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# Government as God: An Update on Federal Intervention in the Treatment of Critically Ill Newborns

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# Government as God:

## An Update on Federal Intervention in the Treatment of Critically Ill Newborns

Dionne Koller Fine\*

### I. INTRODUCTION

Whether a severely impaired or critically ill infant should receive life-saving, and sometimes extraordinary, medical treatment, or be allowed to die, is hotly debated. The issue initially garnered public attention in 1982, when an infant who was born with Down's Syndrome, "Baby Doe," was allowed to die from a correctable birth defect. Following this, the federal government took a lead role in determining the fate of critically ill newborns. In the meantime, doctors, philosophers, and others<sup>1</sup> have debated whether federal interference in this area is appropriate.

This essay will bring the reader up to date on the "Baby Doe" issue by summarizing the contours of the debate and explaining the legislation, in the form of amendments to the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 (CAPTA),<sup>2</sup> that ultimately resulted from the initial "Baby Doe" controversy.<sup>3</sup> This essay also will add an additional voice to the discussion by criticizing federal intervention in this area

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1. See *COMPULSED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS* (Arthur L. Caplan, et al. eds., 1992).

2. Child Abuse Prevention and Treatment and Adoption Reform Act of 1978, Pub. L. No. 93-247, 88 Stat. 4 (codified as amended at 42 U.S.C. §§ 5101-5119a (1994 & Supp. III 1998)); see also Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749, 42 U.S.C. §§ 5101-5106 (1994).

3. See *infra* notes 10-13 and accompanying text.

on three main grounds.<sup>4</sup> The first ground is that the federal government purports to solve a problem that largely does not exist, and in so doing, it oversimplifies the profound moral questions that surround the issue of whether to aggressively treat a severely impaired newborn.<sup>5</sup> Secondly, federal intervention in this area through the CAPTA Amendments is bad policy because it eliminates parents from the treatment decision.<sup>6</sup> Thirdly, the policy fails on a philosophical level because it does not square with our intuitions.<sup>7</sup> Finally, this essay will highlight a view that is largely missing from the debate on this issue — that of the practicing physicians who work with critically ill, severely impaired newborns and their parents every day.<sup>8</sup> The essay will conclude by briefly suggesting an alternative policy approach, which would presume that parents, in consultation with their doctors, are the appropriate decision-makers in these cases unless circumstances warrant otherwise.<sup>9</sup>

## II. THE FEDERAL POLICY MANDATING THE TREATMENT OF CRITICALLY ILL NEWBORNS

### *A. The History of the Baby Doe Controversy*

The issue of withdrawing or withholding treatment from critically ill newborns came on to the federal policy agenda in 1982, when an infant was born in Bloomington, Indiana, with Down's Syndrome and a tracheoesophageal fistula.<sup>10</sup> Because of the fistula, the baby could not take nourishment orally. The condition was therefore life-threatening, but correctable by an operation that has a ninety percent chance of success. The doctors called in to treat "Baby Doe" wanted to transfer the infant to another hospital and perform the life-saving surgery.<sup>11</sup> The obstetrician who delivered the baby, and the parents, took the position that treatment, including food and water, should be withheld on the grounds that the child, because of its birth defects, would have a poor quality of life.<sup>12</sup> The hospital ultimately took the matter to court. The judge ruled that the parents

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4. See *infra* notes 65-95 and accompanying text.

5. See *infra* notes 72-85 and accompanying text.

6. See *infra* notes 65-69 and accompanying text.

7. See *infra* notes 70-71 and accompanying text.

8. See *infra* notes 72-94 and accompanying text.

9. See *infra* notes 95-120 and accompanying text.

10. See *In the Matter of Treatment and Care of Infant Doe*, No. GU-8204--04A, *ISSUES IN L. & MED.*, July 1986, at 77, 78 (1986) (Cir. Ct. Monroe County, Ind. Apr. 12, 1982).

11. See *id.* at 77-78.

12. See *id.* at 78-79.

had the right to refuse treatment, and the child died six days after birth.<sup>13</sup>

Following this, the Reagan Administration quickly responded by framing the issue as one of discrimination against handicapped newborns.<sup>14</sup> The Administration ordered the Department of Health and Human Services (HHS) to issue a notice to hospitals receiving federal funds "reminding" them that handicapped infants were protected by section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against handicapped individuals by any program receiving federal financial assistance.<sup>15</sup> Thus, the Administration was attempting to step in and regulate under the authority of existing legislation, instead of waiting for (or proposing) legislation specifically addressing this issue.

Shortly after the Administration's directive, HHS issued an "interim final rule" requiring hospitals to post in all maternity wards and nurseries a notice regarding the applicability of section 504 and the number of a telephone hotline for people to report suspected violations of the law to HHS.<sup>16</sup> The interim rule also included, among other things, provisions for expedited actions, including full access to patient records, to determine compliance.<sup>17</sup> The interim rules were subsequently struck down because they were promulgated in violation of the Administrative Procedure Act.<sup>18</sup> A few months later, HHS issued new proposed rules regarding the treatment of "handicapped" infants that were substantially similar to the interim final rules.<sup>19</sup> The proposed rules included the same provisions requiring the posting of notices in hospitals, expedited compliance actions, and access to patient records.<sup>20</sup> In addition, the proposed rules required state child protective agencies that received federal assistance to utilize their authority under state law to protect handicapped infants.<sup>21</sup> The final

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13. *See id.* at 80.

14. *See* Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers, 47 Fed. Reg. 26,027 (1982); *see also* American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 397 (D.D.C. 1983).

15. *See* Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers, 47 Fed. Reg. at 26,027; *see also* Heckler, 561 F. Supp. at 397.

16. *See* Nondiscrimination on the Basis of Handicap, 48 Fed. Reg. 9,630 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed Mar. 7, 1983).

17. *See id.*

18. *See* Heckler, 561 F. Supp. at 404.

19. *See* Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

20. *See* Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants, 48 Fed. Reg. at 30,851.

21. *See id.*

rules took effect in 1984.<sup>22</sup>

In *Bowen v. American Hospital Ass'n*,<sup>23</sup> the Supreme Court struck down the final rules as unauthorized by the Rehabilitation Act.<sup>24</sup> In so doing, the Court noted the unprecedented nature of the federal government's regulations. The Court stated that "it is essential to understand the pre-existing state law framework governing the provision of medical care to handicapped infants. . . . [S]tate law vests decisional responsibility in the parents, in the first instance, subject to review in exceptional cases by the State acting as *parens patriae*."<sup>25</sup> The Court went on to note that "prior to the regulatory activity culminating in the [f]inal [r]ules, the Federal Government was not a participant in the process of making treatment decisions for newborn infants."<sup>26</sup>

Further, the Court found that the basis "for federal intervention is perceived discrimination against handicapped infants . . . and yet [HHS] has pointed to no evidence that such discrimination occurs."<sup>27</sup> The Court concluded that federal regulation of health care providers in this area was inappropriate because in all cases where treatment was withheld or withdrawn, it was done with parental consent. The Court stressed that a health care provider is not obligated or authorized to treat an infant without such consent. The Court stated that the Rehabilitation Act "does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children."<sup>28</sup>

In the meantime, in 1984 Congress stepped into the policy debate and passed amendments to the CAPTA which dealt with the issue of withholding treatment from critically ill newborns.<sup>29</sup> This recast the issue from one of discrimination against critically ill newborns to one of medical neglect. In effect, by addressing the issue in a statute dealing with prevention of child abuse, Congress equated parental decisions to limit treatment of severely impaired newborns with outright neglect.

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22. See *Bowen v. American Hospital Ass'n*, 476 U.S. 610, 622 (1986) (indicating that judicial action regarding the government's authority to enforce the Final Rules had already been initiated and an appellate decision as to the merits of the case was rendered on February 23, 1984. This was "six weeks after the promulgation of the Final Rules").

23. 476 U.S. 610 (1986).

24. See *Bowen*, 476 U.S. at 647.

25. *Id.* at 627.

26. *Id.* at 627-28.

27. *Id.* at 643.

28. *Id.* at 647.

29. See Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749, 42 U.S.C. §§ 5101-5106 (1994).

The statute requires states seeking federal funds for child protective services to take certain steps to protect handicapped newborns. The statute provides, in pertinent part:

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 . . . to an infant when . . .

(A) the infant is chronically and irreversibly comatose;

(B) the provision of such treatment would —

(i) merely prolong dying;

(ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or

(iii) otherwise be futile in terms of the survival of the infant; or

(C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.<sup>30</sup>

Thus, under the statute, withholding treatment is considered to be medical neglect unless the infant is in a permanent coma or death is essentially imminent and certain.<sup>31</sup> In addition, parental input into the treatment decision is not contemplated by the statute. Indeed, the clear thrust of the statute is that any parental judgment short of treating the infant is considered neglect.

The Department of Health and Human Services has issued regulations similar to those that were previously struck down implementing the CAPTA Amendments. The regulations track the statute's definition of "withholding of medically indicated treatment." In addition, the regulations clarify that the term "infant" refers to a child of "less than one year of age."<sup>32</sup> By implication, then, *after* one year of age, parents and physicians have discretion as to whether and how to treat a critically ill child.<sup>33</sup> Indeed, the statute and regulations seem to suggest that when a child is

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30. 42 U.S.C. § 5106(g)(6) (1994 & Supp. III 1998).

31. *See* 42 U.S.C. § 5106a(b)(2)(B). "[M]edical neglect" includes "instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions." *Id.*

32. 45 C.F.R. §1340.15 (b) (1997).

33. *See id.*

under one year of age, there is a temptation, a dark impulse, on the part of the parents to simply let their critically ill infant die. Whether this is actually so is likely an issue best left to the mental health community. From a legal and policy perspective, however, it is unclear why this one-year carve out of federal regulation is necessary or in the best interests of the infant. In fact, as discussed below, it has unintended consequences that raise their own ethical issues.

### *B. From Baby Doe to Baby K*

The CAPTA Amendments and implementing regulations are as far as the federal intervention in this area goes. Courts are very clear that CAPTA does not create a private right of action.<sup>34</sup> However, the debate over the treatment of critically ill infants has gone beyond CAPTA and played out in another federal statute, the Emergency Medical Treatment and Active Labor Act (EMTALA).<sup>35</sup> EMTALA was enacted to prevent "patient dumping," where a hospital does not treat or transfers a patient before giving stabilizing treatment because the patient is uninsured or otherwise unable to pay.<sup>36</sup> Ironically, the mandatory treatment of a critically ill infant under EMTALA, in at least one case, has turned on a parent's right to make medical treatment decisions on behalf of a minor child, a right denied by the CAPTA Amendments.

In the case of *In re Baby K*,<sup>37</sup> a Virginia hospital sought a declaratory judgment and an injunction under EMTALA and other federal and state statutes that it was not required to provide extraordinary medical treatment to an anencephalic baby whose mother repeatedly sought to have the baby resuscitated.<sup>38</sup> Because of her anencephaly, the baby had only a brain stem, and she could not hear or see. She was permanently unconscious and had no hope of improving.<sup>39</sup> The court noted that because of the baby's condition, the hospital urged the mother to permit a "Do Not Resuscitate Order" for Baby K, because further aggressive respiratory measures were medically inappropriate.<sup>40</sup> The mother refused. The court noted that "[t]he mother opposes the discontinuation of ventilator treatment when Baby K experiences respiratory distress because she believes that all human life has value, including her anencephalic daughter's life. [The

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34. See *Doe by Fein v. District of Columbia*, 93 F.3d 861 (D.D.C. 1996).

35. 42 U.S.C. §1395dd (1994).

36. *In re Baby K*, 16 F.3d 590, 593 (4th Cir. 1994); see also *Brooks v. Maryland General Hospital, Inc.*, 996 F.2d 708, 710 (4th Cir. 1993).

37. 832 F. Supp. 1022 (E.D. Va. 1993).

38. See *id.* at 1023-27.

39. See *id.* at 1025.

40. See *id.*

mother] has a firm Christian faith that all life should be protected. She believes that God will work a miracle if that is his will."<sup>41</sup> Further, the court said that the mother "believes she has the right to decide what is in her child's best interests."<sup>42</sup>

The court stated that EMTALA requires that any person who comes to the emergency department of a hospital with an emergency condition must be provided with stabilizing medical treatment.<sup>43</sup> The court found that Baby K, when brought to the hospital in respiratory distress, was in an emergency condition, and under the plain meaning of the statute, the hospital was required to stabilize her.<sup>44</sup> The court rejected the hospital's argument that it did not have to stabilize her where, given the child's anencephalic condition, such aggressive measures were "futile" and "inhumane."<sup>45</sup> The court also held that Baby K was a disabled individual such that a refusal by the hospital to resuscitate her would violate the Rehabilitation Act and the Americans with Disabilities Act.<sup>46</sup>

The Fourth Circuit affirmed the decision on the grounds that "EMTALA gives rise to a duty on the part of the hospital to provide respiratory support to Baby K when she is presented at the hospital in respiratory distress and treatment is requested for her."<sup>47</sup> The court noted that there was nothing in the statute or legislative history to indicate that stabilizing treatment did not have to be provided where the treatment "would exceed the prevailing standard of medical care," or where it is care that the treating physicians considered "morally and ethically inappropriate," as the Baby K physicians did.<sup>48</sup>

### *C. Philosophical Underpinnings of the Federal Policy*

The federal policy is best understood in light of the moral theories which shaped it. The statute and the implementing regulations reflect what is called the "sanctity of life" view. This view "values human life independent of its capacities, holding that human dignity, worth, and sanctity are from God (in its religious form) or is naturally inherent (in its secular form)."<sup>49</sup> Earl E. Shelp notes that the foundations for the "sanctity

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41. *Id.* at 1026.

42. *In re Baby K*, 832 F. Supp. 1022, 1026 (E.D. Va. 1993).

43. *See id.* at 1026-27.

44. *Id.* at 1026.

45. *Id.* at 1027.

46. *See id.* at 1027-29.

47. *In re Baby K*, 16 F.3d 590, 592 (4th Cir. 1994).

48. *Id.* at 596.

49. EARL E. SHELP, BORN TO DIE?: DECIDING THE FATE OF CRITICALLY ILL NEWBORNS 132 (1986).

of life" view are found in the Judeo-Christian tradition, which teaches that the value of life comes from God, not some "quality, capacity, trait, or property of life."<sup>50</sup> Therefore, proponents of the "sanctity of life" view believe that where there is human life, it is wrong to let it end. In the case of critically ill newborns, this view stresses the "equality of life" of each infant. As Robert Weir explains, "[g]ranted that some infants are born with severe mental and physical defects, they are not to be judged as being inferior in some sense merely because of their defects. Instead, decisions about treatment options should be made from a perspective that emphasizes 'the equality of particular lives regardless of their state or condition.'"<sup>51</sup>

Proponents of the "sanctity of life" view believe that any principle short of protecting and preserving every life would lead to a slippery slope, whereby some individuals would be allowed to die (or be killed) because they are disabled or disadvantaged in some way. Indeed, they argue that decisions about whether to treat a critically ill newborn should not be made with reference to the infant's quality of life. As Weir explains, when parents look at "quality of life" factors two problems occur. First, a birth-defective neonate inevitably loses out in the comparison with a normal infant who will have "a life worth living." Second, a birth-defective neonate's life is further devalued when it becomes clear that "quality of expected life . . . entails in principle the view that a particular human life is replaceable by another."<sup>52</sup>

The "sanctity of life" view, and accordingly the federal policy, thus explicitly reject any consideration of an infant's "quality of life" in making treatment decisions. In fact, it presumes that to the one living it, *any* type of life is worth living, even if it is filled with severe pain and disability, mental anguish, and, in some cases, an inability to even recognize or appreciate that a life is being lived.

As a philosophical approach, the "quality of life" view, like the "sanctity of life" position, recognizes human life as a value. The "quality of life" view differs, however, in that it recognizes distinctions in the type of life a severely impaired newborn who is "saved" may have, compared to a child that is healthy. Shelp explains that advocates of the "quality of life" position "search for and weigh or order the features, qualities, properties, or capacities of human life that make it of worth for the one who lives it."<sup>53</sup>

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50. *Id.*

51. ROBERT F. WEIR, SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE 148 (1984).

52. WEIR, *supra* note 51, at 147-48.

53. SHELP, *supra* note 49, at 135-36.

Weir further explains that under this view, some human beings have life in the sense that they have “vital and metabolic processes with no human functioning.”<sup>54</sup> Other human beings, indeed most human beings, have “life” in quite a different sense: “a state of *human* functioning (or capacity thereof), of well being.’ When parents and physicians have this understanding, they realize that there are times in which it is wrong to preserve ‘the life of one with no capacity for those aspects of life that we regard as *human*.’”<sup>55</sup> Accordingly, proponents of the “quality of life” view recognize that in some cases, it is merciful to let the infant die — survival is an injustice.<sup>56</sup>

Thus, the current federal policy, in mandating treatment in almost every case where death of the infant is not imminent, reflects a “sanctity of life” view, and eliminates any consideration of the burden on the infant or its quality of life.

### III. IS FEDERALLY-MANDATED TREATMENT OF CRITICALLY ILL NEWBORNS GOOD POLICY?

In answering this question, it is helpful to look at the primary arguments for and against the policy, and examine a view that is often left out of the policy debate — that of the health care providers who treat critically ill newborns every day.

#### A. Arguments for the Federal Policy

Arguments for the federal policy generally come down to an assertion that there is a grave problem of discrimination against critically ill infants, and that a strong policy valuing all human life, in all circumstances, is therefore necessary. This view is best characterized by a report from the United States Commission on Civil Rights, entitled “Medical Discrimination Against Children with Disabilities” (Commission Report).<sup>57</sup> The Commission’s purpose was to “attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government.”<sup>58</sup> The Commission noted that its report:

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54. WEIR, *supra* note 51, at 165.

55. *Id.*

56. *See id.* at 161.

57. U.S. COMM’N ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES (1989) [hereinafter COMMISSION REPORT].

58. *Id.* at 1.

focuses solely on the question of discrimination, addressing medical services provided or required to be provided, that are withheld from individuals with disabilities precisely because of their disabilities. It is neither the province nor the purpose of the Commission to oversee, evaluate, or question the exercise of legitimate medical judgment inherent in decision making concerning medical treatment.<sup>59</sup>

This deceptively simple statement could not hide the true position of the Commission — that any “legitimate medical judgment” not to treat was discrimination, and therefore not “legitimate” at all.

The Commission Report stated that “[t]he Commission is convinced that the evidence supports a finding that discriminatory denial of medical treatment, food, and fluids is and has been a *significant* civil rights problem for infants with disabilities.”<sup>60</sup> The Commission concluded that its inquiry “leaves no doubt” that newborns “have been denied food, water, and medical treatment solely because they are, or are perceived to be, disabled.”<sup>61</sup> In so concluding, the Commission dismissed the views of those who argued for allowing parental discretion in making treatment decisions, along with consideration of the infant’s quality of life, as grounded in ignorance. The Commission Report stated that “the arguments typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities.”<sup>62</sup> The Commission focused heavily on children with Down’s Syndrome to underscore “the good lives that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies.”<sup>63</sup>

The Commission thus strongly supported the federal policy. Indeed, in the Commission’s view, the policy did not go far enough, and was not adequately enforced by HHS. The Commission stated “[i]f adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.”<sup>64</sup>

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59. *Id.* at 2.

60. *Id.* at 12 (emphasis added).

61. *Id.* at 3.

62. COMMISSION REPORT, *supra* note 57, at 3.

63. *Id.* at 34.

64. *Id.* at 7.

*B. Arguments Against the Federal Policy.*

Despite the endorsement of the United States Commission on Civil Rights, and others, the federal policy has received significant criticism. This criticism has focused on two main areas: (1) the policy eliminates parental discretion in making treatment decisions; and (2) it fails to consider the burdens on infants that treatment can impose.

Professor Stephen A. Newman, in arguing that the federal policy may be unconstitutional, notes that "underlying the statute seems to be a view of parents as suspect bystanders, presumptively ready to commit child abuse by depriving their infants of necessary medical care."<sup>65</sup> Similarly, John Arras also argues that the federal policy is indefensible because it ignores the parent's role. He states that "the only discretion accorded to parents by this Act is the 'discretion' to treat."<sup>66</sup> Arras further states that "the Act regards parental participation in such decisions to be tantamount to child abuse."<sup>67</sup> This view is further echoed by Professor Dale L. Moore, who states that under the federal policy, "parental choices in favor of nontreatment . . . are suspect and perhaps unworthy of the deference traditionally accorded to parental decisions. The reason seems to lie in a concern that such nontreatment decisions may be tainted. . . ." <sup>68</sup> Many others have made similar arguments.<sup>69</sup>

The second main objection to the federal policy is that it fails to allow for considerations of the burdens on, and suffering of, the critically ill newborn. Newman states that the federal policy "set[s] a norm for aggressive, even relentless, treatment, with little regard for the suffering and grave burdens such aggressive care may generate."<sup>70</sup> Likewise, noting that the HHS regulations only allow for nontreatment essentially where death is imminent, Arras states that the federal policy would "appear to require corrective surgery on the esophageal atresia of a Trisomy-13 or -18 infant, despite the severity of his underlying defect and his predictably brief life — a requirement that flies in the face of current medical practice

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65. Stephen A. Newman, *Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants*, 15 AM. J. LAW & MED. 5 (1989). This paper will not explore the technical legal objections, discussed by Professor Newman and others, to the current legislative and regulatory scheme.

66. John D. Arras, *Ethical Principles for the Care of Imperiled Newborns: Toward an Ethic of Ambiguity, in WHICH BABIES SHALL LIVE?* 83, 127 (Thomas H. Murray & Arthur L. Caplan eds. 1985).

67. *Id.*

68. Dale L. Moore, *Challenging Parental Decisions to Overtreat Children*, 5 HEALTH MATRIX 311, 318 (1995).

69. See, e.g., JEFF LYON, *PLAYING GOD IN THE NURSERY* (1985).

70. Newman, *supra* note 65, at 2.

and moral common sense."<sup>71</sup>

### C. The Clinical View

Essentially missing from the debate is data from the medical community on what really happens in the neonatal intensive care nursery. The physicians who work with critically ill newborns every day provide enormous insight into whether the current federal law makes for good policy. Looking at the policy from the caregivers' perspective highlights two significant issues. First, the CAPTA Amendments and implementing regulations are simply unnecessary. Second, this seemingly unnecessary legislation has the unintended effect of mandating what physicians, and likely the general public, would consider unethical over-treatment.

In a recent study, Dr. Stephen Wall and Dr. John Partridge reviewed the records of a university-based intensive care nursery over a period of three years "[t]o determine the frequency of selective nontreatment of extremely premature, critically ill, or malformed infants . . . and to determine the reasons documented by neonatologists for their decisions to withdraw or withhold treatment."<sup>72</sup> Doctors Wall and Partridge noted that in light of the controversy surrounding the ethics and legality of limiting treatment for critically ill newborns, "knowledge of current clinical practices is an essential element in the discussion."<sup>73</sup> This element, however, is frequently left out. As previously noted, in the Commission Report, the clinical realities were only selectively considered, with an emphasis on newborns with Down's Syndrome, and not accurately analyzed.<sup>74</sup>

The authors found that over the three-year period, 165 infants died among the 1609 admitted.<sup>75</sup> One hundred eight deaths "followed withdrawal of life support, [thirteen] deaths followed the withholding of treatment, and [forty-four] occurred while infants continued to receive maximal life-sustaining treatment."<sup>76</sup> The authors concluded that in cases where death followed withdrawal or withholding treatment, "the most frequently documented reason for limiting life support was the neonatologist's belief that continued treatment was futile in the face of imminent death, noted in 74% of these deaths."<sup>77</sup> In 51% of the deaths, the authors

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71. Arras, *supra* note 66, at 127-28.

72. Stephen N. Wall, M.D. & John Colin Partridge, M.D., *Death in the Intensive Care Nursery: Physician Practice of Withdrawing and Withholding Life Support*, PEDIATRICS, Jan. 1997, at 64.

73. Wall & Partridge, *supra* note 72, at 65.

74. See generally COMMISSION REPORT, *supra* note 57, at 27-31.

75. See Wall & Partridge, *supra* note 72, at 64.

76. *Id.*

77. *Id.* at 66.

noted that "quality of life concerns" was documented as a reason to limit treatment.<sup>78</sup> "Quality of life" concerns included the prognosis for severe disabilities and the belief that the infant would unnecessarily suffer as a result of continued treatment. The authors further found that "quality of life" concerns, exclusive of any reference to the futility of treatment were noted in 23% of the deaths attributable to withdrawing or withholding treatment.<sup>79</sup> Of these deaths, the overwhelming majority of the infants (96%) suffered from either hypoxic-ischemic encephalopathy or intracranial hemorrhage.<sup>80</sup>

Also insightful is the fact that the authors found that in all of the deaths, the treatment withdrawn or withheld was intubation and mechanical ventilation.<sup>81</sup> None of the deaths were attributable to the withdrawal or withholding of fluids.<sup>82</sup> Moreover, in the overwhelming majority of deaths, withdrawal of ongoing therapy that was deemed ineffective and inappropriate was more common than withholding treatment.<sup>83</sup> The authors concluded that "the practice of selective nontreatment described at our institution may be typical of other tertiary care nurseries in the United States."<sup>84</sup> The authors stated that despite the efforts of the federal government in the wake of the Baby Doe controversy, "[n]either governmental regulations . . . nor court decisions have resolved these moral and ethical questions."<sup>85</sup>

Thus, according to this study, the law and regulations that serve to resolve this issue are not grounded in reality. Indeed, this study does not paint a picture of widespread discrimination or tainted parental decision-making, but instead illustrates that, not surprisingly, cases involving critically ill newborns are complex, posing serious ethical questions. Many of these cases push the bounds of our medical knowledge. As such, the moral questions are even more complex, and the parents and physicians find themselves in uncharted territory. Such an area is not appropriate for federal intervention.

The physicians' perspective also highlights the unintended, and arguably unethical consequence of CAPTA and the implementing regulations:

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78. *See id.*

79. *Id.*

80. *See Wall & Partridge, supra note 72, at 66.* The fact that "quality of life" concerns are reflected in physician's treatment decisions indicates that the federal policy may have little effect in everyday life. Nevertheless, the issue is not simply academic — the statute and regulations are still the law.

81. *See Wall & Partridge, supra note 72, at 66.*

82. *See id.*

83. *See id.*

84. *Id.* at 68.

85. *Id.* at 69.

aggressive overtreatment that results in a prolonged, painful death.<sup>86</sup> A recent article by the American Academy of Pediatrics addressed the issue of the "profound moral questions" involved in providing treatment to critically ill newborns.<sup>87</sup> The Academy pointed out that the public policy measures enacted to protect disabled infants may have had "unintended consequences."<sup>88</sup> The Academy states that "attention concentrated on saving the lives of infants, some with permanent, severe disabilities or neurogenerative disorders, has hampered sufficient attention to the possible overuse of [life-sustaining medical technology]."<sup>89</sup> The Academy noted that after the CAPTA Amendments, "surveys of neonatologists indicated that many . . . believe[d] they were legally constrained to provide life-sustaining medical treatment to infants even where their medical judgments and the views of the parents concur that withholding treatment is preferable."<sup>90</sup> The Academy stated that the evidence "continues to indicate that the decreased mortality brought about by neonatal intensive care has been accompanied by increased morbidity, i.e., serious mental and physical limitations among survivors that impose burdens on affected children and their families."<sup>91</sup>

Perhaps most striking is the Academy's view that "no reliable evidence that decisions endangering children have been widespread exists."<sup>92</sup> The Academy asserted that the Baby Doe controversy of the 1980s gave the false impression that parents and physicians commonly withhold treatment from critically ill newborns who could be saved.<sup>93</sup> In fact, the Academy stated that "[m]ost cases of lethal nontreatment . . . [involve] infants with trisomy 21 and myelomeningocele."<sup>94</sup>

Thus, from the perspective of the medical community, the federal policy has done little to resolve the issue of whether it is appropriate to withhold or withdraw treatment from critically ill newborns. Indeed, the policy addresses a "discrimination" problem that largely does not exist. In so doing, the federal policy requires doctors to continue treatment even where, in the physician's view, continued treatment is unethical and not in the infant's best interests.

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86. See American Academy of Pediatrics, *Ethics and Care of Critically Ill Infants and Children*, PEDIATRICS, July 1996, at 149; see also Wall & Partridge, *supra* note 72, at 64-65.

87. American Academy of Pediatrics, *supra* note 86, at 149.

88. *Id.*

89. *Id.*

90. *Id.* at 149-50.

91. *Id.* at 150.

92. American Academy of Pediatrics, *supra* note 86, at 150.

93. See *id.*

94. *Id.*

It appears, then, that seventeen years after the death of Baby Doe, the issue is far from settled, despite the federal government's attempts to establish a policy. At the time the federal government intervened in this area, there was no moral consensus on the issue of treatment for critically ill newborns. We are no closer now, despite the federal government's attempt at setting a uniform moral vision. One thing, however, is certain. As the Supreme Court noted in *Bowen*, it is unprecedented for the federal government to be involved in treatment decisions for newborns.<sup>95</sup> Thus, the questions we are left with are: (1) is it good policy; and (2) if not, what is?

#### IV. CONCLUSIONS AND PROPOSALS

The federal statute and implementing regulations that mandate treatment of critically ill newborns is bad policy. This is so for three reasons. First, the policy purports to resolve a problem of "discrimination" that largely does not exist. Second, in setting a uniform federal standard, the policy dramatically oversimplifies the complex moral and ethical issues presented by the decision of whether to treat a critically ill newborn. Third, as a philosophical matter, the policy does not square with our intuitions.

As the American Academy of Pediatrics explained, and the Supreme Court noted in its opinion in *Bowen*, there is no evidence that there in fact exists a "problem" of discriminatory or otherwise unjust withdrawing or withholding medical treatment from critically ill newborns.<sup>96</sup> There is no question that there were a few well-publicized cases in the 1980s that, to the outside observer, involved unjust withholding of medical treatment. However, the evidence shows that these cases were not representative of what actually goes on in neonatal intensive care nurseries.<sup>97</sup> Thus, the federal policy rests on a foundation not of necessity and fact, but exaggeration and hysteria.

In addition, the federal policy drastically oversimplifies the issue of withdrawal or withholding medical treatment from critically ill newborns. This is clear from the first federal initiative in this area, when the Reagan Administration framed the issue as one of "discrimination" against "handicapped" newborns.<sup>98</sup> The court in *In re Baby K* relied on much of the same reasoning. In casting the issue in this light, the federal government made the issue appear to be as simple as other issues involving dis-

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95. See *Bowen v. American Hospital Ass'n*, 476 U.S. 610, 627-28 (1986).

96. See generally American Academy of Pediatrics, *supra* note 86, at 149.

97. See Wall & Partridge, *supra* note 72, at 64-65; American Academy of Pediatrics, *supra* note 86, at 150.

98. See *supra* note 14 and accompanying text.

abled individuals. Policymakers were thus able to shoehorn the newborn issue into the general consensus against discrimination against the disabled. Yet this issue is far different from the question of whether an otherwise qualified disabled individual is entitled to a job or whether an individual in a wheelchair is entitled to access to public accommodations. Most of us would agree that denying employment and access to handicapped individuals is simply wrong. In contrast, most of us would not as quickly come to a consensus on whether a newborn infant, who faces a life (perhaps guaranteed to end prematurely) of severe physical and mental disabilities, and painful, burdensome medical treatment, should be kept alive. Arras, in arguing for an "ethic of ambiguity," stresses this point. He states that:

By attempting to erect an entire social policy on the slender reed of a few miscarriages of justice, [the federal policy] burdens the American people with a hopelessly *simplistic* rule. As we shall see, the Infant Doe Rule oversimplifies an extraordinarily complex moral and factual situation. Adequate social policy needs to be formulated on the basis of a broad understanding of moral and medical realities, not on moral outrage directed, no matter how appropriately, against a few highly publicized cases.<sup>99</sup>

The advocates of the federal policy, as demonstrated by the Commission Report, dismiss this more difficult, and realistic, presentation of the issue. Instead, borrowing from traditional arguments made on behalf of the disabled community, the advocates argue that the real problem is simply one of ignorance, stereotypes, and plain discrimination.<sup>100</sup> Yet it is clear that this issue is not as simple as whether a child with Down's Syndrome will lead a productive, fulfilling life, as the Commission Report repeatedly stressed.<sup>101</sup> Indeed, as the American Academy of Pediatrics noted, the case of "Baby Doe" was an exception, not the rule.<sup>102</sup> Moreover, medical evidence shows that the overwhelming majority of critically ill newborns who are aggressively treated are severely impaired for the rest of their lives.<sup>103</sup> This fact cannot and should not be overlooked.

My previous two objections to the federal policy underscore the final, and most important problem with it: the policy does not comport with our intuition. First, it cuts parents out of the decision of whether to treat their

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99. Arras, *supra* note 66, at 99.

100. See COMMISSION REPORT, *supra* note 57, at 12-17, 103-10.

101. See *id.* at 36.

102. See American Academy of Pediatrics, *supra* note 86, at 149

103. See American Academy of Pediatrics, *supra* note 86, at 150; see also *supra* note 91 and accompanying text.

critically ill children. Regardless of whether someone embraces the sanctity of life or quality of life view (or something in between), that person would almost certainly accept that as a general matter, parents should be the primary decision-makers on behalf of their children. In fact, the case of *In re Baby K* turned on such a view.<sup>104</sup> Eliminating parents from the decision-making equation breaks with well-established legal tradition and quite simply, the reality of the situation. As Professor Newman notes, “[b]oth law and society regard parents as the primary protectors of their child’s best interests.”<sup>105</sup> Indeed, the Supreme Court has long recognized that parents are presumed to be the appropriate decision-makers on behalf of their minor children.<sup>106</sup>

Moreover, as others have noted, the reality of the situation concerning critically ill newborns is that parents *suffer*. Indeed, if their severely impaired children are kept alive, the families often face a lifetime of burden and suffering — emotionally and financially. Although it intervenes to the point of mandating that critically ill, severely impaired infants should be aggressively treated, the federal government is far less willing to provide assistance and social programs to infants who manage to survive and grow up to be severely handicapped individuals. For this reason, many ethicists have argued that the “plight of parents” must be considered, and they should not be cut out of the decision-making process.<sup>107</sup> The federal policy, however, is framed with suspicion toward parents. Instead of recognizing that most parents, in all but rare cases, agonize over decisions to treat their critically ill newborns and in many cases insist on what physicians would consider unethical over-treatment, the federal policy casts them in a suspicious light, as “interested” parties whose interests will “taint” the decision-making process. Yet our intuition tells us that “direct killing and euthanasia are never part of a relationship that should exist between parents and newborns.”<sup>108</sup> This intuition has been recognized by the Supreme Court, which noted that the “natural bonds of affection lead parents to act in the best interests of their children.”<sup>109</sup> By the same token, our intuition also tells us that parents should have a say in the treatment decision.<sup>110</sup>

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104. See *In re Baby K*, 832 F. Supp. 1022, 1030-31 (E.D. Va. 1993).

105. Newman, *supra* note 62, at 5.

106. See *Bowen v. American Hospital Ass’n*, 476 U.S. at 627-28; see also *Wisconsin v. Yoder*, 406 U.S. 205, 213-14 (1972); *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

107. WEIR, *supra* note 51, at 159.

108. WEIR, *supra* note 51, at 161.

109. *Parham*, 442 U.S. at 602.

110. See SHELP, *supra* note 49, at 140; see also American Academy of Pediatrics, *supra* note 86, at 150-51.

Also showing that the federal policy does not square with our intuitions, is its failure to consider the infant's suffering in the face of continued treatment and the infant's quality of life if it survives. The federal policy erroneously assumes that a presumption in favor of "life" is always in an infant's best interests. In fact, we know this is not true. As noted by the medical community, the issue of aggressive over-treatment presents an important ethical dilemma, one not simply overlooked by the federal policy but likely borne out of it. As stressed by Professor Moore, "demands for over-treatment that disregard a child's best interests should be challenged and resisted."<sup>111</sup>

Moreover, as Shelp argues, considerations of the infant's quality of life are consistent with the values of society.<sup>112</sup> This view is also echoed by Newman, who states that "[g]iven the potential for grave burdens accompanying treatment, infants, like all other incompetent individuals, deserve the right to have harms to themselves given full consideration . . . ."<sup>113</sup> Newman goes on to state that "[l]egal, medical, and ethical thinking support the centrality of a benefits/burdens analysis" to come up with a treatment decision.<sup>114</sup>

This is consistent with the view taken by at least some courts. For instance, the District of Columbia Court of Appeals recently upheld the decision of a lower court, acting as *parens patriae*, to enter a Do Not Resuscitate (DNR) order for a neglected two year old who was in a comatose state and "neurologically devastated."<sup>115</sup> The court found that despite the mother's wishes for "aggressive resuscitation" efforts to be used in the event K.I., as predicted, developed respiratory distress, "[the child's] 'best interests would be served by issuing a DNR order.'"<sup>116</sup> The court noted that the mother's refusal to consent was "unreasonable and contrary" to the child's well being, given the child's condition and the fact that aggressive treatment would cause the child pain without any hope of future recovery.<sup>117</sup>

Thus, cases such as *In re K.I.* and *In re Baby K* show the other side of the moral equation — a side that the federal policy does not contemplate. Assuming, as the federal policy does, that parents may have a selfish desire to let their infant die, there is an equally if not more plausible desire for some parents to selfishly demand aggressive, painful treatment for

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111. Moore, *supra* note 68, at 315.

112. See SHELPS, *supra* note 49, at 69.

113. Newman, *supra* note 65, at 40.

114. *Id.*

115. *In re K.I., B.I., and D.M.*, 735 A.2d 448, 450 (D.C. 1999).

116. *Id.* at 452.

117. *Id.* at 456.

their doomed infant. This desire to continue the biological life of an infant for the *parents* well being, as opposed to the infant's, was likely at work in *In re K.I.* and *In re Baby K.* Ironically, the neglected K.I. may have had her interests better served than Baby K because the court was free to consider K.I.'s interests.<sup>118</sup>

While proponents of the federal policy criticize "quality of life" considerations of this kind as based on ignorance and discrimination, and see mandatory treatment as always in an infant's best interests, the benefits to the infant are often illusory. The truth is that nearly all of us, the proponents of the federal policy included, hold such issues to be important in our daily lives. We routinely speak of spending "quality time" with our children. In choosing jobs, we often cite "quality of life" issues as being important to our decisions. Such considerations permeate most everything that we do. In short, the "sanctity of life" position, as embodied in the federal policy mandating treatment of critically ill newborns, is divorced from the realities of our daily life.

What would be an acceptable policy? As an initial matter, I advocate eliminating the federal role in making treatment decisions that affect severely impaired newborns. To the extent there is a need to protect against the rare parents who would sanction the killing of their newborn on inappropriate grounds, and against accepted medical judgment, the states have a child protective system in place to deal with these cases. Thus, I would return to a system where parents, in consult with their physician, are presumed to be the best parties to make decisions about whether to withdraw or withhold medical treatment. This presumption would not be irrebuttable. As stated above, in the event parents demonstrated they were not acting within the area of reasonable parental discretion, the states have child protective mechanisms that may be invoked. This position is advocated by many others, including the American Academy of Pediatrics, which states that:

the AAP believes that parents and physicians should make reasoned decisions together about critically ill infants using the principles of informed parental permission . . . [s]uch decisions should consider the benefits and burdens of treatment alternatives. . . . In rare instances, as required by law and sound ethical standards, it may be necessary to invoke established child protective mechanisms if parents wish to forego [life-saving medical treatment], physicians disagree, and the parties cannot resolve their differences

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118. *Id.* at 453-56 (applying the "best interest of the child standard" instead of the "substituted judgment test" because the baby's parents disagree over the proper course of action and the baby "will forever lack, the ability to express a preference").

with help from subspecialists, ethics consultants, or ethics committees.<sup>119</sup>

Thus, the issue of whether to treat critically ill newborns should not be swept aside with a simplistic social policy that overlooks the profound ethical, medical, and legal questions that such situations pose. Because of the unique and complex issues that each critically ill newborn presents, parents, working with their doctors, families, clergy, and others, are in the first instance the best decision-makers.

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119. American Academy of Pediatrics, *supra* note 86, at 150.