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# **WHY THE CAPTA'S BABY DOE RULES SHOULD BE REJECTED IN FAVOR OF THE BEST INTERESTS STANDARD**

**Loretta M. Kopelman \***

## **INTRODUCTION**

The current Baby Doe Rules are formally the Child Abuse Amendments of 1984<sup>1</sup> to the Child Abuse Prevention and Treatment Act (CAPTA).<sup>2</sup> The CAPTA Amendments, which concern the treatment of infants less than one year of age,<sup>3</sup> went into effect on May 15, 1985 and set federal funding requirements for states to receive grants.<sup>4</sup> CAPTA's Baby Doe Rules require all infants to receive maximal treatment, including all medications, feeding and hydration, unless in the treating physician's or physicians' reasonable medical judgment one of the following exceptions is met:

- (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

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1. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101-5106ii (2006) and implemented in relevant part by 45 C.F.R. § 1340.15 (2008)). These amendments are informally known as the CAPTA or Baby Doe Rules or Amendments. "Baby Doe" refers to the child in Indiana whose death precipitated the law.

2. Child Abuse Prevention and Treatment Act (CAPTA), 42 U.S.C. §§ 5101-5107, 5118 (2006), and implemented in part at 45 C.F.R. 1340.15(b)(2) (2006).

3. 45 C.F.R. § 1340.15(b)(3)(i) (defining "infant").

4. 42 U.S.C. § 5106ia(b)(2)(B) (2006).

- (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.<sup>5</sup>

The Rules were named after an infant known as “Baby Doe” who was born in 1982.<sup>6</sup> The baby had Trisomy 21 (Down’s syndrome) and an esophageal atresia. On the advice of their obstetrician, the infant’s parents refused to give permission for the life-saving surgery to remove the baby’s intestinal blockage; the baby’s pediatrician and hospital administrators sought a court order, but the Indiana courts sided with the parents; the baby died as an appeal was being made to the United States Supreme Court.<sup>7</sup>

Ronald Reagan, who was President at the time, intended the Rules to restrict medical decisions that doctors, parents and guardians could make for imperiled infants: “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.”<sup>8</sup> Reagan rejected the quality of life ethic and sought to forbid the withholding or withdrawing of medications, hydration, or nutrition unless in the reasonable medical judgment of physicians the infant was irreversibly comatose or interventions would only prolong dying.

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5. 45 C.F.R. § 1340.15(b)(2) (2008) (“The term ‘withholding of medically indicated treatment’ means 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—(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).

6. See ALBERT JONSEN, A SHORT HISTORY OF MEDICAL ETHICS 112–13 (Oxford Univ. Press 2000).

7. JONSEN, *supra* note 6, at 112.

8. Ronald Reagan, *Abortion and the Conscience of the Nation*, in ABORTION, MEDICINE AND THE LAW 355 (J. Douglas Butler & David F. Walbert eds., 3d ed. 1986).

Reagan's Surgeon General, C. Everett Koop, also strongly supported these regulations, agreeing with Reagan that they are in infants' best interests:

[M]edicine, 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.<sup>9</sup>

### I. CRITICISMS OF THE BABY DOE RULES

Criticisms of CAPTA's Baby Doe Rules soon came from many sides. In a survey conducted shortly after the Rules were enacted, neonatologists and other pediatricians reported that they sometimes interfered with the doctors' duties to act in the best interests of their patients.<sup>10</sup> Up to one-third of respondents when evaluating a hypothetical case stated that the Rules would force them to act counter to their judgment of what was in the infant's best interest.<sup>11</sup> These respondents also reported that these amendments were unnecessary to defend the rights of imperiled infants, ignored parental rights, and failed to offer adequate consideration of the infant's suffering.<sup>12</sup>

The criticisms had similarities to those of the United States Supreme Court in *Bowen v. American Hospital Association*<sup>13</sup> in its consideration of an earlier set of similar Baby Doe Rules<sup>14</sup>

9. C. Everett Koop, *The Challenge of Definition*, 19 HASTINGS CENTER REP. 2, 3 (1989).

10. Loretta M. Kopelman, Thomas G. Irons & Arthur E. Kopelman, *Neonatologists Judge the "Baby Doe" Regulations*, 318, 11 NEW ENG. J. MED. 677, 677-83 (1988); Loretta M. Kopelman, Arthur E. Kopelman & Thomas G. Irons *Neonatologists, Pediatrics and the Supreme Court Criticize the "Baby Doe" Regulations*, in COMPELLED COMPASSION 237-66 (Arthur L. Caplan, Robert H. Blank & Janna C. Merrick eds., 1992).

11. Loretta M. Kopelman, Arthur E. Kopelman & Thomas G. Irons, *Neonatologists, Pediatrics and the Supreme Court Criticize the "Baby Doe" Regulations*, *supra* note 10.

12. *Id.* at 254; *accord infra* Table 1.

13. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 630-48 (1986).

14. Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants—HHS Final Rules, 49 Fed. Reg. 1,622-54 (Jan. 12, 1984).

promulgated as regulations under section 504 of the Rehabilitation Act of 1973.<sup>15</sup> The Supreme Court held that these rules could not be issued using this section of the Rehabilitation Act of 1973.<sup>16</sup> The Court rejected the Reagan administration's argument that the failure to provide maximal treatments, unless one of the three exceptions existed, was discriminatory and violated infants' civil rights.<sup>17</sup> The Court criticized the rules for ignoring parents' traditional role to decide what was in their infant's best interest.<sup>18</sup> The Court further stated that concerned parents might select among different treatment plans recommended by the infant's physicians; the rules took an oversimplified view of medical decision-making in supposing it was discriminatory and prejudicial to evaluate an infant's disability in choosing a treatment. In fact, the Court explained, the degree of a person's disability was relevant to making good medical treatment decisions, including those regarding life-sustaining interventions. These rules thus represented an unjustifiable effort to influence medical standards of care even though no evidence of discrimination was shown.<sup>19</sup> The Court was also critical of the Reagan administration for exerting undue pressure on state agencies to comply.<sup>20</sup>

While certain right-to-life and religious groups supported the Baby Doe Rules,<sup>21</sup> some theologians were critical of enacting such a highly restrictive view of what was best for sick infants. William May, a well-known Protestant theologian, argued that taking death as the

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15. Rehabilitation Act of 1973, Pub. L. No. 93-112, 29 U.S.C. § 794 (2000). The first set of Baby Doe Regulations were issued in 1984 and based upon Section 504 of the Rehabilitation Act of 1973: "No otherwise qualified handicapped individual . . . shall, solely by reason of this handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." The first set of Baby Doe Rules were regulated federally and not optional. The Supreme Court struck them down in 1986 in *Bowen*. In contrast, CAPTA's Baby Doe Rules are requirements for states to receive federal money and are technically optional. See *Nondiscrimination on the Basis of Handicap*, *supra* note 14.

16. *Bowen*, 476 U.S. at 642-47.

17. *Id.* at 636.

18. *Id.* at 627, n.13.

19. *Id.* at 643.

20. *Id.* at 639-42.

21. Thomas H. Murray, *The Final, Anticlimactic Rule on Baby Doe*, 15 HASTINGS CENTER REP. 5, 7-8 (1985). See Reagan, *supra* note 8, at 352-58.

highest evil is not a sanctity of life position, but an idolatry of the physical.<sup>22</sup> Sanctity of life should be understood as a duty to prevent untimely death and not as a justification for preserving life at all costs.<sup>23</sup> H. Danner Clouser argued that sanctity of life should be understood as the duty to preserve life unless a higher duty exists.<sup>24</sup> Richard McCormick, a well-known Jesuit theologian, maintained that when people lack the potential for interpersonal relationships there is no obligation to require life-saving treatments.<sup>25</sup>

Some members of the leadership of the American Academy of Pediatrics (AAP) argued that these criticisms were misguided and it was mistaken to suppose that the Rules disrupt standards of care, inhibit reasonable medical judgment, or interfere with acting in infants' best interest.<sup>26</sup> Robert Haggerty, M.D., who was President of the AAP when they were passed, saw them as no threat and reportedly said, "[i]t would appear that the final rule reaffirms the role of reasonable medical judgment and that decisions should be made in the best interests of the infant."<sup>27</sup> A decade later, members of the AAP's 1996 Committee on Bioethics agreed, contending that the Rules allow considerable discretion because they include the words "reasonable medical judgment" and "appropriate" and allow non-treatment where it is "inhumane."<sup>28</sup>

These AAP interpretations, however, are not supported by the text, which requires maximal life saving interventions, including appropriate nutrition, hydration and medication unless the infant is dying or comatose. Discontinuing maximal life-saving interventions (other than appropriate nutrition, hydration and medication) may be

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22. WILLIAM F. MAY, *THE PHYSICIAN'S COVENANT: IMAGES OF THE HEALER IN MEDICAL ETHICS*, 68-69 (Westminster Press 1983).

23. *Id.*

24. K. Danner Clouser, "*The Sanctity of Life*": *An Analysis of a Concept*, 78 *ANNALS OF INTERNAL MED.* 119, 123 (1973).

25. Richard McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229, 2 *J. AM. MED. ASS'N* 172, 175-76 (1974).

26. Am. Acad. of Pediatrics (AAP), Committee on Bioethics, *Ethics in the Care of Critically Ill Infants and Children*, 98 *PEDIATRICS* 149, 149-52 (1996).

27. See Murray, *supra* note 21, at 6.

28. See AAP, *supra* note 26; see also 45 C.F.R. § 1340.15(b)(2) (2008).

permitted when, in the treating physician's or physicians' reasonable medical judgment, one of the three conditions has been fulfilled. The first exception is that the infant is in an irreversible coma. This one and only quality of life consideration that is permitted is very restrictive. The second exception contains three clauses each of which states an exception; it permits the discontinuing of maximal life saving interventions when 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."<sup>29</sup> The first and third clauses express exceptions clarifying that the infant must be dying or that the interventions would be futile in promoting the infant's survive. It would be an error to suppose, as the 1996 Committee on Bioethics did, that the second clause of the second exception allows doctors and families the discretion to discontinue maximal life-saving interventions whenever some life-threatening conditions cannot be corrected.<sup>30</sup> The second clause of this exception, "ameliorating or correcting all of the infant's life threatening conditions,"<sup>31</sup> cannot mean any life threatening condition which may shorten a life in the long term rather than the short term. If parents and doctors were at liberty to discontinue life-saving measures anytime they could not improve or correct *all* life-threatening conditions, the door of discretion would be opened too widely; it would not only subvert the Baby Doe Rules but also the Best Interest Standard if families and doctors could agree not to provide maximal life-saving treatment to infants who, while they may have a life-threatening condition, could live well for many years. All humans must die and nothing is effective in ameliorating or correcting that condition. It would also be an error to suppose, as this AAP committee did, that the third exception allows special consideration to relieve suffering because it states doctors need not provide "inhumane" treatments.<sup>32</sup> Although

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29. AAP, *supra* note 26; 45 C.F.R. § 1340.15(b)(2)(ii).

30. AAP, *supra* note 26; 45 C.F.R. § 1340.15(b)(2)(ii) (2008).

31. 45 C.F.R. § 1340.15(b)(2)(iii) (2008).

32. *See* AAP, *supra* note 26.

the word “inhumane” is used, the text is as follows: “[t]he 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.”<sup>33</sup> This passage does not permit consideration of the infant’s suffering unless survival is “virtually futile”<sup>34</sup> and this is generally understood to mean the infant is dying, especially in the context of an intensive care unit.<sup>35</sup>

Although CAPTA’s set of Baby Doe Rules went into effect in 1985, they were only recently interpreted by an appellate state court. In *Montalvo v. Borkovec*,<sup>36</sup> the Wisconsin Court of Appeals reviewed the CAPTA amendments. The case concerned an infant born at twenty-three week, three day-old gestation who was given maximal life-saving treatments. Such infants are at the limit of viability and those who survive often have considerable morbidity. For this reason, several of the AAP committees and the Nuffield Council in the United Kingdom recommend discussions with families about treatment options for such infants, including whether to pursue comfort care rather than life-prolonging treatments.<sup>37</sup> In *Montalvo*, the infant’s parents sued, claiming that they were insufficiently informed about their child’s prognosis when they agreed to some of the life-prolonging interventions.<sup>38</sup> The Wisconsin court, however, disagreed: “[t]he implied choice of withholding treatment, proposed by the plaintiffs, is exactly what CAPTA prohibits.”<sup>39</sup> The court

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33. 45 C.F.R. § 1340.15(b)(2)(iii) (2008).

34. *Id.*

35. For a fuller discussion, see Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 799–800 (2005); Loretta M. Kopelman, *Rejecting the Baby Doe Regulations and Defending a “Negative” Analysis of the Best Interests Standard*, 30 J. MED. PHIL. 331, 346 (2005).

36. 647 N.W.2d 413, 419 (2002).

37. AAP, *supra* note 26, at 150; William Oh, Lillian Blackmon & Am. Acad. of Pediatrics, Comm. on Fetus & Newborns, *The Initiation or Withdrawal of Treatment for High-Risk Newborns*, 96 PEDIATRICS 362, 362–63 (1995); Arthur Kohrman, Ellen Wright Clayton & Am. Acad. of Pediatrics, Comm. on Bioethics, *Guidelines on Foregoing Life-Sustaining Medical Treatment*, 93 PEDIATRICS 532, 532 (1994); Nuffield Council on Bioethics, *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues* 24 (2006), available at [http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD\\_web\\_version\\_8\\_November.pdf](http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_8_November.pdf).

38. 647 N.W.2d at 415–16.

39. *Id.* at 419.

found that unless a child was dying or comatose, parents had no role in consenting to or refusing maximal treatment and thus no claim under the state's informed consent statute.<sup>40</sup> Consequently, this state court interpreted the Rules in a way that rejects the sort of individualized decision-making advocated by such important groups as the AAP committees<sup>41</sup> and the United Kingdom's Nuffield Council.<sup>42</sup> This court's understanding exactly reflects the views of President Reagan<sup>43</sup> and his Surgeon General Koop<sup>44</sup> who proposed both sets of Baby Doe Rules as a way to protect infants' best interests.

*A. Are CAPTA's Baby Doe Rules in Infants' Best Interests?*

CAPTA's Baby Doe Rules were intended to promote infants' best interest.<sup>45</sup> Yet consider the following case:<sup>46</sup>

X.D. was diagnosed at birth with holoprosencephaly and since then he has reacted only to painful stimuli. Now ten months old, X.D. has edema and is admitted to the hospital with renal failure of unknown cause. While he cannot be cured, his kidney disease can be managed with renal dialysis, which he seems to find very uncomfortable. Should renal dialysis be required, optional, or contra-indicated given his underlying condition? Who should decide what is best for this child?

Holoprosencephaly is an irreversible condition that results from the faulty division of the embryonic forebrain and the improper formation of the double lobes of the cerebral hemisphere. In the most

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40. *Id.*

41. AAP, *supra* note 26; Kohrman, et al., *supra* note 37; Oh, et al., *supra* note 37.

42. The Nuffield Council, *supra* note 37.

43. *Montalvo*, 647 N.W.2d 413; Reagan, *supra* note 8.

44. *Montalvo*, 647 N.W.2d 413; Koop, *supra* note 9.

45. Reagan, *supra* note 8; Koop, *supra* note 9; Murray, *supra* note 21.

46. This case illustrates the conflict between these two guidance principles and has been discussed more fully in Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 192-93 (2007).

severe cases, infants have only single lobe brain structure and they usually die before birth. All persons with holoprosencephaly are mentally retarded but the severity depends upon the degree to which the lobes separate, ranging from most severe to near normal. X.D. has a very extreme form: he reacts only to pain, including discomfort from the treatments keeping him alive.

The Rules would require maximal lifesaving treatments for this child because he is not dying, can survive with treatments, and is not in an irreversible coma. Most adults, however, faced with the prospect of a life holding out only uninterrupted pain-filled consciousness, prefer palliative care.<sup>47</sup> Relief of pain and suffering is of primary importance to adults most of whom want life and death choices made by themselves or by their representatives with the advice of clinicians.<sup>48</sup> From this perspective the Rules are inflexible and allow decision-makers no discretion to make comfort care primary unless persons are dying or comatose.

In what follows, a central criticism of CAPTA's Baby Doe Rules will be developed, namely that reasonable persons sometimes decide that preserving a life violates duties to avoid unnecessary suffering when too little compensatory benefit exists to justify the pain. In such cases, higher duties may exist to provide comfort care. Many committees, councils, and organizations recommend flexibility and allowing families and doctors to decide what is in the best interests of incompetent persons or incapacitated adults who have not left

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47. Ira Byock, Arthur Caplan, & Lois Snyder, *Beyond Symptom Management: Physician Roles and Responsibility in Palliative Care*, in PHYSICIAN'S GUIDE TO END OF LIFE CARE 63–66 (Lois Snyder & Timothy E. Quill eds., 2001); DEREK DOYLE ET AL., OXFORD TEXTBOOK OF PALLIATIVE MEDICINE 1–4 (Oxford Univ. Press 2004); CHRISTINA FAULL, YVONNE H. CARTER & LILIAN DANIELS, HANDBOOK OF PALLIATIVE CARE 10–11 (Blackwell Publ'g) (2d ed. 2005); JOANNE LYNN, JANICE LYNCH SCHUSTER & ANDREA KABCENELL, IMPROVING CARE FOR THE END OF LIFE: A SOURCEBOOK FOR HEALTH CARE MANAGERS AND CLINICIANS 1–5 (Oxford Press 2000); NAT'L HOSPICE ORG. (NHO), STANDARDS OF A HOSPICE PROGRAM OF CARE (Arlington, Va.: Nat'l Hospice Org. 1990); Peter A. Singer, Douglas K. Martin, & Merrijoy Kelner, *Quality End-of-Life Care: Patients' Perspectives*, 281 J. AM. MED. ASS'N 163, 163–68 (1999); Karen E. Steinhauser et al., *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, 284 J. AM. MED. ASS'N 2476, 2476–82 (2000); President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*, presentation at The President's Council, Wash., D.C. (2005).

48. See source cited *supra* note 47.

advance directives. This includes allowing them to decide when it is best to withdraw or withhold maximal life-prolonging treatment to fulfill comfort care goals.<sup>49</sup> In contrast, the Rules only allow pain or suffering to be considered if the treatment would be virtually futile in terms of survival.

The President's Council on Bioethics,<sup>50</sup> in discussing what sort of care should be provided to elderly persons with dementia lacking advance directives, recommends flexibility and individualizing treatment decisions based on an evaluation of their burdens and benefits in the life of each particular person. If a life is only a burden, guardians and clinicians should have the option to decide it is in a patient's best interest to make comfort care primary.

To illustrate these points, the President's Council describes selection of treatment for a woman in the middle stages of Alzheimer's disease who needs dialysis three times a week to live.<sup>51</sup> The woman becomes agitated and confused when taken from her home. The Council concludes that renal dialysis is optional even though she will die quickly without it and might live many years with it. According to the Council, the Best Care or Best Interests Standard incorporates duties to do no harm (nonmalificence). One of its final recommendations stresses that maintaining biological life as long as possible should not always be the highest goal: "[t]he goal of ethical caregiving in a clinical setting is not to extend the length or postpone the end of a patient's life as long as is medically possible, but always to benefit the life the patient still has."<sup>52</sup> The President's Council defends individualized and compassionate care for incapacitated and incompetent persons with adequate attention to relief of suffering. If the same principles were applied to the child with holoprosencephaly,

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49. See sources cited *supra* note 37; President's Council on Bioethics, *supra* note 47; Steinhauser et al., *supra* note 47; Singer et al., *supra* note 47; *Standards of a Hospice Program of Care*, *supra* note 47; Byock et al., *supra* note 47; FAULL ET AL., *supra* note 47; LYNN ET AL., *supra* note 47; DOYLE ET AL., *supra* note 47.

50. President's Council on Bioethics, *supra* note 47.

51. *Id.* at 182.

52. *Id.* at 212.

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decision makers should have the option to conclude that his life is only a burden and that dialysis is not obligatory to keep him alive.

The President's Council explicitly rejects inflexible policies and acknowledges guardians may be at liberty to select different life and death options. Their views about the harms of over-treatment and duties to individualize decisions for incompetent or incapacitated patients stand in sharp contrast to the inflexibility of the Rules. The President's Council, therefore, rejects Baby Doe-type rules for incapacitated adults who have not left advance directives.

Some may argue that special rules are needed for infants less than one year of age because guardians' choices are less trustworthy than they are for older children or adults. Yet I know of no data to support such a sweeping conclusion. Individual cases offer no proof about what is done generally or what occurs with people of different ages. Others may argue that the trajectory for elderly persons is known but not known for infants. But as in the case discussed above, sometimes the prognosis is as certain as it is for many elderly persons. Still others argue we must take any chance—even one in a thousand—to save an infant's life. But adults would rebel if such reasoning applied to them, so some account must be given as to why we should have a policy for infants that adults would reject for themselves.<sup>53</sup> Recommendations for compassionate and individualized decision-making are the norm in many policies for all persons and are widely supported in the pediatric literature including published AAP policies.<sup>54</sup>

In what follows, I will argue that infants are better protected by the older standard for making decisions for incompetent and incapacitated persons who have not left advance directives, the Best Interests Standard. Unlike the Rules, which apply only to persons under one year of age, the Best Interests Standard applies to all

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53. These points are developed more fully in Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 799–800 (2005); Loretta M. Kopelman, *Rejecting the Baby Doe Regulations and Defending a "Negative" Analysis of the Best Interests Standard*, 30 J. MED. PHILOSOPHY 331, 346 (2005); Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 192–93 (2007).

54. See sources cited *supra* note 37.

incompetent individuals or persons lacking capacity to make decisions who have not left directives.

After the Best Interests Standard is clarified and defended in the next section, it is argued that the Best Interests Standard is a better infant care decision-making guidance principle than the Rules for reasons of compassion and fairness. I will argue that the Rules not only unfairly single out infants for the sort of treatments many or most adults reject for themselves, but also fail to promote the best interest of some infants as judged by what informed, competent, and reasonable adults want for themselves.<sup>55</sup>

## II. AN ANALYSIS AND DEFENSE OF THE BEST INTERESTS STANDARD AS A PRACTICAL GUIDANCE PRINCIPLE

The Best Interests Standard is a widely defended standard for decision-makers to use when guiding practical decisions when individuals lack decision-making capacity, including infants, children, and adults lacking advance directives. For example, the Court of Appeals of Maryland 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.”<sup>56</sup> Article Three of the United Nation’s Convention on the Rights of the Child provides as follows: “[i]n all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”<sup>57</sup> But what can it mean to require people to act in the *best* interest of *all* children? In this section I will offer analysis of the Best Interests Standard that reflects how this guidance principle is used in practical situations such as medical decision-making.

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55. President’s Council on Bioethics, *supra* note 47; Steinhäuser et al., *supra* note 47; Singer et al., *supra* note 47; *Standards of a Hospice Program of Care*, *supra* note 47; Byock et al., *supra* note 47; FAULL ET AL., *supra* note 47; LYNN ET AL., *supra* note 47; DOYLE ET AL., *supra* note 47.

56. *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807, 853 (Md. 2001).

57. United Nations, *Convention on the Rights of the Child*, Art. 3 (1989).

The Best Interests Standard when used as a practical standard has both objective and subjective features.<sup>58</sup> It has “subjective” features in the sense that it is shaped by the values, views, and perceptions of decision-makers. Children’s guardians should be their primary decision-makers because they are typically the most knowledgeable and concerned, bear the consequences of choices, and need to make personal decisions in a way that may accommodate their particular values and religious, ethic, social, or philosophical views.

In addition, the Best Interests Standard has “objective” features in the sense that the guardians’ choices must be “good enough.” What is “good enough” should be assessed by sound logical, medical, and scientific views and by what honors justifiable duties. Parents who believe that warm baths are more effective to treat their child’s cancer than their child’s life-saving and well-tested chemotherapy are wrong on objective grounds. If parents’ ideas about what is best endanger their child, their preferences should be challenged.<sup>59</sup> Parental beliefs do not substitute for evidence about what options are acceptable as judged by such sources as science and medicine. Judges sometimes have to make difficult decisions about what parental choices are sufficiently good for them to keep custody of their child.<sup>60</sup> Parents who smoke around their children who have severe asthma may lose custody of them temporarily or permanently for endangering them.

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58. For greater development of these ideas about the Best Interests Standard, see Loretta M. Kopelman, *Analyzing the Best Interests Standard*, 10 ASBH EXCH. 10 (2007); Loretta M. Kopelman & Arthur E. Kopelman, *Using a New Analysis of the Best Interests Standard to Address Cultural Disputes: Whose Data, Which Values?*, 28 THEORETICAL MED. & BIOETHICS 373, 373–91 (2007); Loretta M. Kopelman, *Using the Best Interests Standard to Decide Whether to Test Children for Untreatable, Late-Onset Genetic Diseases*, 32 J. MED. & PHIL. 375, 375–94 (2007); Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 192–93 (2007); Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 799–800 (2005); Loretta M. Kopelman, *Rejecting the Baby Doe Regulations and Defending a “Negative” Analysis of the Best Interests Standard*, 30 J. MED. PHILOSOPHY 331, 346 (2005); Loretta M. Kopelman, *The Best Interests Standard as a Threshold, Ideal, and Standard of Reasonableness*, 22 J. MED. & PHIL. 271, 271–89 (1997) [hereinafter *Kopelman’s Best Interest Standard Articles*].

59. HARRY D. KRAUSE, *FAMILY LAW IN A NUTSHELL* 166–70 (West Publ’g Co. 2d ed. 1986).

60. *Id.*

The Best Interests Standard was developed to establish that incompetent or incapacitated individuals have rights independent of their guardians and are not their property.<sup>61</sup> The Best Interests Standard requires choices for incapacitated or incompetent persons lacking advance directives that are reasonable or such that competent and informed people of good will would not find unreasonable.

More precisely, the Best Interests Standard, when used as a practical guide, should be analyzed in terms of three necessary and jointly sufficient features to reflect these subjective and objective features:<sup>62</sup>

1) First, decision-makers should use the best available information to assess the incompetent or incapacitated person's immediate and long-term interests and set as their prima facie duty that option (or from among those options) that maximizes the person's overall or long-term benefits and minimizes burdens.

2) Second, decision-makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of good will regard to be acceptable were they in the person's circumstances.

3) Third, decision-makers should make medical choices compatible with moral and legal duties to incompetent or incapacitated individuals (those unable to make decisions for themselves).

By clarifying that the Best Interests Standard requires reasonable (or not unreasonable) choices, certain differences of opinion about what is best can be accommodated, given the available options. Some families may decide to pursue highly experimental treatment to extend their infant's life briefly while others prefer comfort care at home.

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61. See *id.* at 170.

62. These ideas are presented or developed in Kopelman's *Best Interest Standard Articles*, *supra* note 58.

In addition, this analysis of the practical use of the Best Interests Standard allows us to distinguish *prima facie* from actual duties. For example, suppose it might be best for someone to have a heart and lung transplant so he can live another year. If this scarce resource cannot be obtained, however, it cannot be an actual duty.<sup>63</sup>

We should aspire to do better than minimally acceptable, however, so the Best Interests Standard should not be regarded as a “good enough” standard.

### III. RESPONDING TO CRITICS OF THE BEST INTERESTS STANDARD

This analysis enables us to respond to critics who argue that the Best Interests Standard is self-defeating, individualistic, unknowable, or vague.<sup>64</sup> It is not self-defeating or incoherent because it does not require what is best or ideal for everyone; it is not unknowable because it does not require a crystal ball to look into the future and see what is best; it is not too individualistic because it does not require one to ignore all others' interests, needs, resources, or values and pick out what is best or perfect for one person.

Other critics<sup>65</sup> regard the Best Interests Standard as vague, subjective, and open to abuse because it fails to give enough direction to parents or doctors. This criticism, however, fails to take into account that decision-makers using this standard should be guided by standards of care and established moral and legal duties to the incompetent or incapacitated person as well as by a consensus grounded upon what reasonable and informed competent adults of good will would want for themselves or others in similar situations. Previous moral, medical, social, or legal judgments should help guide decisions by clarifying what constitutes acceptable thresholds of care and what rights children have. The threshold can be modified when

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63. For a fuller discussion, see Kopelman's *Best Interest Standard Articles*, *supra* note 58.

64. For a detailed response to these criticisms and those holding them, see Kopelman's *Best Interest Standard Articles*, *supra* note 58.

65. See Reagan, *supra* note 8; Koop *supra* note 9; for a detailed response to these criticisms and those holding them see Kopelman's *Best Interest Standard Articles*, *supra* note 58.

new information or resources become available. For example, some acceptable medical interventions in the past would be considered abusive or neglectful today.

A related criticism is that the Best Interests Standard is vague and useless because it fails to offer an unambiguous threshold about what is acceptable. On this view, if a clear standard can be articulated it should be stated; if it cannot be articulated, the Best Interest Standard should be abandoned.<sup>66</sup> The insight that should be taken from this criticism is not that this standard should be abandoned, but that this highly abstract guidance principle needs to be specified and clarified by reasonable, competent and informed people of good will in particular circumstances. In a specific situation—such as whether surgery for an infant’s heart defect is in his best interests—a considerable body of existing information and recommendations by experts should inform decisions about how to balance benefits and burdens or draw upon standards of care in deciding the best option for the baby. The Best Interests Standard will be hard to use when there is no consensus about what options are unreasonable. Yet disputes about how to interpret abstract principles or how to decide difficult or borderline cases arise in the use of many or most standards and so should not be seen as a unique problem for the Best Interests Standard. Our disagreement may be based upon different understandings of one’s duties, upon insufficient data, misunderstandings, miscommunications, or value conflicts.

This analysis of the Best Interests Standard is intended to be compatible with legal definitions of it in terms of a reasonable person standard. The President’s Council, for example, distinguishes the Best Interests Standard from the moral standard of providing the “best care,” writing:

Best interest: a legal standard of caregiving for incompetent patients, defined by the courts in terms of what a “reasonable

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66. Thomas J. Balch, *Are There Checks and Balances on Terminating the Lives of Children with Disabilities? Should There Be?*, 25 GA. ST. U. L. REV. 959 (2009).

person” would decide in the same situation. A consideration of best interests generally attempts to weigh the burdens and benefits of treatment to the patient *in his present condition*, when no clear preferences of the patient can be determined.<sup>67</sup>

The analysis offered herein is not intended to be limited to a legal standard. It is hoped that its various meanings can be united under one umbrella to strengthen its role in providing moral, legal, medical, social, or other guidance.<sup>68</sup>

#### IV. WHY THE BEST INTERESTS STANDARD IS SUPERIOR TO THE BABY DOE RULES

The three exceptions found in the Rules were intended to severely restrict the quality of life choices that parents and doctors could make, limiting them to decisions about whether or not to maintain the life of comatose or dying infants.<sup>69</sup> Though the Reagan Administration and right-to-life groups strongly supported the Rules,<sup>70</sup> two reasons will be given for regarding the Best Interests Standard as the better guidance principle and for rejecting the Rules.

First, the Rules single 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 a life and preventing intractable pain and suffering sometimes believe that there are worse things than dying.<sup>71</sup> This attitude is reflected in the first priority of palliative care as the relief of pain and suffering.<sup>72</sup> Most adults do not want the sort of inflexible regulations found in the Rules. For example, wide legal, moral, and social support exists to withdraw some medication, nutrition, and hydration or give sufficient pain

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67. See President's Council on Bioethics, *supra* note 47, at 231.

68. See Kopelman's *Best Interest Standard Articles*, *supra* note 58.

69. See Reagan, *supra* note 8; Koop, *supra* note 9.

70. See Murray, *supra* note 21.

71. See Steinhäuser et al., *supra* note 47; Singer et al., *supra* note 47; Byock et al., *supra* note 47.

72. See NHO, *supra* note 47; Byock et al., *supra* note 47.

medication to fulfill palliative goals.<sup>73</sup> 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.

In contrast, the Best Interests Standard applies to persons of all ages lacking decision-making capacity or competency who have not left advance directives, and it permits the sort of compassionate and individualized decision-making widely recommended, including at the end of life.<sup>74</sup> The President's Council on Bioethics sums this up in one of its final recommendations: "[t]he clearest ethical grounds for foregoing life-sustaining treatments are an obligation to avoid inflicting treatments that are *unduly burdensome to the patient being treated* and an obligation to avoid treatments that are not at all (or not any longer) efficacious in attaining their desired result."<sup>75</sup>

Second, for reasons of compassion as well as fairness, infants should have the same opportunities for comfort care as adults want for themselves. When adults cannot make decisions for themselves, they generally want their guardians or families and doctors deciding what choices are best given the circumstances. Most adults do not want to prolong minimally or permanently unconscious life.<sup>76</sup>

The President's Council recommends decision-makers should make reasonable and prudent choices given the particular circumstances because simple rules and blanket interpretations will not cut finely enough for such individualized and compassionate choices: "[t]hese kinds of questions—and more broadly, the relationship between treatment and well-being for persons with dementia—can be considered only in concrete cases, with due regard for both the moral principles that should guide all care giving

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73. See NHO, *supra* note 47; Byock et al., *supra* note 47. Surveys of adults show adequate pain control is a top concern in end-of-life care. See Steinhauser et al., *supra* note 47; Singer et al., *supra* note 47.

74. See NHO, *supra* note 47; Byock et al., *supra* note 47; Steinhauser et al., *supra* note 47; Singer et al., *supra* note 47.

75. See President's Council on Bioethics, *supra* note 47, at 213.

76. See NHO, *supra* note 47; Byock et al., *supra* note 47.

decisions and the irreducible particularity of every clinical situation.”<sup>77</sup>

## V. CONCLUSION

To summarize, CAPTA's Baby Doe Rules and the Best Interests Standard can offer incompatible guidance for infants who are not dying or comatose but live with intractable pain sometimes from the technologies keeping them alive. In such cases, life comfort care may be a higher duty. The Rules are inconsistent with the broad medical, legal, moral, and social support to withdraw some medication, nutrition and hydration or give sufficient pain medication to fulfill palliative goals.<sup>78</sup>

An analysis of the Best Interests Standard is given to clarify its use as a practical guidance standard and to answer critics. When used as a practical guidance principle, it contains both objective and subjective features, and should be analyzed in terms of three necessary and jointly sufficient features: 1) First, decision-makers should use the best available information to assess the incompetent or incapacitated person's immediate and long-term interests and set as their prima facie duty that option (or from among those options) that maximizes the person's overall or long-term benefits and minimizes burdens. 2) Second, decision-makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of good will regard to be acceptable were they in the person's circumstances. 3) Third, decision-makers should make medical choices compatible with moral and legal duties to incompetent or incapacitated individuals (those unable to make decisions for themselves).<sup>79</sup> Properly understood, the Best Interests Standard does

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77. See President's Council on Bioethics, *supra* note 47, at 177.

78. See NHO, *supra* note 47; Byock, et al., *supra* note 47.

79. This analysis was discussed in more detail in Kopelman's *Best Interest Standard Articles*, *supra* note 58.

not, as critics charge, require people to do what is best or ideal for the incompetent individual, ignoring all other interests, resources or perspectives, nor is it incoherent, self-defeating, vague or open to abuse.

The Best Interests Standard is superior to CAPTA's Baby Doe Rules because, first, it is fairer since it offers the same guidance for all incompetent and incapacitated individuals who have not left advance directives. Second, it is more compassionate as judged by the sort of individualized and compassionate decision-making that adults want for themselves,<sup>80</sup> and it is also better as judged by recommendations made by prestigious pediatric groups for the care of imperiled infants that allow for pain and suffering.<sup>81</sup> For reasons of fairness and compassion, then, parents or guardians of infants should have options similar to those making decisions for their incapacitated or incompetent adult relatives lacking advance directives. Decision-makers' choices using the Best Interests Standard should be reasonable (or not unreasonable) and made within acceptable limits and with the agreement of clinicians. Their options 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.

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80. See President's Council on Bioethics, *supra* note 47; Singer, et al, *supra* note 47; Steinhauser, et al., *supra* note 47; NHO, *supra* note 47; J. Lantos, *Seeking Justice for Priscilla*, 5 CAMBRIDGE Q. HEALTHCARE ETHICS 485, 485-92 (1996).

81. See sources cited *supra* note 37.

**TABLE 1: CRITICISMS OF CAPTA'S BABY DOE RULES 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., SUPRA NOTE 10 (1988) AND (1992))**

**The BDR-II will result in improved care for all infants**

|                     | <b>% Agree</b> | <b>% Uncertain</b> | <b>% Disagree</b> |
|---------------------|----------------|--------------------|-------------------|
| Neonatologist       | 5              | 14                 | 81                |
| Other pediatricians | 6              | 16                 | 78                |

**The BDR-II were needed to protect the rights of handicapped infants**

|                     |    |    |    |
|---------------------|----|----|----|
| Neonatologist       | 14 | 10 | 76 |
| Other pediatricians | 20 | 12 | 67 |

**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 |

**The BDR II allows adequate consideration of suffering**

|                     |    |    |    |
|---------------------|----|----|----|
| Neonatologist       | 29 | 11 | 60 |
| Other pediatricians | 30 | 14 | 56 |

**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 |

**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 |

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 |

The BDR-II have exacerbated the shortage of NICU beds

|                     |    |    |    |
|---------------------|----|----|----|
| Neonatologist       | 17 | 32 | 51 |
| Other pediatricians | 24 | 50 | 25 |