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Rejecting the Baby Doe Rules and Defending a “Negative” Analysis of the Best Interests Standard

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Two incompatible policies exist for guiding medical decisions for extremely premature, sick, or terminally ill infants, the Best Interests Standard and the newer, 20-year old “Baby Doe” Rules. The background, including why there were two sets of Baby Doe Rules, and their differences with the Best Interests Standard, are illustrated. Two defenses of the Baby Doe Rules are considered and rejected. The first, held by Reagan, Koop, and others, is a “right-to-life” defense. The second, held by some leaders of the American Academy of Pediatrics, is that the Baby Doe Rules are benign and misunderstood. The Baby Doe Rules should be rejected since they can thwart compassionate and individualized decision-making, undercut duties to minimize unnecessary suffering, and single out one group for treatment adults would not want for themselves. In these ways, they are inferior to the older Best Interests Standard. A “negative” analysis of the Best Interests Standard is articulated and defended for decision-making for all incompetent individuals.

Keywords: *American Academy of Pediatrics, Baby Doe, Best Interests Standard, end of life treatment, ethics, infants, Koop, law, neonatal, right-to-life, Reagan, sanctity of life*

I. INTRODUCTION

The Best Interests Standard is a widely defended moral and legal standard for guiding decisions when individuals lack decision-making capacity,

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including infants, children, and adults lacking advance directives (Faden, Beauchamp, & King, 1986; Buchanan and Brock, 1989; Kopelman, 1990; 1997; *Grimes*, 2001; *Bowen*, 1986; and *Miller*, 2003). Another newer policy, however, exists for infants under one year of age based on the 1984 Amendments to the Child Abuse Prevention and Treatment Act (CAPTA, 1985) Law. They are called the "Baby Doe Rules," and went into effect in 1985 (DHHS, 1984). Many neonatologists and other pediatricians soon charged that the Baby Doe Rules and the Best Interests Standard were incompatible; they reported that the Baby Doe Rules altered standards of care and limited clinicians' and parents' ability to make individualized and compassionate decisions about what was in the best interests of infants (Kopelman, Kopelman, & Irons, 1988, 1992). Some defenders of the Baby Doe Rules, such as President Ronald Reagan, his Surgeon General, C. Everett Koop, and other "right-to-life" advocates (Reagan, 1986; Doerflinger, 1989; Koop, 1989; Bopp, 1990), however, claimed the Baby Doe Rules were best for infants and were needed to stop unacceptable "quality of life" interpretations about what was best for them. Other defenders, including some members of the American Academy of Pediatrics leadership,¹ held that the Baby Doe Rules were compatible with the Best Interests Standard for radically different reasons; they claim that properly understood, these rules allow doctors and parents to select the same sort of compassionate, individualized medical choices using reasonable medical judgments permitted by the Best Interests Standard. Both defenses are considered and rejected.

I will argue that the Best Interests Standard and Baby Doe Rules offer incompatible guidance about how to treat infants. After discussing why there were two sets of almost identical Baby Doe Regulations, I use a case to display differences between the Baby Doe Rules and the Best Interests Standard. I argue that the Baby Doe Rules should be rejected because they sometimes require actions that violate duties to act compassionately, provide individualized treatment decisions at the end of life, and minimize unnecessary suffering. Moreover, the Baby Doe Rules unfairly single out one group, infants under one, for treatments adults do not want for themselves, violating duties to treat others as we want to be treated. In contrast, the Best Interests Standard offers the same guidance for all incompetent individuals, directing decision-makers to select the sort of individualized and compassionate decision-making that adults want for themselves and that are recommended by professional groups such as the American Academy of Pediatrics and Hospice organizations for end-of-life treatments (National Hospice Organization, 1990; AAP, 1994; 1995; 1996; Singer, Martin, & Kelner, 1999; Steinhauer et al., 2000; See Byock, Caplan & Snyder, 2001). Finally, I articulate and briefly defend what I call the "negative" analysis of the Best Interests Standard for many forms of decision-making for incompetent persons, arguing it reflects how this standard is used, avoids common criticisms, and is superior to the Baby Doe Rules.

II. BACKGROUND

The current Baby Doe Rules are formally known as the Child Abuse Amendments to Public Law 98-457 or the Child Abuse and Prevention and Treatment Act. They went into effect on May 15, 1985, about three years after the death of the Baby Doe from Bloomington, Indiana, after whom two sets of rules were named. After summarizing the Baby Doe Rules, I will discuss how there came to be two substantially similar sets of regulations, one promulgated under civil rights law and rejected by the Supreme Court and the other still on the books as federal funding requirements for states to receive money to combat child abuse and neglect.

The current Baby Doe Regulations prohibit anyone from withholding or withdrawing food, water, medications, or other treatments appropriate to maintain survival, allowing only three exceptions for withholding life-supporting treatments:

- (i) The infant is chronically and irreversibly comatose;
- (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
- (iii) 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 (DHHS, 1985: 1340.15(B)2, p. 14887).

The full text is supplied in Table I, showing that the regulations only allow physicians to use reasonable medical judgment in deciding if one or more of these exceptional situations exist or what form of interventions, medications, nutrition or hydration to use in maximally supporting an infant's life. Some defenders support these restrictions, applauding their "right-to-life"

TABLE 1 BDR-II offers substantially similar requirements and exceptions as the BDR-I regarding treatment of all infants with life-threatening conditions under one year of age:

[The withholding of medically indicated treatment is] the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply: (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) 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 [DHHS, 1985:1340.15(B)2, pp. 14887-14888].

stance (see Reagan, 1986; Doerflinger, 1989; Koop; 1989 Bopp, 1990). Other defenders insist these rules are misunderstood and allow the same sort of discretion that doctors may consider for other persons.² In what follows, I will criticize both defenses, arguing that these rules should be rejected in favor of the older Best Interests Standard, which applies to all persons lacking competency, not just infants under one year of age.

The first set of rules that came to be called the Baby Doe Regulations was promulgated by the Reagan Administration using civil rights laws. They responded to the events surrounding an infant born with a tracheosophageal fistula and trisomy 21 or Down Syndrome in Bloomington, Indiana, on April 9, 1982. The fistula had to be repaired for the baby to live but physicians disagreed about how the baby ought to be treated. Some wanted to do the repair and others, principally the obstetrician, recommended against it. (Today more is known about trisomy 21 and it seems likely that doctors would not offer such diverse recommendations to parents.) The family elected not to operate.

Some pediatricians and hospital administrators sought an emergency session with a circuit judge, who ruled that the parents had the right to make this decision, especially given disagreements among the physicians about the recommended course of treatment. Upon appeal, both the County Circuit Court and the Indiana Supreme Court also ruled in favor of the parents. An appeal was made to the Supreme Court for an emergency stay, but the baby who became known as Baby Doe died, making the request moot. The legal principle, then and now, is that parents are the primary decision makers for infants and may select the option that they believe is in their child's best interests, and unless there is an emergency, doctors should seek a court order if they disagree with the parents (*Miller*, 2003).

These events became widely publicized. President Ronald Reagan ordered the Department of Justice and the Department of Health and Human Services to issue regulations that came to be called the "Baby Doe Rules," under Section 504 of the Rehabilitation Act of 1973 (U.S., DHHS, 1984). The theory was that the failure to provide infants maximal treatments, unless one or more of the three stated exceptions existed, was discriminatory and violated their civil rights. Because of these Baby Doe Rules, neonatal intensive care units were required by March 22, 1983, to display prominently a large poster stating the rules and a hotline phone number so that anyone could call the Department of Health and Human Services if they believed an infant was not being treated appropriately. If a notice was received, a team was sent to investigate.

The first set of Baby Doe Rules were challenged in the courts after the birth on October 11, 1983, of a baby who came to be known as Baby Jane Doe at St. Charles Hospital in New York. She was soon transferred to the neonatal intensive care unit at State University of New York at Stony Brook because of her spina bifida, hydrocephalus, microcephaly, and kidney

damage. Her parents were told she would be severely retarded, paralyzed below the lesion, and suffer from frequent kidney and bladder infections. There was considerable disagreement among doctors about whether it was in her best interest to have corrective surgery. The parents declined surgery and a legal battle ensued that eventually reached the Supreme Court. The Supreme Court in *Bowen vs. American Hospital Association, et al.* (1986) decided in favor of the American Hospital Association and the Stony Brook Hospital, thereby supporting the parents' right to decide. The court held that the first set of Baby Doe Rules could not be issued using Section 504 of the Civil Rights Act and that no need for these rules had been shown.

When it became clear that the courts were rejecting the Reagan Administration's interpretation of the Civil Rights Act (Section 504 Rehabilitation Act of 1973) upon which the first set of Baby Doe Rules were based, the U.S. Congress adopted a similar set of Baby Doe Rules as requirements for states to receive funds to combat child abuse (DHHS, 1984). Unlike civil rights laws, these federal funding requirements are technically optional, although most states adopted them. The second set of Baby Doe Rules went into effect in 1985; but, unlike the first set of Baby Doe Rules, they have not been tested by the U.S. Supreme Court. Table II illustrates their differences.

My colleagues and I conducted a large survey of neonatologists and other pediatricians shortly after the second set of Baby Does Rules were adopted (Kopelman et al., 1988, 1992). It was sent to all members of the Perinatal Pediatric Section of the American Academy of Pediatrics and a random sampling of other pediatricians selected by the Academy. Their responses contrasted with the views of the Academy's leadership, who had worked with members of Congress and the Reagan Administration to write the second set of Baby Doe Rules (Murray, 1985). The survey showed the respondents found that the rules were unnecessary to protect the rights of disabled infants, interfered with parents' rights to select the action that was

TABLE 2 The First set of Baby Doe Regulations (BDR-I) were issued in 1984 and based upon the Section 504 of the Rehabilitation Act (1973): "No otherwise qualified handicapped individual...shall solely by reason of this handicap, be excluded from the participation in or be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance." States must abide by civil rights law, so BDR-I was regulated federally and not optional. The Supreme Court struck them down in 1986 in *Bowen v. AHA*. In contrast, the second set of Baby Does Regulations (BDR-II) are funding requirements for states to receive federal money, are regulated by the states and are technically optional.

BDR-I: Section 504 Rehabilitation Act of 1973	BDR-II: 1984 Child Abuse Amendments
Based on civil rights law	Funding requirements for states
Not optional	Technically optional
Regulated federally	Regulated by the states
U.S. Supreme Court in <i>Bowen v. AHA</i> rejects BDR-I	Untested by the U.S. Supreme Court

in the best interests of their children, offered inadequate consideration of infants' suffering, and ignored resource allocation (See Table III). They also reacted to three hypothetical but common cases discussed in the pediatric literature as paradigms for withholding or withdrawing life-saving treatments. Most neonatologists (75–86%) agreed about what they would consider to be in a child's best interest using good medical judgments. But, in some cases, up to a third of respondents perceived a conflict between obligations to act in a child's best interest and the legal requirements under the Baby Doe Regulations.

Their responses squared with the Supreme Court's reasoning in *Bowen* (1986) for rejecting the first set of Baby Doe Rules (Kopelman et al. 1988, 1992). The Supreme Court, as noted, also judged that the Baby Doe Regulations were unnecessary. The court supported the Best Interests Standard,

TABLE 3 Criticisms of the Baby Doe Regulations from 494 members of the Perinatal Section of the American Academy of Pediatrics (49% response rate) and from a random sampling of 730 AAP pediatricians who were not neonatologists (25% response rate) surveyed in 1986 (see Kopelman, et al., 1988, 1992).

	% Agree	% Uncertain	% Disagree
1. The BDR-II will result in improved care for all infants			
Neonatologist	5	14	81
Other pediatricians	6	16	78
2. The BDR-II were needed to protect the rights of handicapped infants			
Neonatologist	14	10	76
Other pediatricians	20	12	67
3. The BDR-II will not affect parental rights to consent to or refuse treatment based upon what is in the infant's best interest			
Neonatologist	19	15	66
Other pediatricians	19	17	65
4. The BDR II allows adequate consideration of suffering			
Neonatologist	29	11	60
Other pediatricians	30	14	56
5. Most critically ill infants are over treated when the chances for their survival are very poor			
Neonatologist	56	13	31
Other pediatricians	62	18	19
6. If the federal government requires life-saving treatment of severely handicapped infants, then it should guarantee payment for that treatment			
Neonatologist	82	6	12
Other pediatricians	76	8	16
7. If the federal government requires life-saving treatment of severely handicapped infants, then it should guarantee payment for their rehabilitative care			
Neonatologist	82	6	12
Other pediatricians	75	9	16
8. The BDR-II have exacerbated the shortage of NICU beds			
Neonatologist	17	32	51
Other pediatricians	24	50	25

agreeing with the appellate division ruling in the case of “Baby Jane Doe” “that ‘concerned and loving parents’ had ‘chosen one course of appropriate medical treatment over another’ and made an informed decision that was ‘in the best interest of the infant’” (*Bowen*, 1986; *University Hospital*, 1984). The Supreme Court in *Bowen* concluded that there was no evidence of discrimination or discriminatory withholding of care, and that authorities had acted inappropriately. This *Bowen* Court was critical of the Reagan Administration’s use of the Civil Rights Law to promulgate regulations that would undermine the traditional role of parental consent and medical judgment, and exert undue pressure on state agencies to comply. This *Bowen* Court also rejected the Reagan Administration’s view that it is unjust and prejudicial to evaluate an infant’s disability in choosing a treatment. The Supreme Court agreed with the appeal court’s ruling that the administration’s view of medical decision making was oversimplified (*Bowen*, 1986; *University Hospital*, 1984). The Supreme Court and the Second Circuit Court of Appeals concluded that the purpose of the first set of Baby Doe Regulations was to alter standards of care, and they were critical of this.

As the courts were rejecting the first set of Baby Doe Rules, the second set was being fashioned in a political compromise among members of the leadership of the American Academy of Pediatrics, “right-to life” groups, Congress, and the Reagan Administration (Murray, 1985). As soon as the second set of Baby Doe Rules were adopted “right-to-life” groups, influential political figures such as Reagan (1989) and Koop (1989), and the leadership of the American Academy of Pediatrics all claimed victory, but, as we shall see, the Academy’s leadership had very different views from the others about what the rules meant.

In the next section, I discuss a case to illustrate what is at stake, and then I turn to defenses and criticisms of both the Baby Doe Rules and the Best Interests Standard, arguing that the Best Interests Standard is better than the Baby Doe Rules at allowing the sort of compassionate and individualized decision-making recommended by hospice groups for adults and by the American Academy of Pediatrics for children.

III. FINDING A GOOD TREATMENT PLAN FOR ANGEL

The Baby Doe Regulations are linked in my mind to the controversies in which I was involved over finding a good treatment plan for an infant whom I will call “Angel.” Disputes over how to care for Angel illustrate why many neonatologists and other pediatricians and the courts were hostile to the Baby Doe Rules. Angel was born shortly after Congress enacted the second set of Baby Doe Regulations.

Angel was at the center of impassioned disagreements among doctors, nurses, social workers, and hospital administrators for over two years. Angel

was born at full term, and doctors quickly agreed that there had been prenatal damage to her central nervous system of unknown origin. Her prognosis was that she would continue to be functionally quadriplegic, with severe respiratory distress, and dependent upon a ventilator to breathe. Her lungs were often infected and she had frequent seizures associated with apoxic spells. Interventions necessary to sustain her life were not only painful but caused complications. She did not feed well by mouth and hardly responded to stimuli. Her family was poor and overwhelmed with a variety of other social and economic problems; they stopped visiting after a few weeks, leaving treatment decisions to clinicians.

From the day of her birth, clinicians, social workers, nurses, and others met frequently to consider whether palliative treatment, focusing upon relieving her suffering, was a better goal for Angel than aggressive care to prolong her life. The overwhelming consensus was that palliative care would be in her best interest and what we would choose for ourselves or our family members in such circumstances. Yet, aggressive life-support continued because a few people wanted more data, feared legal entanglements in light of the Baby Doe Regulations, or worried about bad publicity.³

After a few months, she was transferred to the Pediatric Intensive Care Unit (PICU) from the NICU. For the sake of continuity, several nurses, a social worker and a pediatric neurologist provided most of her care. The conferences continued and three groups quickly formed. Group 1, composed of her long-term caregivers, favored maximal life saving and aggressive treatments as being in her best interest; they believed that she would eventually do well enough to interact with people and enjoy her life.

Members of Group 2 disagreed with those in Group 1 on factual grounds, arguing that evidence showed her prognosis was grim and that her development was arrested at less than three months; they believed she would develop more life-threatening complications and die slowly and painfully. The pediatricians, other than her neurologist, agreed with members of Group 2, and as the controversy became known throughout the hospital so did most of the other clinicians. They believed that palliative care was the most compassionate approach because there was too much suffering and too little compensatory benefit to justify such burdensome interventions. One consultant grumbled that her long-term caregivers had lost their objectivity and they were like unrealistic parents (Kopelman, 1990).

Although these two groups had factual disputes about whether Angel would get past the suffering of a barely conscious, pain-filled existence to a life worth living, they agreed in principle that their actions should be guided by the Best Interests Standard or what was in Angel's best interest, given the available options. They could not agree what was best for her as long as disputes about her prognosis existed.

A third group of clinicians and administrators (Group 3) insisted upon aggressive treatment because of the (then) newly adopted Baby Doe

Regulations. Since Angel was not in a coma, not dying, and treatments were not virtually futile in terms of survival, they reasoned that maximal care must be provided. They were unconvinced by arguments that Angel met the second exception that treatment would “merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant...” because she was not dying or terminally ill. Moreover, the members of Group 3 did not want their hospital to test the meaning or legal standing of the second set of Baby Doe Rules, including how it relates to the older Best Interests Standard. Institutionally, the safest legal course, they concluded, was to provide Angel maximal life-saving treatments.

Members of Groups 1 and 3 agreed that clinicians should continue maximal life-saving treatment, but for different reasons. Members of Group 1 believed Angel would eventually do well and maximal treatment was in her best interest. Members of Group 3, however, agreed that it was probably in her best interest to have palliative care and would be what they would want for themselves or their family members facing an existence like that of Angel. Yet, since treatment was keeping her alive, she was not in an irreversible coma, and none could say she was dying, they believed the prudent option was to follow what they regarded as their duties under the law, given the Baby Doe Rules.

Month after month, the three groups continued to discuss treatment plans for Angel. Although they agreed that she was in pain and barely conscious, they disagreed about her prognosis and whether to be guided by the Best Interests Standard or the second set of Baby Doe Rules. Because there was no consensus, maximal treatment continued. Angel’s room, filled with stuffed animals and bright pictures, showed how much people cared about her. In the center was a tiny infant surrounded by large machines. She scarcely moved, struggled to breathe, and looked uncomfortable from the very technologies keeping her alive. Eventually all three groups agreed, but it took over two years. After a series of medical complications, it was clear that treatments were only prolonging her death.

Unlike the members of Group 3, some defenders of the Baby Doe Rules hold that the regulations serve infants’ best interests because they defend a “right-to-life” view.⁴ Other defenders hold that these rules are misunderstood and that properly understood, the Baby Doe Regulations do not restrict doctors and families from using reasonable medical judgment in selecting individualized treatment plans, and serving the best interests of infants.⁵ I will argue that this benign interpretation cannot be supported by the language or purposes of the Baby Doe Rules. I conclude that neither the “right-to-life” defense nor the “benign” interpretation of the Baby Doe Rules are compatible with individualized and compassionate decision-making favored by adults, and advocated by the courts, the American Academy of Pediatrics, and professional organizations about how to make end of life treatment decisions.

A. The “Right-to Life” Defense

“Right-to-life” groups claimed that the second set of Baby Doe Rules represented a victory because these regulations severely restricted the quality-of-life considerations that parents and doctors can use in making treatment choices (Murray, 1985).

The Reagan Administration used the Baby Doe Regulations to set strict parameters about what treatments for imperiled infants like Baby Doe were “appropriate,” “useless,” “reasonable,” or “futile” (Reagan, 1989; Koop, 1990). Reagan wrote, “. . . the real issue is whether to affirm and protect the sanctity of all human life, or to embrace a social ethic where some human lives are valued and others are not. As a nation we must choose between the sanctity of life ethic and the ‘quality of life ethic’” (Reagan, 1989, p. 355). Reagan wanted to insure that institutions would never again use quality of life determinations to withhold or withdraw appropriate medications, hydration, or nutrition. His Surgeon General, C. Everett Koop, strongly supported these regulations, agreeing with Reagan that Baby Doe was mistreated:

. . . medicine, nutrition and fluids are life itself and regardless of age individuals should be protected; they should receive whatever treatment is indicated. That does not mean prolonging the act of dying. But it does at least mean providing her with the nutrition and fluids needed to sustain life at its most basic level (Koop, 1989, p. 3).

The Baby Doe Rules reflect the right-to-life position defended by Reagan and Koop. Appropriate medication, hydration, and nutrition may never be withheld, and one and only one quality of life consideration is permissible for withholding or withdrawing maximal life saving treatment, namely, for chronic and irreversible coma (the first exception); “futile” treatments must be understood strictly as those that would only prolong dying (second exception); there is a provision to withhold or withdraw interventions that are “virtually futile in terms of survival” and “under such circumstances” would be inhumane (the third exception).

Even before the Baby Doe Rules were enacted, some theologians criticized the attempt by “right-to-life” advocates, such as Reagan, to link the view that maximal treatment was required for all non-dying minimally conscious life to religious beliefs about the “sanctity of life.” Richard McCormick, a well-known Jesuit theologian, argued that when people lack the potential for interpersonal relationships, there is no obligation to require life-saving treatments (1974). Even if there is a duty to protect life, this does not mean it should be treated as an absolute value. In fact, if it were treated as an absolute value, respirators could never be turned off for adults or children. We would not only have to bankrupt our country to provide resources for this, but also limit the liberty of most adults,

giving them no choice in the matter about when to withdraw life-saving treatments.

K. D. Clouser (1973) also objected to attempts to link “sanctity of life” to a “life at all costs” position. It is more plausible, he argued, to understand sanctity of life as the duty to preserve life unless there is a higher duty. In some cases, preserving a life violates duties to avoid unnecessary suffering, for example, when there is too little compensatory benefit to justify the pain. Life is not always the highest value, and we generally agree there are sometimes higher duties, such as relieving suffering, or risking one’s life to save others.

William May, a well-known Protestant theologian, argued that taking death as absolute evil is not a sanctity of life position, but an idolatry of the physical (1983). Sanctity of life should be understood as a duty to prevent untimely death, and not as some have argued, a justification for preserving life at all costs, no matter how minimal (see also Paris, Crone, & Reardon, 2001).

These theologians argued that selecting medical treatments for imperiled and incompetent individuals should, to the extent possible, be based on their best interests. Yet, we do not always agree about what is best; and/or parents and clinicians often struggle with difficult treatment decisions such as how to balance duties to prolong life and relieve suffering when dealing with severely ill individuals. Some argue that special rules are needed for infants less than one year of age because parental choices may reflect poor bonding rather than what is best for the baby. There is a paucity of data to reach such a sweeping conclusion.

Recommendations for compassionate and individualized decision-making are the norm in many policies for older children and incompetent adults and are widely supported in the pediatric literature and in other American Academy of Pediatrics policies (May, 1983; Faden et al., 1986; Freeman, 1988; Buchanan and Brock, 1989; Paris, et al., 1990; 2001; AAP, 1994; 1995; 1996; Lantos, 1996; Byock et al., 2001; NHO, 2001). This right-to-life position advocates a policy adults would not want for themselves (Singer, Martin, & Kelner, 1999; Steinhauer et al., 2000).

B. The Benign and Misunderstood Defense

In sharp contrast, some members of the leadership of the American Academy of Pediatrics supported the second set of Baby Doe Regulations, because they believed that the rules were reasonable and would not alter standards of care. Properly understood, on this account, the Baby Doe Rules leave doctors free to use reasonable medical judgment in making treatment plans, act in infants’ best interests in providing palliative care, and use their discretion to withhold or withdraw hydration, nutrition, or medication.⁶ The American Academy of Pediatrics’ President when the Baby Doe Regulations

were passed was Robert Haggerty, M.D., who is reported as saying, "It would appear that the final rule reaffirms the role of reasonable medical judgment and that decisions should be made in the best interests of infants" (Murray, 1985, p. 6). These rules leave standards of care unchanged, these defenders contend, allowing doctors to use all reasonable medical judgment in framing treatment plans. This view persists (AAP, 1996). The 1996 Committee on Bioethics of the American Academy of Pediatrics contend that these rules use the words "reasonable medical judgments," "appropriate," and "inhumane" in ways that allow considerable discretion. The survey taken by my colleagues and me (Kopelman et al., 1988, 1992) is used by them to show how badly neonatologists and other pediatricians misunderstood the regulations (AAP, 1996). I will argue that the text does not support their benign interpretations and the "right-to-life" advocates who applauded these rules and the Academy's rank and file and the Supreme Court who criticized them got their meaning right.

First, the rules permit reasonable medical judgment, but only insofar as it is necessary to apply the Baby Doe Rules. Doctors, for example, must use reasonable medical judgment and practice standards to make the diagnosis that an infant is dying or in an irreversible coma. As noted, Reagan and Koop sought to restrict choices about what was "reasonable."

Second, the regulations state that "appropriate nutrition, hydration, and medication" may never be withheld, and the Committee on Bioethics is mistaken in saying they may be removed when doctors judge that they are not "appropriate." Appropriate can mean what is appropriate for a particular condition (it is appropriate to give antibiotics for bacterial pneumonia) or what is appropriate treatment for a particular patient. Traditional medical judgment is individualized, determining the benefits of a proposed treatment for a particular patient. Parents and physicians may decide it is not appropriate to give antibiotics to a dying infant who has bacterial pneumonia. The 1996 Committee on Bioethics seems to have mistakenly read "appropriate" in its traditional way in thinking that clinicians may omit what they consider inappropriate hydration, nutrition and medication. This interpretation is not only implausible in terms of what the guidelines say, but also in terms of Reagan's and Koop's intention in framing these rules. On the Committee's interpretation, parents and doctors could have turned to the Baby Does Rules for support in allowing them to stop all medications, nutrition, or hydration from babies like Baby Doe and Baby Jane on the grounds that they thought that they were "inappropriate" given their overall condition. Yet, blocking such discretion is what caused the Baby Doe Rules in the first place.

Thus, defenders' interpretation on this point misrepresents the intention as well as the language of the regulations. Clearly, the Reagan Administration and disability groups did not want to permit this kind of discretion. They framed rules to require doctors to provide all appropriate nutrition,

hydration, and medication for the condition and exceptions are impermissible unless the infant is in an irreversible coma, is dying, or if treatment would be virtually futile in terms of survival and therefore inhumane. (Reagan, 1986; Koop, 1989; see Table I). Physicians may use reasonable medical judgment, but only to apply these rules.

Third, defenders may look to the second clause of the second exception to defend their view: "The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant" (DHHS, 1985:1340.15(B) 2). Defenders may say that this means anytime one cannot correct *all* the infant's life-threatening conditions, life-saving treatments may be withheld or withdrawn. This interpretation, however, is implausible when taken in context since it is clear that "ameliorating or correcting all of the infants' life threatening conditions" must be assessed in terms of whether this would "merely prolong dying" (the first clause) or "otherwise be futile" (the third clause). Moreover, if taken out of this context of "prolonging dying" (in the first clause) and "otherwise futile in terms of survival" (in the third), we get an interpretation that might offer too little protection. If you were at liberty to discontinue life-saving measures *anytime* you could not improve or correct all life-threatening conditions, the door of discretion would be opened so widely that families and doctors could settle on non-treatment for infants likely to die of their conditions when death is years away. Moreover, all finite creatures must die and there is nothing effective in ameliorating or correcting *that* condition. This interpretation, then, is implausible in light of the text of the Baby Doe Rules and the clear intent of the Reagan Administration to prohibit such discretion (Reagan, 1986; Koop, 1989).

Fourth, defenders argue that the third exception allows adequate consideration of duties to relieve suffering because it states doctors need not provide "inhumane" treatments. Although the word "inhumane" is used, the text does not support this interpretation. It states, "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" (DHHS, 1985:1340.15(B) 2). This passage does not permit consideration of the infant's suffering *unless* survival is "virtually futile" and this is generally understood to mean the infant is dying, especially in the context of an intensive care unit.

Thus, claims by some members of the leadership of the American Academy of Pediatrics that the Baby Doe Rules are misunderstood and allow all reasonable discretion are implausible. The words "reasonable medical care," "appropriate," and "inhumane" taken in context do not permit the discretion these defenders assert (Murray, 1985; AAP, 1996). Consequently, these members of the American Academy of Pediatrics' leadership

got the meaning wrong. As discussed, those who got it right included Reagan, Koop, and other “right-to-life” defenders, such critics as the Supreme Court, and many neonatologists and other pediatricians (Kopelman et al., 1988, 1992).

While the current set of Baby Doe rules has not been tested by the Supreme Court as the first set of Baby Doe rules were in *Bowen*, the Wisconsin Court of Appeals has interpreted and applied these rules in *Montalvo v. Borkovec* (2002). This appellate court offers an unambiguous interpretation, showing that these federal funding regulations do not allow the sort of discretion needed for individualized and compassionate decisions for infants advocated by the American Academy of Pediatrics. Wisconsin’s appellate court understood these regulations as requiring maximal treatment unless the infant is in an irreversible coma or dying. The case concerned a 23-week-old premature infant where the Wisconsin appellate court ruled that the baby’s parents had no role in consenting or refusing maximal treatment because the child was not dying or comatose. “The implied choice of withholding treatment proposed by the plaintiffs, is exactly what CASTA prohibits.” (*Montalvo v. Borkovec*, 2002, p. 19). This was the same interpretation the US Supreme Court gave in its review of an earlier but similar set of “Baby Doe” rules in *Bowen*, which President Reagan promulgated under civil rights law. In contrast to the Wisconsin Court in *Montalvo v. Borkovec* (2002), however, the Supreme Court in *Bowen* (1986) offered scathing criticism of the first set of Baby Doe rules themselves, saying no evidence had been given for the need to adopt these rules and that they ignored the role of parental consent, sought to alter standards of care, and took an oversimplified approach to medical decision-making.

Critics of the Baby Doe Rules say that the text clearly singles out one group, infants under the age of one, for a set of rules that most adults would not tolerate for themselves. Adults faced with a choice between prolonging unconscious life or prolonging life and preventing pain and suffering, sometimes believe that there are worse things than dying (Singer et al., 1999; Steinhauser et al., 2000; Byock, Caplan & Snyder, 2001). This attitude is reflected in the first priority of palliative care as the relief of pain and suffering (NHO, 1990). If we agree that it is wrong to do to others what we would not want for ourselves and that we would not want a Baby Doe policy for ourselves, then we should not adopt such a policy for infants under one year of age. The Best Interests Standard applies to all persons lacking decision-making capacity or competency, and permits the sort of compassionate and individualized decision-making widely recommended. It is a matter of debate and regional practice how much influence the current Baby Doe Regulations exert on patient care. Some doctors, hospital attorneys, and administrators may find them irrelevant and use the older Best Interests Standard as they would for all other children and incompetent adults. Unless a survey similar to that conducted by my

colleagues and me years ago is repeated, it is hard to estimate how many neonatologists and pediatrician are guided by the Best Interests Standard and how many by the Baby Doe Regulations.

IV. THE “NEGATIVE” ANALYSIS OF THE BEST-INTERESTS STANDARD

In this section, I will argue that the Best Interests Standard is a better standard than the Baby Doe Rules for making decisions for imperiled infants. After offering an analysis of the meaning of the Best Interests Standard when used to make many decisions for incompetent persons, I defend it against two criticisms (that it requires what is ideal and that it is too vague).

The Best Interests Standard is a well-established legal principle (see Buchanan and Brock, 1986; Faden, et al., 1986; Kopelman, 1990; 1997; Bowen, 1986; Miller, 2003). For example, the Maryland Court of Appeals recently stated, “we have long stressed that the ‘best interests of the child’ is the overriding concern of this Court in matters relating to children...” (Grimes, 2001, p. 853). The Supreme Court of Texas, in *Miller v. HCA* (2003), held that parents have the right to consent or refuse treatments for infants, and that other than in emergencies, a court order must be obtained to overrule parental refusals. This Court reaffirmed that parents have the primary responsibility to choose because such a policy will promote children’s best interest, welfare, and safety in evaluating the various factors that shape complicated medical decisions. To override parental authority in a non-emergency case, the state must prove, often by clear and convincing evidence, that the child has suffered or is in danger of suffering serious harm (Lee, 1981; Kraus, 1986).

Parents or others given the authority to make choices for an incompetent individual should justify decisions in terms of established moral and legal duties to them (Holmes, 1989). Parents or guardians are the primary decision-makers because it is assumed they are most knowledgeable about the needs of the individual and because the family bears the consequences. In addition, families need support and privacy to make personal decisions in a way that accommodates different values, religious, ethical, social or philosophical views.⁷

The Best Interests Standard is sometimes used to express an ideal (all children should have excellent education) but in many kinds of decision making for incompetent persons, it is used differently (Kopelman, 1997). It is used to find choices that are at least not unacceptable given the different values, needs, and duties of the decision makers. To capture the way it is used in such decisions for incompetent individuals and answer common

criticisms, I defend what I will call the “*negative version of the Best Interests Standard*,” which applies to incompetent individuals of all ages and

1. *instructs decision makers to decide what act(s) are in the incompetent individual's immediate and long-term interests and maximize his or her net benefits and minimize net burdens, setting that act(s) as a prima facie duty;*
2. *presupposes a consensus among reasonable and informed persons of good will about what choices for the incompetent individual are, all things considered, not unacceptable; and*
3. *determines the scope of the Best Interests Standard in terms of the scope of established moral or legal duties to incompetent individuals.*

One advantage in analyzing the Best Interests Standard in this way is that we make room for differences of opinion about what is best given the available options. Some people may decide to forego painful and highly experimental treatment to save their dying infant for pain-free weeks at home, while others might want to pursue every chance no matter how small. Neither choice is unreasonable as judged by what adults want for themselves and established moral and legal duties.

A second advantage of this moral analyzing of the Best Interests Standard is that it clarifies that the decision about what is best may set a *prima facie* not an actual duty for decision makers. For example, we should acknowledge if it would be best for an individual if he or she received a liver transplant and thus set as a *prima facie* duty seeing if it can be obtained. However, it may not be an actual duty to get it since not every individual who needs this scarce resource can have it. It might be marginally beneficial to prolonging the infants' life for a day for him or her to get an expensive drug, but it may not be an actual duty if his or her getting it bankrupts the family or community, or denies it to someone who could have many years of life.⁸

This analysis, which I can only sketch here, avoids some criticisms that are often aimed at the Best Interests Standard and corresponds to how it is generally used in making medical decisions for children (Lee, 1981; Krause, 1986; Kopelman, 1997). Critics of the Best Interests Standard have argued that it is self-defeating, individualistic, unknowable, vague, dangerous and open to abuse. I have responded to these criticisms elsewhere in detail (Kopelman, 1997) in part by separating the different meanings and uses of this standard. In what remains, I focus on two criticisms of it that are especially relevant to medical decision making for incompetent persons and then argue it is preferable to the Baby Doe Rules for guiding decisions for infants less than one year of age.

First, a persistent criticism of the Best Interests Standard is that it always directs people to do what is ideal for the incompetent individual, no matter how marginal the benefit or what the resources, perspectives, or interests of others are. If this were true, the Best Interests Standard would be incoherent since not everyone can have the best, whether it is a scarce resource or the

services of the best surgeon. Although I have noted the Best Interests Standard is sometimes used to express an ideal (it is best if children always ate nutritious food and got plenty of sleep), this interpretation misrepresents its meaning when used in making decisions for incompetent individuals.

The scope of the Best Interests Standard, in these cases, needs to be understood in terms of the scope of the moral and legal duties people have to incompetent individuals. Historically, the Best Interests Standard was developed to clarify that incompetent individuals were not their guardian's property and thus gave them independent rights (Kopelman, 2004). Before the Best Interests Standard was adopted, the courts did not even overrule parents' steadfast refusal of life-saving interventions for their child, as they do today, since they viewed children as the parents' property. Because of the Best Interests Standard, children's interests can be considered independently of parents. A doctor and family may try to consider the best therapeutic option for a child given the circumstances. They should consider what would be ideal, but it may not be possible given their options. As often used by the courts and in medicine, the Best Interests Standard does not require one to do what is ideal for the individual, since this may be impossible (Kopelman, 1997). A judge in a custody dispute must place a child somewhere and seeks what is best given the options, usually with one or the other parent or joint custody; it is rarely ideal and sometimes barely tolerable.

A related criticism is that the Best Interests Standard is problematic in requiring one and only one right or "best" answer. Critics point out that often there is not one best solution, but a range of socially, morally and legally permissible choices. The "negative" analysis I have offered answers this and clarifies that in practice, the Best Interests Standard generally allows a range of morally, socially, and legally acceptable options. As noted, the Best Interests Standard requires a choice for incompetent persons that reasonable, competent and informed people of good will would not reject as inappropriate. It is a normative choice, since it requires what is reasonable, and one with constraints about the nature of people's moral and legal duties to the incompetent person and a consensus about when they are not being fulfilled. In this way, it makes room for individualized and compassionate choices that may reflect somewhat different values.

Second, some critics argue that the Best Interests Standard is too vague and subjective, failing to give enough direction to parents or doctors.⁹ This criticism, however, does not take into account that when the Best Interests Standard is used to make decisions for incompetent individuals, it needs to be understood in terms of established moral and legal duties to them and presupposes a consensus about what choices are unacceptable. There is a consensus that it is worth enduring pain for a short time as a path to a long and healthy life. The factual dispute between Group 1 and Group 2 was whether Angel would get past the suffering of a barely conscious, pain-filled

existence to a life worth living. Until Solving this dispute over her prognosis and thus how to balance benefits and burdens, they could not agree on how to apply the Best Interests Standard. There was also a consensus about the Baby Doe Rules among many neonatologists (Kopelman et al., 1988; see Table III). When presented with three hypothetical cases, there was overwhelming consensus among neonatologists about what was best for infants. About a third, however, found the Baby Doe Rules would require them to act against what was, in their view, in the best interests of the infants. Thus, our survey shows a consensus among neonatologists and other pediatricians, whom we assume are reasonable, competent, and informed persons of good will, about when discontinuing life-support treatments would be in an infant's best interest (Kopelman et al., 1988, 1992). As noted, there was also remarkable agreement on these points with the Supreme Court's reasoning in *Bowen* (1986).

In every neonatal intensive care unit, however, certain cases will elicit sustained disagreement. The disagreement may be based upon insufficient data, different understandings of one's duties, miscommunications, misunderstandings, or value conflicts. If disagreements were the rule rather than the exception among informed and competent people of good will, it would be hard to justify the consensus that is presupposed in using the Best Interests Standard. Occasional disagreements do not undermine the Best Interests Standard, however, since disputes about difficult or borderline cases arise in all fields. The analysis I have offered sometimes permits different choices.

The Best Interests Standard in use does not use vague or suspect categories since it should be guided by established moral and legal duties to incompetent individuals and a consensus grounded upon what reasonable and informed competent adults of good will would want for themselves or others in similar situations. These choices should guide what we should want for these infants in similar situations. Most adults want choices and not the sort of inflexible regulations found in the Baby Doe Rules; for example, there is wide legal, moral, and social support to withdraw some medication, nutrition, and hydration or give sufficient pain medication to fulfill palliative goals (NHO, 1993; Byock et al., 2001). Surveys of adults show adequate pain control is a top concern in end-of-life care (Singer et al., 1999; Steinhäuser et al., 2000). Most adults want compassionate and individualized decision-making where families and doctors decide what is best under the circumstances within a framework of established moral and legal duties and a consensus about what acts are not acceptable. We should provide the same consideration to infants.

V. CONCLUDING REMARKS

The Best Interests Standard and the Baby Doe Rules are incompatible and the Baby Doe Regulations should be rejected. Enacted two decades ago as

requirements for states to receive federal funding to combat child abuse and neglect, they, if followed, thwart important duties to prevent unnecessary pain, fail to promote individualized and compassionate decision-making by parents and doctors, and do not treat others as we would wish to be treated. Adults do not want Baby-Doe-type rules for themselves because they want individualized decision-making, and the opportunities for families and doctors to give adequate pain medication and to withdraw some medication, hydration, and nutrition to fulfill palliative goals (Singer et al., 1999; Steinhauer et al., 2000). Moreover, most adults do not want to prolong minimally or permanently unconscious life (NHO, 1993; Byock et al., 2001). Many neonatologists and other pediatricians have been critical of the Baby Doe Rules and their objections resemble the reasons given by the Supreme Court for rejecting an earlier set of rules promulgated under the Civil Rights Law. I have considered and rejected defenses of the Baby Doe Rules coming from two extremes, both of which hold they are consistent with the Best Interests Standard. One view, held by Reagan, Koop, and others is that these rules are in infants' best interests because they honor a "right-to life" stance. Another view held by members of the American Academy of Pediatrics' leadership is that the Baby Doe Rules allow doctors to use their reasonable medical judgments to make informed decisions that are compatible with the sort of end-of-life care recommended for older children and adults.

I have defended the Best Interests Standard for making medical and other decisions for incompetent individuals that reflects how it is often used. Properly understood, it does not, as critics charge, require people to do what is ideal for the incompetent individual, ignoring all other interests, resources or perspectives. It would not be possible for the Best Interests Standard to provide practical guidance for decision makers if it required what was ideal for the incompetent person. For example, parents can balance interests among their children within their families and have legal protections from critics who complain that the parents are not doing what is ideal from the critics' perspectives. As long as the parents' choices are acceptable to reasonable and informed people of good will and fulfill basic duties, they have considerable freedom to make such important choices as relates to their child's schooling, religion, education. Families of infants, as well as incompetent adults and older children, should also have some freedom, within acceptable limits and with the agreement of clinicians, about how to rank duties for their imperiled relatives, such as whether to provide comfort care, to pursue remote life-saving strategies or to support permanent non-conscious biological life. I have argued that the Best Interests Standard should be understood in terms of established moral and legal duties to the incompetent individual and a consensus about what choices are unacceptable as judged by informed and reasonable people of good will. It is not, as critics have charged, too vague to serve as a guide. I have argued that this analysis which I have called the "negative" analysis of the

Best Interests Standard for making many medical and other decisions for incompetent individuals, is superior to the Baby Doe Rules when clinicians and parents make decisions for extremely premature, imperiled, or terminally ill infants. This analysis of the Best Interests Standard offers the same guidance for all incompetent individuals allowing the sort of individualized and compassionate decision-making that adults want for themselves.

NOTES

1. Committee on Bioethics of the AAP, 1996; Murray, 1985. For more information, see Kopelman, 2005.

2. For example, The American Academy of Pediatrics Committee on Bioethics (1996) took this view. Also see Fleishman as quoted in Paris et al., 2001, and Murray, 1985. For a fuller discussion of this see Kopelman, 2005.

3. Eventually, this group became the core of an ethics committee (Kopelman, 1990).

4. See Reagan, 1986; Bopp, 1990; Doerflinger, 1989; Koop, 1989. Typically, they defend special rules for infants under one because they claim that parents have not yet bonded to their infants, that clinicians overestimate the discomfort or disabilities faced by imperiled infants, or because of the vagueness of the older Best-Interests Standard.

5. See The American Academy of Pediatrics Committee on Bioethics, 1996, and Fleishman as quoted in Paris et al., 2001, and Murray, 1985.

6. For example, The American Academy of Pediatrics Committee on Bioethics, 1996 takes this view. Also see Fleishman as quoted in Paris et al., 2001; Haggerty quoted in Murray, 1985 and Murray, 1985.

7. I have discussed these points more fully elsewhere (Kopelman, 1997).

8. It is important to separate the ideal use of the Best Interests Standard from what I've called a threshold use or seeking a reasonable standard. Many children do not live in ideal circumstances and the state does not intervene because the child is not in danger. The threshold for intervention in child abuse and neglect cases is not stated in terms of what is ideal. (Krause, 1986; Lee, 1981). The state must establish that parental choice is endangering a child and thus fall below a certain acceptable threshold. Once this is shown, I have argued there is a second step where the court can be understood as applying the Best Interests Standard to find the most reasonable course to take with the child.

9. Reagan, 1986 and Koop, 1989 take this view.

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