necessary and salutary in the areas of employment, education, and most aspects of medical care—can only cause further misery when brought to bear on truly tragic choices in the neonatal nursery.

We can now abandon this attempt to seek answers to treatment dilemmas from the principles of civil rights law. We have seen that the fundamental question is *not* whether an "otherwise normal" child would have received a certain treatment. Rather, the question is: Are there any morally significant differences between certain imperiled newborns and their normal counterparts that might justify nontreatment?

The President's Commission and the "Best Interest" of the Child

The President's Commission has recently suggested a substantive moral principle that would yield, in a very narrow range of cases, an affirmative answer to this question. In place of the Reagan administration's nondiscrimination principle, the Commission has recommended that the "best interests of the child" should govern decision-making in the neonatal nursery. Significantly, such a standard would preclude any and all consideration of possible adverse effects of a child on her parents, siblings, or society at large. "Burden to others" is thus ruled out as a possible justification for nontreatment of an imperiled newborn.

Likewise, a "best interest" standard would attempt to screen out a certain bias for normalcy on the part of adult decision-makers. Having grown accustomed to the satisfactions of physical and psychological normalcy, many normal adults might well prefer death *for themselves* rather than live with severe handicaps. For them, a life bereft of the capacity for sight, locomotion, hearing, and continence—not to mention the capacity for thought, conversation, and creative activity—might well be considered a life not worth living. But what of the severely handicapped child who has never (and never will) enjoy many of the ordinary pleasures of everyday life? He enjoys no higher standard of comparison from which his present quality of life might appear to be intolerably low. For him, this is the only life that there is. For him, it is not a choice between normalcy and retardation; it is, rather, a choice between life, with all its limitations and handicaps, and the abyss.

Thus, in advocating a "best interest" standard, the President's

Commission has taken care to specify *the point of view* from which the child's best interests are to be assessed. Eschewing the "idiosyncratic" values of normal adults, who might prefer death to retardation, the commission insists that interests be assessed *from the child's point of view.* We must ask, not about the preferences of normal adults, but rather whether *this* defective child would prefer to die rather than continue living with his handicaps. Viewed from this stringent "child-relative" perspective, many of the controversial cases of the recent past would appear relatively straightforward. For example, in the case of the Bloomington Baby Doe, born with Down's syndrome and an esophageal defect, it could not have been plausibly argued that he would see death by starvation (or by other means) as being in his best interest. To be sure, Down's syndrome children do not grow up to be doctors, lawyers, or bioethicists; but if we were to ask them, most would respond that their lives are well worth living.

As it stands, this best-interest standard is ethically attractive—who would quarrel with nontreatment once it is agreed that death is truly in a child's best interest?—but it is also disconcertingly abstract. Without the additional guidance of concrete *criteria* that would tell us when and under which circumstances a child's best interests were no longer served by continued life, the polarized debate over imperiled newborns threatens to break out once again, this time over the meaning of the "best interests" of the child. Concerning the fate of any given child, some will argue that death is preferable to life, while others will contend that treatment and continued existence best serve the child's interests. What criteria could help us arbitrate such disputes?

The President's Commission offers us the following "test" for permissible nontreatment: "[S]uch permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant" (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 218). This criterion has its own difficulties: How are we to decide whether continued life constitutes a "net benefit" to an infant? Moreover, is "net benefit" necessarily the primary question? After all, many unfortunates may lead lives so bleak or miserable that it is questionable whether their continued existence yields a net benefit, yet they cherish their lives just the same. But if we focus on the commission's explanation that "net benefit is absent only if the burdens imposed on the patient by

the disability or its treatment would lead a competent decision-maker to choose to forego the treatment," we can conclude that net benefit is absent in at least one type of situation. This is when the infant will suffer chronic, severe, and intractable pain. Although we usually believe that life is good or desirable—even when it fails to yield a "net benefit"—the prospect of a lifetime of unmanageable pain and suffering shatters this everyday confidence. Indeed, pain of this scope and magnitude can eclipse the child's capacity for enjoying those normal human pleasures that ordinarily predispose us to believe that life is good. Although it might be somewhat paradoxical to say that death would be a "benefit" for such a child, we *can* say that, matched against a life of unmitigated suffering, death could be viewed as the lesser of two evils.

Earlier we asked if there might be any "morally relevant differences" between some defective and normal babies—differences that could *justify* unequal treatment or even nontreatment resulting in death. We can now respond that the prospect of a life of pain and suffering constitutes just this kind of relevant moral difference. We can surmise that a child facing such a future would likely prefer an early death as the lesser of two evils; and we may conclude from this that non-treatment of such a child is consistent with respecting her as a human person of inestimable worth. Unequal treatment in such a case is not discrimination in a morally pejorative sense; indeed, equal treatment—interpreted as maximal treatment for all children, no matter how burdened—would contravene some children's best interests and constitute an injustice to them.

Thus, the commission's principle is a clear improvement on the administration's nondiscrimination maxim; it allows us to focus on the infant as an individual and assess his best interests, rather than merely asking if a diseased or defective organ can be medically improved by a corrective procedure. If an infant's life would be one of intolerable and unrelenting pain, we can conclude that nontreatment would be in her best interests, as viewed from her own perspective. But what does this "best interests from the infant's perspective" tell us in regard to the infant whose life will be very short and extremely limited, but not filled with excruciating pain?

The commission rejected another frequently utilized standard for decision-making—the "substituted judgment" standard, which requires that the decision-maker decide as the patient himself would decide.

This standard was rejected because, with newborns, we have no way of knowing what their wishes would be. The commission states that while, in general, the substituted judgment standard is preferable, for patients who have never been competent, and whose wishes are, therefore, impossible to discern, the surrogate decision-maker should rely on the best interests standard (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 134–36). But the commission then emphasizes that in assessing best interests we must adopt the viewpoint of the infant (Ibid. 219, n. 79), a standard that seems to impose upon us essentially the same impossible task. An infant given the choice between an early death and five months of a blind, deaf, immobile, and profoundly retarded life—but one without severe pain—might, were he competent to decide, judge his best interests to be five months of life. This could be the case for an infant with holoprosencephaly, Trisomy 13, Trisomy 18, or even anencephaly. Or he could believe that such a life is not worth it; we simply cannot know. After all, competent patients faced with severely limited life prospects make widely disparate decisions about life with handicaps versus death.[20] Preferences of infants, could we discern them, would probably also vary widely.

Since we cannot be sure that this infant, if competent to evaluate his situation, would opt for nontreatment even when his life will be short and extremely limited, then it seems that treatment is necessary, no matter how miserable or incapacitated the child will be in the long run. This is particularly true since the commission would limit "meaningless" prolongations of life to those situations where the infant's life will in any case be measured in hours or days, not in years (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 219, n. 81). Thus, the injunction to view the situation from the infant's perspective has the effect, in the absence of unrelievable pain, of (1) giving us an impossible task, and (2) seeming to require treatment even when it appears inappropriate or virtually futile. This outcome will, of course, be tempered by the commission's procedural recommendations that decisions in ambiguous cases be made by parents and physicians, with

[20] See, e.g., *In re Quackenbush*, 156 N.J. Super 282, 383 A.2d 785 (1978), upholding an elderly patient's refusal of amputation of his gangrenous legs. Although many patients of course choose life even with the loss of limbs and mobility, this patient competently chose otherwise.

oversight by ethics committees, and by its suggestions that in ambiguous cases good-faith decisions by parents and physician should prevail. Yet, even if this procedure permits nontreatment, the commission's substantive principle gives us no ethical justification for taking this option.

The injunction to assume the infant's perspective can help decision-makers avoid imposing their values on others; just as the concert pianist must not judge the life of a tone-deaf acquaintance to be meaningless, doctors or parents must not decide by fiat that a life limited by some degree of retardation lacks meaning or value. But the truly hard cases cannot be decided by embarking on the impossible task of assuming the infant's perspective. The notion that we can assume the infant's perspective and decide accordingly seems to be an attempt to avoid admitting that independent third parties must make quality-of-life judgments in this area and must make them from the only perspective they know—their own. This perspective must be broad, it must incline heavily in favor of preserving life, and it must "take the infant's point of view" not in a strict sense, but in the sense of recognizing that his choices are not normalcy versus retardation or physical handicap, but life with such handicap versus nonexistence. Values concerning the joys of participating in intellectual activities or athletic events must be cast aside. But just as these hard decisions are ethical, not strictly medical, they can be made only by rational, concerned individuals asking the anxiety-ridden question of whether the infant's quality of life warrants performing the particular medical procedure.

Toward a Principle Based on Quality of Life

Thus, the principle that nontreatment is justified if it is in the best interests of the infant as judged from the infant's perspective will provide a powerful justification for withholding treatment in a certain set of cases. The problem is that the set of cases is exceedingly narrow, far narrower than those situations in which treatment is omitted in practice, and narrower than the commission seems to have believed in propounding this principle. How, then, do we go beyond this principle and provide a justification for nontreatment in cases where the infant is not in severe pain but in which decision-makers simply

feel that treatment is not an act of kindness, or even good sense, but is rather a mindless and futile flexing of medical hardware?

The first step is to accept forthrightly that decision-makers in these cases are inevitably unable to act as agents who ascertain and implement the patient's desires. The injunction to take the infant's perspective is misleading, because it focuses on the unknowable and suggests that infants in similar circumstances would have similar preferences, could they somehow be ascertained. Moreover, it diminishes the import of the crucial fact that the most devastatingly affected infants either will lack the conceptual apparatus to develop preferences or will not live long enough to develop them. Thus, this focus diverts us from the truly important issue, which is not the infant's hypothetical desires, but rather is what sorts of lives society wishes to labor to preserve. If the judgment is that all lives except the excruciatingly painful must be preserved, then the only question is whether the infant will suffer intense, unremitting pain. But if we recognize that some lives are so burdened and limited that preservation is problematical, we must acknowledge that decisions cannot be based on the hypothetical preferences of infants destined to live these lives.

Second, we can make explicit those features of the "easy" cases that make them relatively straightforward. For example, most people would agree that if an infant's life span is inevitably limited to days or weeks, physicians are not obliged to extend this ill-fated life to its outer limits. But *why* is this relatively uncontroversial? After all, even a terminally ill infant, if she could form or express a preference, could prefer a week of warmth, feeding, and love to instant extinction. Moreover, terminally ill cancer patients often place a very high value on a few more weeks of life, at least if they are not riddled by excruciating pain. The difference, it seems, is that in his brief time the infant has no opportunity to develop or to do any of the things that humans characteristically do and value, while the cancer patient may be able to finish a project, accept his fate, help a loved one adjust to the loss, or simply experience his life for a few immeasurably precious weeks. Were the weeks to be filled with unremitting pain, or experienced in an immobile and comatose state, the patient would most likely value them less.

So the reason that a short period of living can have value is that in this time, a person can *really live,* i.e., can do at least some of the things humans characteristically do. If the person cannot live in

this fashion, as in the case of the anencephalic infant, these days or weeks simply do not justify our medical efforts. Even at this fundamental level, with the dying or anencephalic infant, we are making a quality-of-life judgment—the judgment that a brief, biological existence bereft of human responses and joys does not, by our lights, merit preservation. The term "quality of life" has acquired a misleadingly pejorative connotation, implying a willingness to withhold treatment from any infant that is less than perfect. But as the preceding example shows, judgments that are based (if we are honest) on quality-of-life considerations are, in this area, wholly unavoidable. The length of time is relevant; but far more crucial is that the infant, unlike the cancer patient, can do and feel little during this time. Moreover, even a lengthy life, if lived in a wholly unconscious state, is one that few would feel must be sustained. Again, this judgment can only be based on the belief that the quality of life sans consciousness is morally distinct from that of conscious human life.

The relevant distinction is not, then, simply between prolonging living and prolonging dying; prolonging dying can be a valid and even ethically mandatory endeavor if the person wants his dying prolonged, while prolonging living can be cruel if the life is painful, or futile if it is mere vegetative existence. But whether the dying will occur in a day, a week, a month, or a year, if the infant cannot laugh or love or grow in this time, medical procedures will yield no real benefit. Father John Paris and Father Richard McCormick have expressed this standard as follows: "If [the infant's] potential [for human relationships] was simply nonexistent or would be utterly submerged and undeveloped in the mere struggle to survive, that young life had achieved its potential and no longer made life-sustaining claims on our care" (Paris and McCormick 1983, 313, 316). This is especially clear when we recognize that life-sustaining procedures are not neutral, but involve at least some degree of bodily pain and invasion. When they yield no benefit, not in the narrow sense of medically benefiting an organ, but in the broader sense of providing at least some level of experience or activity, the game is simply not worth the candle.

This harm/benefit calculus provides, we believe, ethical justification for withholding life-sustaining treatments from infants with disorders such as Trisomy 13 or 18, where the life span is brief and, more important, where the ability to participate in the human experience during this

short life is so radically limited. We submit that these lives, with these handicaps, are neither long enough nor full enough to require preservation by means of burdensome medical procedures. This means neither that the infants and their lives lack value nor that we cannot love these babies and cherish them while they live. It merely means that we believe it appropriate to decide, from our own perspective (which realistically we cannot escape), that these infants' lives are so radically affected by their multiple malformations that they do not partake sufficiently of human experience to render treatment morally required.

If the standard is, as we have suggested, whether the infant has sufficient potential to live at least a minimally human life for a reasonable time span, a major problem is where to draw the line. We have made a little progress; almost all writers in this area, whatever their theory, conclude that anencephalic infants need not (and should not) be treated, while Down's syndrome children should. Between these polar extremes, there is massive confusion and conflict. We have managed to give good reasons for placing infants with disorders such as Trisomy 13 or 18 in a category similar to anencephalic infants. This conclusion is similar to that of other writers who have considered these particular disorders (Strong 1981, 83, 85; Weir 1984, 235). It also conforms with the actual practice of pediatric surgeons and pediatricians (Shaw, Randolph, and Manard 1977, 588; Levin 1985). (Although medical agreement does not, of course, settle the ethical questions, it is significant that doctors' unanimity on this is second only to their agreement about nontreatment of the anencephalic infant.)

Other disorders which result in a radically shortened life span, or little or no ability to develop cognitively, should likewise justify withholding aggressive treatment, though infants with such disorders should be given warmth, comfort, and ordinary care. When the life would be very short (say one year or less), or, despite its length, virtually nonsentient, or, perhaps, respirator-dependent with no potential for detachment, these meager benefits are not worth it. On the other side, infants with handicaps such as Down's, most cases of spina bifida, and a host of other quite serious disorders can clearly partake of enough of life's experiences to make medical treatment for them morally required.

This standard, like any that seeks a middle ground, has distressingly fuzzy edges. One can accept the principle, yet disagree violently as

to whether doctors must aggressively treat the 650 or 700 gram infant with major intraventricular hemorrhages who may well die anyway, who will probably be severely or profoundly retarded if she does live, but who could possibly survive intact. Similarly, one can accept this standard yet feel hopeless confusion if a newborn with Tay-Sachs for some reason requires major medical care soon after birth. How aggressive should doctors be in treating this infant? Harder still is the case of the infant who may live for many years, but with such massive brain damage that retardation will almost surely be profound. There can be genuine disagreement as to where we draw the line and say that this life—being blind, deaf, paralyzed, and profoundly retarded, or perhaps severely retarded, or perhaps 3 of these 4—is not one that we feel should be aggressively preserved.

These questions cannot be definitively answered under this standard. The issue is especially hard when we realize that prognosis may be uncertain and that between the extremes of maximal treatment and no treatment lie a host of intermediate levels of care. Nonetheless, a quality-of-life principle allows the debate to be centered on grounds that are intellectually and humanly realistic: What do *we* think of this sort of life? This "we" is on one level social and political; public debate and documents such as the Commission's Report have recognized and contributed to the growing societal consensus that although infants with disorders such as Down's may cause much hardship to their families, these children can live happy lives and must be treated. But although these judgments are *public* choices insofar as they establish general guidelines and the limits of parental discretion, they are experienced as intensely *personal* decisions in the crucible of individual cases. The family's role must be recognized, and treated with compassion and respect. The commission's recommendations—that in ambiguous cases, the family should decide, with agreement by the physician and review by ethics committees—accomplishes this admirably. Certainly, where the infant can live a life of some human experience, its right to life must be protected. But when the issue is debatable, we agree with the commission that the family must decide. To eliminate parental discretion (as did the Baby Doe rules), is to forget that an infant is a part of the most important social unit in existence, and one whose lives and interests intertwine. Of course, parents have interests in these situations, such as not wanting a handicapped child, that may conflict with those of the child. However, the major decision-making

role played by doctors and hospital staff is itself a significant safeguard against self-serving parental decisions, and ethics committee review of ambiguous cases will provide an additional check.

Thus, quality-of-life decisions must be made, and our public policy must honestly admit that they are both necessary and appropriate. The President's Commission, though avoiding the phrase "quality of life," adopts a standard and procedure that will allow some such decisions. Decisions to terminate treatment for other classes of patients are made on the basis of quality-of-life judgments[21] and these decisions, plus the recommendations of the commission, clearly show that such decisions, if made according to appropriate standards and procedures, are ethically and legally acceptable.

Amending the Child Abuse Prevention and Treatment Act

Despite the harsh rejection of the "Infant Doe Rule" in the courts, the cogent recommendations of the President's Commission, and the support of various writers for a flexible policy based on a quality-of-life principle (Paris and McCormick 1983, 313, 316), advocates of governmental intervention on behalf of imperiled newborns continued their quest. Since the Second Circuit had found no legislative authorization for the "Final Rule" in the Rehabilitation Act of 1973, they were forced to seek fresh legislation. During the summer and fall of 1984, an odd collection of liberal and conservative senators joined forces with an equally unlikely assortment of disability advocates and medical groups to forge a remarkable political compromise. The result was a crucial "Baby Doe" clause incorporated in H.R. 1904, the 1984 amendments to the Child Abuse Prevention and Treatment Act (henceforth referred to as "the Act").

The Act defines a new category of medical neglect: the withholding of "medically indicated treatment" from "disabled infants with life-threatening conditions" (*Congressional Record* 1984). This variant of medical neglect is further defined as "the failure to respond to the

[21] See, e.g., *In re Dinnerstein*, 380 N.E.2d 134 (Mass. App. 1978) authorizing a "no code" order for a terminally ill woman with Alzheimer's disease who was paralyzed and in an essentially vegetative state.

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. . . ." Although thus far this sounds remarkably like the original "Infant Doe Rule" language, the Act contains a set of enumerated exceptions, which provide that treatment shall *not* be required when: "(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."

Against the background of our critical assessments of the "Infant Doe Rule" and the recommendations of the President's Commission, we shall conclude this essay with an assessment of the ethical principles and administrative processes incorporated in this Act. Our assessment will proceed in three steps. First, we inquire into the meaning of "medical neglect" as defined by the Act; second, we ask how this compromise Infant Doe *principle* measures up to the ethical standard articulated in the previous section of this article; and third, we assess the adequacy and desirability of the *policy* designed to implement this principle.

A. *The Interpretation of "Medical Neglect."* At first blush, the language of the Act looks like a legislative retread of the Infant Doe Rule: the ethical decision whether or not to treat an impaired newborn is once again characterized as a question of "medical indications" and "reasonable medical judgment." There are no references to the child's "best interests," to the quality of the child's expected life, or to parental discretion in difficult and ambiguous cases. Despite this, a sympathetic reading of the various exceptions to this "medical indications policy" reveals a number of possible concessions to the advocates of quality-of-life reasoning. Although the ultimate interpretation of these exceptions will have to wait for the promised DHHS regulations based upon them, and for the historical record of enforcement by state child protection agencies and the courts, we can base a provisional gloss of their meaning on the text of the Act itself.

In order of increasing interest and controversy, we note first that

the Act carves out a major exception (B) for treatments deemed futile to stave off the child's impending death. In terms reminiscent of the Infant Doe Rule—and of every coherent "pro-life" position—the Act excludes from its scope treatments that would merely prolong the process of dying. As Kant put it, "ought implies can"; there can be no ethical or legal obligation to do the impossible. If, ex hypothesi, nothing can reverse the process of dying in a given child, physicians cannot be obligated to deploy curative treatments.

In addition to this uncontroversial proviso, however, the Act also says that treatment shall not be required when it would "not be effective in ameliorating or correcting *all* of the infant's life-threatening conditions" [our emphasis]. Thus, if an infant is simultaneously threatened by two or more life-threatening conditions, and if medical science cannot effectively treat each and every one of these conditions, the child's care-givers are not obligated to treat all of the conditions that *are* amenable to treatment. This clause wisely heeds Paul Ramsey's (1970, 130) exhortation to view the whole patient, "and not diseases one by one," as the proper subject of medical treatment. If the patient, as the unity of all the diseases that he or she suffers, cannot be saved, surely there can be no moral imperative to treat each and every life-threatening condition that can be reversed.

Although this principle is sound, the clause is subject to multiple interpretations. For example, a baby born with Trisomy 13 and duodenal atresia will not live long whether or not the atresia is corrected. But the life-threatening chromosomal abnormality might not claim this infant for six months or even a year. Do the framers intend this exception to justify withholding of surgery for the atresia? Or do they mean instead that death from the untreatable life-threatening condition must be "imminent"—i.e., a matter of hours or days? Whether this exception will represent a real moral advance over the "Infant Doe Rule" will thus depend on subsequent interpretations of the term "life-threatening condition."

The next major concession (C) exempts the provision of life-sustaining treatment when such treatment would be "virtually futile" in terms of preventing the infant's death *and* the treatment itself would be "inhumane." This clause pertains to two separate variables: the child's prospect of survival and the effects of the treatment itself on the child.

Although this exemption seems at first glance merely to reiterate the lesson of section (B) regarding the provision of futile treatments,

the inclusion of the words "virtually futile" does appear to expand significantly the ambit of permissible nontreatment. This qualification appears to mean that one need not be *absolutely certain* that further treatment will prove futile in terms of the infant's survival; it is enough that the child's physicians, exercising "reasonable medical judgment," deem the treatment to be *virtually* futile. In other words, they might think that the child has some chance of survival—albeit a slight chance—and still opt for nontreatment.

In order to pursue this option within the terms of the Act, however, physicians must *also* deem the administration of the contemplated treatment to be "inhumane" under such circumstances. Presumably, this means that the proposed treatment (already judged to be virtually futile) must also be considered excessively invasive, or painful, or otherwise burdensome. The withholding of "humane" treatments—i.e., measures designed to provide comfort rather than cure?—would appear to fall under the heading of "medical neglect."

This exception is most likely to apply to extremely premature infants suffering both from their fragile condition and from the iatrogenic effects of life-sustaining interventions. For example, it would seem to cover the case of a respirator-dependent 500 gram baby, born at 23 weeks gestation, who manifests failing kidneys and a damaged heart. Although a narrow, short-term perspective might yield a decision to maintain this baby on the respirator, to dialyze him, and perhaps even to perform cardiac surgery on him, the child's extremely slim chances of survival, coupled with the pain and discomfort of the proposed treatments, would appear to authorize nontreatment under the revised Act.

Although this exception obviously resorts to some sort of "quality-of-life" reasoning to reach its conclusion, and although the only "pro-life" group to oppose the Act did so in part to protest the inclusion of such alleged "weasel words" (thus did Gary Curran, spokesman for the American Life Lobby, characterize this provision of the Act in a telephone interview, September 12, 1984) as "virtually futile," it would be a mistake to interpret this provision as a generalized apology for quality-of-life arguments in the strict sense of this phrase. The crucial element precluding this result is the Act's insistence that, given a child's slim chances of survival, the *treatment itself,* rather than the child's subsequent *life,* be considered inhumane. Thus, even though the care-givers of a severely impaired child might view her subsequent

life, should she somehow manage to survive, as "inhumane" (i.e., painful, isolated, limited), they are not licensed to forego treatment under this provision of the Act unless the treatment itself (e.g., surgery), under the circumstances, is deemed "inhumane."

The third and final category of nontreatment (A) exempted from the framework of "medical neglect" concerns infants judged to be "chronically and irreversibly comatose." The interesting thing about this category of patients is that it has been defined without any reference to the child's impending or imminent death. In contrast to all of the other exceptional cases mentioned above, patients in category (A) need not be considered to be engaged, virtually or otherwise, in the process of dying. For such *nondying* patients, then, the rationale for nontreatment cannot be based on the futility of further treatments "in terms of the survival of the infant." Indeed, if nontreatment is to be justified in such cases, our justification must rest on the judgment that *this sort of life* is simply not worth sustaining. As we suggested previously, such a justification requires an assessment of the child's quality of life.

Although this exception clause gives greater leeway to quality-of-life judgments—allowing a child's care-takers to consider not merely the "humaneness" of certain treatments but also the quality of his or her future *life*—it would again be a mistake to conclude that the Act thereby publicly sanctions a general quality-of-life standard. To be sure, the Act sanctions—without, of course, actually saying so—quality-of-life judgments, but only in the most extreme cases at the lowest end of the qualitative scale. In order to justify nontreatment in such cases, it will not do to predict that the child will merely never marry, hold a job, or ambulate; nor will it do to predict that the child will suffer from chronic pain and isolation; nor will it do to predict that an early death would be in the child's best interest. To justify nontreatment it must rather be shown that a child will never regain consciousness—undoubtedly a quality-of-life judgment, but one that is very narrowly restricted.

In spite of the framers' manifest intention to cabin such quality-of-life reasoning within a narrow and clear-cut range of cases, clinical realities will no doubt frustrate that intention, at least to some extent. Although the Act merely insists on a standard of "reasonable medical judgment"—rather than infallibility—in gauging the irreversibility of a child's coma, such judgments are notoriously difficult to make.

Given children of such young age, it is extremely difficult to tell if they will remain comatose or eventually (perhaps within months or years) regain consciousness. This element of pervasive uncertainty in clinical prognostication will undoubtedly tend to blur the edges of this sharply defined category of patients. We can, accordingly, expect to see underlying differences in treatment philosophy subtly reflected in "reasonable 'medical' judgments" regarding the irreversibility of comatose states.

B. *Assessing the Compromise Principle.* Having determined, albeit in a highly tentative and provisional fashion, the meaning of the new standard of "medical neglect," we can now attempt to assess its soundness. Does this particular version of a "medical indications policy" mark a significant advance over previous "Baby Doe" formulae? If so, does it go so far as to yield an adequate guide to decision-making in the neonatal nursery?

If the above reading of the intent and scope of the Act turns out to be roughly accurate, this law will clearly be preferable to all previous incarnations of the "Infant Doe Rule." As we have seen, the "Infant Doe Rule"'s insistence on "equal treatment" for handicapped and otherwise normal children generated morally inappropriate results in some tragic cases. Applied to the case of the child doomed to an early death by severe holoprosencephaly, for example, the "equal treatment" standard appeared to require surgery to create an artificial nasal passage. (We would have done so for an "otherwise normal" child.) Likewise, that standard appeared to mandate all kinds of invasive treatments for equally doomed Trisomy 13 children so long as they would achieve some very narrowly defined notion of "medical benefit." Under the new compromise principle, however, failure to treat under such conditions will probably fall outside the ambit of "medical neglect." Assuming a reasonable interpretation of (Bii), care-givers could justify nontreatment in these cases on the grounds that treatment would not correct *all* of the infant's life-threatening conditions.

Likewise, the "no quality-of-life judgments" gloss of nondiscrimination would appear to have required the continuation of life-sustaining therapies even for children judged to be chronically and irreversibly comatose. But given the unfortunate fact that such children will never be able to participate even minimally in the human experience, such a mandate to treat defied moral common sense and pressed medicine into the service of an uncompromising and misguided vitalism. The

compromise principle directly addresses this problem, excluding treatment of the irreversibly comatose from the category of medical neglect in section A.

Finally, because the nondiscrimination standard was devised in response to such cases as those of Bloomington Baby Doe and Baby Jane Doe of Long Island—i.e., cases involving full-term infants born with congenital anomalies linked with retardation—that rule proved inadequate to deal with the ambiguities and uncertainties posed by the birth of extremely premature babies. A straightforward reading of the "Infant Doe Rule," coupled with an appropriately narrow understanding of "medical benefit," would appear to generate the conclusion that, so long as there is some chance of medical benefit, all extremely premature babies must be kept alive, no matter how painful or invasive the proposed treatments. The Reagan administration's response to this problem was, in effect, to say that their rule did not literally apply to such cases. The problem of prematurity was thus "solved" by means of an ad hoc and ethically unexplained exception for the category of very low birthweight infants in the administration's list of permissible examples of nontreatment.[22] The new legislation, by contrast, addresses the problem of extreme prematurity on the level of principle, excluding (in section C) "virtually futile" and "inhumane" treatments from the category of medical neglect. In spite of the fact that both the "Infant Doe Rule" and the compromise principle ultimately reach the same conclusion regarding very low birthweight infants, the latter does not attempt to disguise a clear-cut, *ethical,* policy judgment as an instance of "medical" discretion.

Although the compromise principle thus represents a significant improvement over the "Infant Doe Rule," and although the sponsors of this legislation deserve a great deal of credit for achieving consensus on a question many partisans considered "too important" to admit of any compromise, the new standard of "medical neglect" still leaves much to be desired. In particular, we object to the new legislation's excessive stringency with regard to quality-of-life judgments and its exclusion of parents from decisions to forego treatment.

It is true that the compromise principle does extend sotto voce a certain legitimacy to quality-of-life considerations. As we have seen,

[22] See *Final Rules*, supra note 10, at 1654.

the Act takes the "inhumaneness" of certain treatments into account in certain circumstances, and it sanctions the withholding of treatments from irreversibly comatose but "nondying" infants. But while the Act recognizes the moral relevance of these particular quality-of-life considerations, it refuses to bestow the mantle of legitimacy on others that are at least equally relevant from a moral point of view. Moreover, the Act and its accompanying "Joint Explanatory Statement" (*Congressional Record* 1984) fail to provide a coherent, principled analysis of why quality-of-life factors are relevant in some situations, but not in others.

In stark contrast to the conclusions of the President's Commission, the compromise principle regards as morally and legally irrelevant the (very real) possibility that continued life may not be in the best interest of a particular child. Suppose an infant suffers from the sort of multiple malformations that plagued Baby Jane Doe, perhaps to an even greater degree. A large, high level spinal lesion, combined with a grossly deformed spine, massive hydrocephalus, and severe microcephaly ensure that the infant will be paralyzed, incontinent, in pain, in need of multiple operations, and so profoundly retarded that he will never even recognize his care-takers. Immediate surgical repair of the spina bifida lesion will stave off any short-term threats to life, but cannot alter the child's abysmal prognosis. How would the compromise principle have us respond to such a tragic case? Since surgical repair of the spina bifida lesion is by no means "virtually futile" in terms of preventing the child's death, and since he is not "chronically and irreversibly comatose," his case would appear to fall outside of the Act's range of exceptions. He must, therefore, be treated.

We find this conclusion to be unacceptable. As we have argued in previous sections, certain conditions can make an impaired child significantly different from otherwise normal children for the purpose of moral deliberation about treatment. Specifically, we have argued that life-sustaining treatments may be foregone when (1) continued life is no longer in a child's best interest, or (2) the child lacks basic human capacities. A strong case could be made that this baby satisfies both of these conditions. If such considerations are indeed morally relevant, our public law should not ignore them.

Unfortunately, our public law does more than merely ignore certain powerful arguments for nontreatment. It has, in effect, determined that withholding treatment in this and similar cases amounts to

"medical neglect"—legally, a form of *child abuse*—on the part of parents and care-givers. While this charge might well be appropriate and necessary in other sorts of cases—for example, those involving Down's syndrome children with repairable atresia—we find it to be a thoughtless and cruel torment for the parents of infants such as this one across this country. Our public policy ought to be cognizant of these considerations. It should realize that there are cases—albeit relatively few—in which continued life is clearly not in the best interest of children, and that there are many other cases in which loving parents and dedicated care-givers are caught in the grip of tragic perplexity regarding their child's best interests. In such cases, the law ought to recognize a legitimate, if carefully circumscribed, area of parental discretion. The compromise principle's failure to acknowledge any role whatever for parents in such cases was a significant and unjustifiable omission.

C. *From Principle to Process.* Although it is important to distinguish clearly between substantive moral principles and the procedures designed to implement them—i.e., between the questions, "What's right?" and "Who should decide?"—these separate variables invariably condition and influence one another. Thus, the choice of certain principles can automatically rule out incompatible procedures, while certain procedural mechanisms can alter the way principles work in practice. This latter possibility suggests a way to rectify the theoretical flaws of the compromise principle. In spite of that principle's failure to recognize the moral relevance of quality-of-life judgments beyond the pale of its own narrowly drawn exceptions, and notwithstanding its failure to acknowledge a (carefully delimited) range of parental discretion, prudently designed procedures can make up for these shortcomings of principle. In other words, it is still possible for us publicly to cleave to an overly restrictive ethical standard while acting in such a fashion as to secure morally correct results in most cases. Given the contemporary political climate and the seeming impossibility of obtaining better legislation on this controversial issue—indeed, given the distinct likelihood of obtaining a far worse bill in lieu of the amended Act—we believe that this kind of practical accommodation to political realities is presently our best hope for a reasonable policy.

Whether or not the compromise principle will conform in practice to the ethical framework proposed in this article, there is no question but that the Act's recommended procedures mark a significant im-

provement over the defunct "Infant Doe Rule." Even if one believes, as we most certainly do, that parents and care-givers ought to be accountable for their decisions regarding impaired newborns, the rubric of civil rights law and flying "Baby Doe Squads" are not the best way to achieve such accountability. In their stead, the amended Act relies for enforcement on already existing state child protection agencies. Furthermore, the Act encourages the voluntary formation of in-house committees in order to educate parents and care-givers, establish hospital policies, and consult on individual cases. Should these mechanisms prove insufficient to protect the welfare of impaired children in some cases, the Act authorizes state child protection agencies to initiate lawsuits in appropriate courts for the purpose of mandating medical treatment.

While we remain unconvinced of the need for such oversight by bureaucratic state agencies—just as we remain skeptical about the actual numbers of children unjustifiably denied medical treatments—we see significant advantages in the specific constellation of procedures established by this Act. First, we hope and expect that most hospitals will establish "Infant Bioethics Committees" which will provide a useful forum for the discussion of truly difficult cases. Although the Act recommends that such committees be established in part for the purpose of upholding the restrictive terms of the compromise principle, we would hope that great weight be given to the considered judgments of such committees, even when they occasionally condone nontreatment in circumstances not contemplated by that principle. As we have argued above, the compromise principle defines the range of allowable exceptions much too narrowly and pays no heed at all to the judgments of parents in the hard cases. We hope that in practice the locus of decision-making will not stray far from those parties most intimately involved—i.e., parents, the child's physicians, and knowledgeable representatives of the hospital and wider community who sit on these committees—and that reasonable judgments based on the child's best interests will be respected.

Likewise, we hope that these committees will establish good working relationships with local child protection agencies. It is extremely important, for example, that the staff members of these agencies be educated about the medical and ethical complexities of the neonatal intensive care unit. Although a bureaucracy staffed largely by social workers and established to handle paradigm cases of child abuse may

not be the best possible agency to oversee these tragic medical cases, it remains true that the kind of oversight provided by these agencies is likely to be relatively low-key and nonintrusive—at least in comparison with the procedural detritus of the "Infant Doe Rule": i.e., the hotline, flying squads (the bioethical equivalent of "Ghostbusters"), and an aggressively litigious Justice Department. Again, one would hope that the staffs of these local agencies will come to appreciate *all* of the morally relevant factors involved and will, accordingly, defer to the decisions made by parents, doctors, and committees, except in cases where the child's best interests are *clearly* being threatened. Judicial proceedings in this area exact such great costs in terms of family privacy, sensational news accounts, and disrupted hospital nurseries, that we as a society should strive as far as possible to keep these cases out of the courts. Accordingly, we recommend that courts follow the same rule as the child protection agencies, and only rule in favor of such agencies when it is *clear* that nontreatment will compromise the child's best interests.

We believe that such an interlocking system, if put into practice, would easily compensate for the shortcomings we found in the compromise principle. Indeed, this kind of practical accommodation could contribute significantly to the establishment of a *genuine* compromise policy—one which gave each side much of what it ought reasonably to expect. Thus, the so-called "pro-life" and disability advocacy groups could take satisfaction from a strict public statement concerning the value of imperiled young lives, and from a public system set up to vindicate a genuine state interest in protecting especially vulnerable citizens. On the other hand, parents and medical professionals could proceed—perhaps with the aid of committees—to make their tragic and anguished decisions (more or less) secure in the knowledge that they will not be overruled by "outsiders" if they honestly attempt to cleave to the best interests of the child.

Can we reasonably expect to see this sort of ethical accommodation worked out in the coming months and years? It is far too early to tell. Other scenarios, many of them considerably less optimistic, are also possible. One can easily imagine, for example, the Department of Health and Human Services issuing exceedingly strict guidelines interpreting the vague language of the compromise principle—e.g., by stipulating that section (Bii) shall refer only to children judged to be *imminently* dying—complete with a refurbished hotline connected

to eager local prosecutors. Since the Act is overly restrictive and lacks adequate ethical analysis, the compromise it forges is a relatively fragile one. To keep it intact, the Department of Health and Human Services must now show that it has learned from the lessons of the recent past, and must enact flexible guidelines that conform to the spirit of this legislative compromise.

Postscript

As this article goes to press, DHHS has just issued proposed federal regulations based on the new statute that confirm our worst fears: the Reagan administration has apparently learned nothing from the lessons of the recent past. DHHS has assiduously rooted out every instance of vague and flexible language—language that was obviously necessary to the achievement of a compromise between medical and pro-life groups—and substituted in every case a narrow and rigid interpretation of its "medical indications" policy. The proposed regulations explicitly require that treatment decisions are not to be based on "subjective quality-of-life" concepts.[23] They specify that the statutory exception for treatments deemed merely to "prolong dying" applies only when death is *imminent.* Likewise, they interpret the statutory exception for treatments that would not ameliorate or correct *all* of the infant's life-threatening conditions as applying only when each condition is *imminently* life-threatening.[24] The proposed regulations would thus appear to require corrective surgery on the esophageal atresia of a Trisomy 13 or 18 infant, despite the severity of his underlying defect and his predictably brief life—a requirement that flies in the face of current medical practice. Finally, although the proposed federal regulations embrace the concept of hospital review committees—citing the President's Commission report as an authority without once acknowledging the commission's strenuous objections to previous (but nearly identical) DHHS standards—they would have such bodies function, not as genuine "ethics committees," but rather as mere "watchdog committees," ensuring that all "medically indicated" treatments be provided. A committee that has no choice but to mandate complex

[23] 49 *Fed. Reg.* 48160, 48163 (Dec. 10, 1984).
[24] 49 *Fed. Reg.* 48164 (Dec. 10, 1984).

surgery for the Tay-Sachs or Trisomy 13 infant is but a parody of an ethics committee. Although the final regulations may possibly restore some of the flexibility that characterized the compromise legislation, the future looks bleak. Instead of giving us strict but sensible guidelines, as advocated by the President's Commission, the pro-life ideologues within the Reagan administration are on the brink of imposing a rigid and counterproductive rule on even the most gravely impaired infants and their families—a rule that would strip parents of any meaningful role in deciding the fate of their own children and would have doctors treat disease entities rather than the infants who suffer from them.

References

American Academy of Pediatrics. 1983. Comments on Rule Regarding Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants. *Federal Register* 48:30846.

Annas, G. 1983. Baby Doe Redux: Doctors as Child Abusers. *Hastings Center Report* 13(5):22–27.

Brackbill, Y. 1971. The Role of the Cortex in Orienting: Orienting Reflex in an Anencephalic Human Infant. *Developmental Psychology* 5:195–201.

Congressional Record. 1984. Conference Report on H.R. 1904, Child Abuse Amendments of 1984. 130(118):9805–17.

Levin, B. 1985. Consensus and Controversy in Treatment of Catastrophically Ill Newborns: Report of a Survey. In *Which Babies Shall Live?: Humanistic Dimensions of the Care of Imperiled Newborns*, ed. A. Caplan and T. Murray. Clifton, N.J.: Humana. (Forthcoming.)

Paris, J., and R. McCormick. 1983. Saving Defective Infants: Options for Life or Death. *America Magazine* 148(16):313–17.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1983. *Deciding to Forego Life-Sustaining Treatment.* Washington.

Ramsey, P. 1970. *The Patient as Person.* New Haven: Yale University Press.

Shaw, A., J. Randolph, and B. Manard. 1977. Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons. *Pediatrics* 60:588–99.

Strong, C. 1981. Can Fluids and Electrolytes Be "Extraordinary" Treatment? *Journal of Medical Ethics* 7:83–87.

Weir, R. 1984. *Selective Nontreatment of Handicapped Newborns.* New York: Oxford University Press.

Address correspondence to: Nancy K. Rhoden, Assistant Professor of Law, Ohio State University, 1659 North High Street, Columbus, OH 43210.