

# The Legal Rights of Disabled Infants to Receive Life-Sustaining Medical Treatment

JEANNINE WYSZKOWSKI

## I. INTRODUCTION

Disabled infants lack the competence to make medical treatment decisions for themselves; therefore, society places these decisions in the hands of proxy decision-makers. This paper outlines the history of federal attempts to regulate medical treatment decisions for disabled infants, and describes the resulting state of the law, whereby parents, subject to limitations only in exceptional situations through the doctrine of *parens patriae*, shoulder the burden of difficult life or death treatment decisions. This paper concludes by evaluating the strengths and shortcomings of alternative proxy decision-makers, and offering suggestions to improve upon the current format of proxy decision-making for disabled infants.

## II. FRAMEWORK

### A. *Scientific Advances in Medical Care for Infants*

Developments in medical technology in the last century have significantly increased the number of treatment options available to newborns in need of medical intervention for survival. Physicians first utilized oxygen and respiratory stimulants to counteract the cessation of breathing in the 1930's.<sup>1</sup> Incubators allowed for caregivers to increase oxygen delivery to infants in the 1940's, until research showed in mid-1950 that high oxygen concentrations could cause blindness.<sup>2</sup> By 1970, the availability of intensive care for infants, including continuous monitoring of blood pressure, heart rate, and breathing rate lead to a marked decrease in infant mortality rates.<sup>3</sup>

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<sup>1</sup> William H. Tooley & Roderic H. Phibbs, *Neonatal Intensive Care: The State of the Art*, in *ETHICS OF NEWBORN INTENSIVE CARE* 12 (Albert R. Jonsen & Michael J. Garland eds., 1976).

<sup>2</sup> *Id.*

<sup>3</sup> As aggressive interventions based on the values observed during continuous monitoring became widely utilized, mortality rates from hyaline membrane disease, a respiratory passage disorder affecting premature newborns, dropped from 60% to 20%, for example. *Id.* at 12-13.

A closer look at the neonatal death rates over the last few decades more conclusively demonstrates the impact of new medical technologies. In 1950, for example, among every 1,000 live births of premature infants, there were 20 deaths.<sup>4</sup> Fifty years later, in 2000, there were less than 10 deaths per 1,000 live births of premature infants, a decrease in infant mortality by over half the previous rate.<sup>5</sup> In the not so distant past, when premature babies perished despite the provision of a warm environment and oxygen, they were presumed simply unable to live.<sup>6</sup> Today, developments in modern medicine no longer enable the acceptance of that presumption. Novel surgical techniques and medications, more powerful diagnostic abilities, and advanced research findings have worked together to further expand the types of interventions that medicine can make to improve and preserve the lives of infants. Due to the many recent medical advances, the question now asked is, "What quality of life will an infant face if provided with the state-of-the art care that is currently available?"

Consequently, while the availability of previously unknown treatments and monitoring devices has increased the prognosis for many infants, it has caused many ethical dilemmas for doctors and parents who must decide whether to utilize these technologies to treat a severely disabled infant.

### *B. Competence*

Since medical treatment decisions extend beyond the competencies of the infants in need of those services, legislators, parents, and doctors must grapple with the ethical issues arising from the development of novel life-sustaining technologies. Many ethical issues involved with infant care overlap with legal issues. Interestingly, many of the legal and ethical issues that surface in the context of medical care for infants also surface in the context of medical care for the elderly. Elders, however, afforded an opportunity to plan for their final moments of life, seem advantageously poised to contend with complex issues of whether to withhold or discontinue life-sustaining treatment when compared to infants. Elders, for instance, may utilize a variety of end-of-life planning tools. They may appoint a health care agent, or they may choose to execute a living will. Infants, by contrast, occupy a more vulnerable position than elders. They

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<sup>4</sup> GLADE B. CURTIS & JUDITH SCHULER, *YOUR PREGNANCY WEEK BY WEEK* 266 (4th ed. 2000).

<sup>5</sup> *Id.*

<sup>6</sup> Clement A. Smith, *Neonatal Medicine and Quality of Life: An Historical Perspective*, in *ETHICS OF NEWBORN INTENSIVE CARE*, *supra* note 1, at 33.

not only lack the chance to execute these types of documents, but they also never have the opportunity to communicate their wishes to their parents, physicians, or guardians. Accordingly, individuals given the power to make treatment decisions on behalf of the infant can never decisively ascertain what the infant's desires would have been when confronted with the choice of receiving life-saving medical treatment and living with a severe, permanent disability, or opting to forgo the treatment.

In addition to the inability to plan in advance for disability, infants inherently lack the competence to make health care decisions for themselves. Three main capacities define the threshold level of competence needed to make health care decisions for oneself: "1) capacities for communication and understanding of information; 2) capacities for reasoning and deliberation; 3) capacity to have and apply a set of values or conception of the good."<sup>7</sup> Normally, the doctor-patient relationship consists of discourse that results in shared goals and a mutual understanding of the best course of treatment for a particular patient.<sup>8</sup> In the absence of competence to make health care decisions, a proxy must be appointed to perform this function for the patient. In the case of infants, a parent or legal guardian traditionally steps in to contribute to the doctor-patient relationship.<sup>9</sup>

The Supreme Court has upheld the right of state law to require surrogate medical decision-makers for incompetent adults to act in the accordance with the adult patient's wishes as expressed by the patient when competent.<sup>10</sup> New parents, however, who never verbally communicate with their infant, lack evidence of what their infant would have wished to do had he been able to make the health care decision himself. Because cutting-edge treatments lack certainty in health outcomes, parents also lack the ability to objectively predict the potential benefits or harms these procedures could afford their child. Above all, parents, who will bear the burden of caring for, financing, and potentially raising their disabled child to majority, may have difficulties separating the best interests of the child from their own self-interested tendencies to protect a certain quality of life. When the parents' concept of quality of life conflicts with the state's views of the legal and moral rights of the

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<sup>7</sup> Dan Brock, *Children's Competence for Health Care Decisionmaking*, in CHILDREN AND HEALTH CARE: MORAL AND SOCIAL ISSUES 184 (Loretta M. Kopelman & John C. Moskop eds., 1989).

<sup>8</sup> Michael S. Grodin, Sharon F. Schwartz & David Todres, *Moral Dilemmas and Problematic Decision Making in Neonatal Intensive Care*, in THE RIGHTS OF CHILDREN: LEGAL AND PSYCHOLOGICAL PERSPECTIVES 28 (James S. Henning ed., 1982).

<sup>9</sup> *Id.*

<sup>10</sup> *Cruzan v. Dir. of Mo. Dep't of Health*, 497 U.S. 261, 290 (1990).

infant, the state may accept legal guardianship and speak in the best interest of the child.<sup>11</sup>

### III. RIGHTS OF DISABLED INFANTS

#### A. Federal

##### 1. Constitutional Rights

As citizens, infants with disabilities are afforded the same legal protections of life, physical integrity, and procedural due process as any nondisabled individual under the United States Constitution.<sup>12</sup> Section 1 of the Fourteenth Amendment, applicable to the states through the Fifth Amendment, provides in relevant part:

All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the [s]tate wherein they reside. No [s]tate shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any [s]tate deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.<sup>13</sup>

The United States Court of Appeals for the Tenth Circuit clarified the applicability of the Fourteenth Amendment to cases involving medical neglect of infants in the 1992 case of *Johnson v. Thompson*.<sup>14</sup> The infants in that case were born with myelomeningocele (“MM”), a form of spina bifida, and became participants in a hospital run study on the management, treatment, and outcomes of infants born with MM. The team of doctors leading the study recommended that each infant plaintiff receive only supportive care, i.e., no treatment other than making the infants as comfortable as possible.<sup>15</sup> Both infants died. Since the study, the hospital changed its practices, and all MM infants now receive vigorous treatment,

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<sup>11</sup> Grodin et al., *supra* note 8.

<sup>12</sup> MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, U.S. COMM’N ON Civil Rights 94 (September 1989).

<sup>13</sup> U.S. CONST. amend. XIV, § 1.

<sup>14</sup> *Johnson v. Thompson*, 971 F.2d 1487 (10th Cir. 1992).

<sup>15</sup> *Id.* at 1491.

i.e., surgery and antibiotics. The plaintiffs, parents of the infants filed suit alleging, *inter alia*, that the conduct of the team violated their substantive due process rights under the Fourteenth Amendment by depriving the infants of the liberty interest in their lives.<sup>16</sup> The court held that while the Due Process Clause does protect an interest in life, there was no Constitutional duty for a state to take steps to preserve life. The court, citing the 1989 Supreme Court case of *DeShaney v. Winnebago County Department of Social Services*, reasoned:

The [Due Process] Clause is phrased as a limitation on the [s]tate's power to act, not as a guarantee of certain minimal levels of safety and security. It forbids the [s]tate itself to deprive individuals of life, liberty, or property without "due process of law," but its language cannot fairly be extended to impose an affirmative obligation on the [s]tate to ensure that those interests do not come to harm through other means.<sup>17</sup>

The court held that a right to treatment only exists in narrow circumstances, which do not include the category of infants born with MM. "Specifically, when the [s]tate takes a person into its custody and holds him there against his will, [then] the Constitution imposes ... a corresponding duty to assume some responsibility for his safety and general well-being."<sup>18</sup> Thus, the court upheld the hospital's actions in this instance, holding that the protections of the Due Process Clause did not apply to the MM infants. Since this holding outlines only very narrow circumstances in which the Due Process Clause may protect the lives of infants, it significantly limits the applicability of Constitutional protections for disabled newborns.

## 2. *Rehabilitation Act of 1973*

Other attempts at invoking federal protections for disabled infants have likewise failed. For instance, Section 504 of the Rehabilitation Act of 1973 (the "Act") guarantees that disabled individuals will have meaningful access to employment, housing, *health care*, and other

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<sup>16</sup> *Id.* at 1495.

<sup>17</sup> *DeShaney v. Winnebago County Dep't of Soc. Servs.*, 489 U.S. 189, 195 (1989).

<sup>18</sup> *Id.* at 199-200.

services.<sup>19</sup> Section 504 provides in relevant part, “No otherwise qualified individual with a disability ... shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving [f]ederal financial assistance.”<sup>20</sup> The Act defines “individual with a disability” as “any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment.”<sup>21</sup>

Attempts to utilize this federal statutory language, however, have proven unsuccessful in protecting the lives of disabled infants. The treatment of disabled infants came to the forefront of national debate in 1982, after two parents decided to withhold surgery from their infant who was born with Down’s syndrome and esophageal atresia.<sup>22</sup> Following the death of Bloomington Baby Doe, as the infant became known, the issue of withholding medically indicated treatment from infants born with Down’s syndrome became a topic of heightened public concern. President Reagan ordered the Department of Health and Human Services (“HHS”) to respond. Soon after, under the auspices of § 504 authority, HHS required health care providers to post notices stating that failure to feed and care for infants with disabilities in facilities receiving federal funds was prohibited.<sup>23</sup> Hotlines opened to receive calls regarding the medical neglect of infants, and “Baby Doe squads” formed to investigate reported allegations of neglect.<sup>24</sup> As the plight of disabled infants became enmeshed in public debate, the use of § 504 to protect these infants came under attack in a series of cases aimed at upholding federalism by limiting the powers of Congress to regulate practices in this realm.

Several benchmark cases from the 1980’s illustrate how courts denied federal protection under the Act to disabled infants in need of medical treatment. In the first case, *American Academy of Pediatrics v. Heckler*, involved an interim final regulation published in March 1983 by the Secretary of the Department of Health and Human Services. The regulation required hospitals receiving federal funds to post conspicuous signs in maternity wards, pediatric wards, and nurseries reading:

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<sup>19</sup> Erin A. Nealy, *Medical Decision-Making for Children: A Struggle for Autonomy*, 49 SMU L. REV. 133, 142 (1995) (emphasis added).

<sup>20</sup> 29 U.S.C. § 794(a) (2002).

<sup>21</sup> 29 U.S.C. § 709(8)(B) (1998).

<sup>22</sup> See *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 632 (1986).

<sup>23</sup> RUTH COLKER ET AL., *THE LAW OF DISABILITY DISCRIMINATION* 813 (4th ed. 2003).

<sup>24</sup> *Id.*

DISCRIMINATORY FAILURE TO FEED AND CARE  
FOR HANDICAPPED INFANTS IN THIS FACILITY IS  
PROHIBITED BY FEDERAL LAW

...

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: [the] Handicapped Infant Hotline [, the] U.S. Department of Health and Human Services[,] . . . or Your State Child Protective Agency . . . Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973. Identity of callers will be held confidential. Failure to feed and care for infants may also violate the criminal and civil laws of your [s]tate.<sup>25</sup>

The court found that the regulation, published without the opportunity for public comment, violated the Administrative Procedure Act, and held the regulation invalid as arbitrary and capricious.<sup>26</sup> Furthermore, the court noted that neither the language of the Act nor the legislative history authorized the provision of heroic medical care to handicapped newborns.<sup>27</sup> The court reached this conclusion by pointing to the definition of “handicapped individual”, now termed “individual with a disability” in the Act. It determined that while some infants born with defects may fit within the broad definition “handicapped individual” (“any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment”), the lack of evidence of Congressional intent to reach into a morally and ethically sensitive area suggested that Congress never intended § 504 to be applied so broadly as to eliminate consideration of the futility of the circumstances within which treatment would be administered.<sup>28</sup> The court further articulated,

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<sup>25</sup> Am. Acad. of Pediatrics v. Heckler, 561 F.Supp. 395, 398 (D.C. 1983).

<sup>26</sup> *Id.* at 399.

<sup>27</sup> *Id.* at 402.

<sup>28</sup> *Id.* (quoting 29 U.S.C. § 706).

[t]he legislative history of ... [§ 504] ... focuses on discrimination against adults and older children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life.<sup>29</sup>

Responding to the court's ruling, HHS subsequently drafted a substantially similar rule, this time offering it for public comment. After considering the nearly 17,000 comments received and negotiating with the American Academy of Pediatrics, HHS promulgated the Final Rule in January 1984.<sup>30</sup> Subsequent litigation would ultimately invalidate the Final Rule and again act to restrict attempts at federal statutory intervention into infant care treatment decisions.

In the meantime, during late 1983 through early 1984, the Second Circuit Court of Appeals in *U.S. v. University Hospital, State University of New York at Stony Brook*, addressed another § 504 issue. In that case, HHS attempted to utilize § 504 to enable it to access the medical records of an infant born with mental retardation and spina bifida whose parents refused consent for medical procedures deemed necessary to prolong the infant's life.<sup>31</sup> The court held, *inter alia*, that the hospital's decision not to override the parental wishes to withhold treatment in this instance did not violate § 504. The court reiterated the sentiments of *Heckler*, concluding that the silence of the Act's legislative history on the subject of medical treatment for disabled infants demonstrated a lack of intent by Congress that § 504 apply to treatment decisions regarding disabled infants.<sup>32</sup> Consequently, the court denied HHS access to the infant's medical records because it lacked the authority to inquire into the records under § 504.

The lack of § 504 authority to protect disabled infants was further solidified by the Supreme Court's decision in *Bowen v. American Hospital*. Here, the Court held that state law vests decisional responsibility for the provision of medical care to handicapped infants in the first instance to the parents, subject to review in exceptional cases by

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<sup>29</sup> *Id.* at 401.

<sup>30</sup> MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, *supra* note 12, at 69-70.

<sup>31</sup> *United States v. Univ. Hosp., State Univ. of N.Y. at Stony Brook*, 729 F.2d 144, 146 (2d Cir. 1984).

<sup>32</sup> *Id.* at 159.

the state acting as *parens patriae*.<sup>33</sup> The Court reasoned that if a parent does not authorize medical treatment for a handicapped infant, then the hospital cannot violate the antidiscrimination provision of § 504 because without parental consent, the infant is neither “otherwise qualified” under the Act, nor can the infant be said to have been denied care solely by reason of his handicap (since the reason he was denied treatment rested also on the parental decision). The Court went further to hold that HHS did not possess the authority to promulgate regulations (referring to the Final Rule promulgated in January 1984) that required posting, reporting, and access to records requirements under § 504, which was enacted to prevent discrimination.<sup>34</sup> Ultimately, the Court held that § 504 was an anti-discrimination statute, and in the absence of evidence that a handicapped infant was the victim of discrimination by a recipient of federal funds, HHS could not employ federal resources to save the lives of infants under § 504.<sup>35</sup> At last, efforts to confer federal protections to disabled infants whose parents had refused consent to medically indicated care under § 504 completely failed.

### 3. *Americans with Disabilities Act (ADA)*

Other attempts to provide federal statutory protections for disabled infants include invoking the Americans with Disabilities Act (the “ADA”). The ADA shares the similar purpose with § 504 of prohibiting discrimination with respect to access to programs, services, and places on the basis of disability. The ADA, therefore, potentially faces the same obstacles to implementation in medical treatment decisions for disabled infants as did § 504. Generally, the ADA states that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”<sup>36</sup> The ADA defines a “public accommodation” to include, among other things, the “professional office of a health care provider, [a] hospital, or other service establishment.”<sup>37</sup> The ADA also provides that:

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<sup>33</sup> *Bowen v. Am. Hosp.*, 476 U.S. 610, 627 (1986).

<sup>34</sup> *Id.* at 645-46.

<sup>35</sup> *Id.* at 647.

<sup>36</sup> 42 U.S.C. § 12182(a) (1990).

<sup>37</sup> 42 U.S.C. § 12181(7)(F) (1990).

[i]t shall be discriminatory to subject an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity.<sup>38</sup>

The court in *In re Baby K* held that the plain language of the ADA prohibits the denial of ventilator services to anencephalic infants (infants partially or completely without a brain), since this service would be available to a nondisabled infant at its parent's request.<sup>39</sup> In that case, the hospital denied ventilator services to the infant despite the request of its mother to provide the therapy because of the futility of the treatment given the circumstances. The Fourth Circuit affirmed the district court's decision, holding that the hospital was legally obligated to provide ventilator support to the infant. The decision, however, was reached on other bases; consequently the court never reached the issue of the application of the ADA to the scenario at hand.<sup>40</sup> The Supreme Court denied certiorari.<sup>41</sup> According to Erin A. Nealy, the district court's reading of the ADA, if analyzed under the Supreme Court's interpretation of the lack of applicability of § 504 to treatment decisions for disabled infants in *Bowen v. American Hospital*, is flawed for a number of reasons.

First, the two statutes are similar in purpose – both are designed to prohibit certain entities from discriminating on the basis of disability, most notably with respect to access to programs, services, and places. Second, the definition of “disability” is identical in both laws. Third, the two statutes cross-reference one another, including an express statement by the ADA that its standards shall be at least as strict as those applied under Title V of the Rehabilitation Act (the title containing Section 504).

Fourth, like the Rehabilitation Act, nothing in the language of the ADA or its legislative history suggests that the statute was intended to interfere with the reasonable

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<sup>38</sup> 42 U.S.C. §12182(b)(1)(A)(i) (1990).

<sup>39</sup> 832 F.Supp. 1022, 1029 (E.D. Va. 1993).

<sup>40</sup> COLKER ET AL., *supra* note 23, at 843.

<sup>41</sup> *Id.*

medical judgments of treating physicians ... [T]he legislative history of the ADA clarifies that a patient's disabilities may be considered when relevant to medical decision-making ... The legislative history illustrates the main premise underlying the analysis. Congress noted that a physician who specializes in burn patients could not refuse to treat the burns of a deaf person because of the deafness. This is so because a person's hearing status is unrelated to his or her burn conditions. On the other hand, Congress did not state that physicians are prohibited from providing different types of treatment where a patient's disability is directly related to, or intertwined with, the medical condition being treated ... In short, a reasonable construction of the ADA is to permit physicians to make treatment decisions based on their best medical judgments, particularly when a consideration of the disability is necessary due to its proximity to the acute medical condition.<sup>42</sup>

Importantly, the court in *In re Baby K* also held that withholding ventilator treatment violated § 504 in the situation presented because the refusal was based on Baby K's disability alone and not on the lack of parental consent, and therefore, ran contrary to the mandate of § 504.<sup>43</sup> Which interpretation of the ADA is correct remains to be decided by the higher courts. If the ADA, however, truly prohibits withholding treatment from disabled infants, even in situations of medical futility, the ADA may also run contrary to the provisions of the Child Abuse Amendments of 1984, discussed below. Based on the clearly carved exceptions to mandatory treatment of infants in futile circumstances, the district court's interpretation of the ADA in *In re Baby K* likely runs astray of Congressional intent.

#### 4. *Child Abuse Amendments of 1984*

In response to the cases from the 1980's and the issues discussed above, Congress passed the Child Abuse Amendments of 1984. Unlike the federal legislation (§ 504 and the ADA) discussed earlier, which creates a federal cause of action, the Child Abuse Amendments of 1984 (the "1984 Amendments") operate in a different manner. Encountering

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<sup>42</sup> Nealy, *supra* note 19, at 146-47.

<sup>43</sup> 832 F.Supp. 1022, 1028 (E.D. Va. 1993).

resistance to direct federal regulation of the provision of medical treatment to disabled infants, the 1984 Amendments indirectly attempt to regulate behavior in this area by creating a federal grant program to act as an incentive for states to monitor and promote the protection of infants with disabilities from medical neglect. The 1984 Amendments arose out of a general federal desire to prevent the denial of medical treatment to children with disabilities.<sup>44</sup> Most significantly, however, the 1984 Amendments address the issue of withholding medically indicated treatment from infants with disabilities.

Passed into law in October 1984, the 1984 Amendments require states receiving funds under the Child Abuse Prevention and Treatment Act to develop and implement procedures

(within the State child protective services system), to provide for (i) coordination and consultation with individuals designated by and within appropriate health-care facilities, (ii) prompt notification by individuals designated by and within appropriate health-care facilities of cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and (iii) authority under State law, for the State child protective service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life threatening conditions.<sup>45</sup>

Consequently, “the federal role is limited to (1) establishing a clearinghouse for information regarding developments in treatment and support services for disabled infants, and (2) promulgating regulations to ensure that states fulfill their obligations under statute” and, thereby, deserve federal funding.<sup>46</sup> Under the 1984 Amendments, only the state child protective services agency in the state receiving federal funds has standing to bring an action to prevent the abuse or neglect of a disabled infant.<sup>47</sup> There is no private right of action against a health care provider

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<sup>44</sup> MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, *supra* note 12, at 79.

<sup>45</sup> 42 U.S.C. § 5106a (2)(B) (1988 & Supp. V 1993).

<sup>46</sup> Erin A. Nealy, *supra* note 19, at 148.

<sup>47</sup> 42 U.S.C. § 5106a(b)(2) (1988 & Supp. V 1993).

under the 1984 Amendments.<sup>48</sup> States failing to comply with the mandates of the 1984 Amendments lose their eligibility for federal grant money.<sup>49</sup>

Despite the lofty objectives of the 1984 Amendments, little financial incentive exists for states that receive funds under the Act to promote compliance with the costly process of protecting children with disabilities from medical neglect as defined by federal statute. For example, in 1988, federal payments, beginning at \$35,980, funded states containing the smallest number of residents under age eighteen.<sup>50</sup> Because of the broad protections afforded children under the Act, this meager figure easily demonstrates the undersized financial incentive provided to states that choose to comply with the Act's administrative mandates. As of December 1988, however, 46 states, the District of Columbia, and Puerto Rico received federal grants under the Act, with only California, Indiana, Ohio, and Pennsylvania denying federal assistance.<sup>51</sup> For the few states that choose not to accept funding under the Act, the harsh consequences of a financial incentive that lacks force manifests itself as the potential for a complete lack of statutory protection for medically neglected disabled infants.

Analyzing the 1984 Amendments assists in highlighting the imbalance between the expectations of the Act and the costliness of its implementation, making it easier to observe why some states may choose not to comply with the federal scheme. First, each state must have procedures to address reports of medical neglect in order to receive federal funds. Although the Act does not define medical neglect, Supplemental Information published by HHS has now been codified as 45 C.F.R. § 1340.15. There, "medical neglect" is defined as:

the failure to provided adequate medical care in the context of the definitions of 'child abuse and neglect' ... The term medical neglect includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition ... The term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening

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<sup>48</sup> *In re Baby K.*, 832 F.Supp. at 1029.

<sup>49</sup> 42 U.S.C. § 5106a(b)(1) (1988 & Supp. V 1993).

<sup>50</sup> Texas received the largest amount of federal funds, \$739,006, in the same year. U.S. COMM'N ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, *supra* note 12, at 82.

<sup>51</sup> *Id.*

conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's ... reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions [with exceptions noted].<sup>52</sup>

Second, the procedures must be in writing, and require coordination with individuals within appropriate health care facilities, prompt notification of suspected medical neglect cases, state law authority for the state child protective service system to pursue any legal remedies, access to medical records so that appropriate investigation of medical neglect can occur, independent medical examination of the infant via court order, and written documentation of continuing eligibility for federal grant monies.<sup>53</sup>

While the Child Abuse Amendments of 1984 contain expansive protections for infants and children of all ages, HHS also acknowledged the existence of exceptional situations where statutory protection would be unwarranted. Specific exceptions to the 1984 Amendments have been codified as 42 U.S.C.A. § 5106g. Life-saving medical intervention is not mandated if an infant is: 1) chronically and irreversibly comatose; 2) the treatment would prolong dying, not effectively ameliorate or correct all of the infant's life-threatening conditions, or be futile for the infant's survival; or 3) would be inhumane due to its futility in assisting the infant to survive.<sup>54</sup> Regardless of the three exceptions, caregivers must continue to provide appropriate nutrition, hydration, and medication in all instances. The exceptions only allow a caregiver to bypass the statutory requirement to provide the treatment most likely to correct or ameliorate the infant's life-threatening condition in situations of medical futility. Importantly, the statute continues to offer very broad protections in that it makes no exception for conditions of persistent vegetative state.

The three exceptions to mandatory treatment for disabled infants offer a humane alternative to providing treatment that ultimately prolongs pain and suffering for fatally ill infants. While "chronically and irreversibly comatose" may be easily defined, however, the other scenarios where medical futility is deemed to exist seem rather ambiguous and subject to the possibility of medical error. Particularly in an area of developing medicine such as infant care, it may be difficult for a doctor to say definitively when a treatment would only prolong dying or be futile in assisting an infant to survive. To prove this point, one need only

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<sup>52</sup> 45 C.F.R. § 1340.15(b)(1-2) (1987).

<sup>53</sup> See 45 C.F.R. § 1340.15(c)(1-5) (1987).

<sup>54</sup> See 42 U.S.C.A. § 5106g(6)(A-C) (1996).

remember the changes in treatment strategies for MM infants after more became known about the disease in *Johnson v. Thompson*. In addition, if these exceptions provide a source of interpretive guidance for other federal statutes, it appears that the district court's interpretation of the ADA in *In re Baby K* (that the ADA does not provide for exceptions to mandatory treatment in situations deemed medically futile) lacks merit.

*B. Rights of Infants with Disabilities Under State Law*

*1. Generally*

Unlike the federal government, states possess the requisite authority to directly regulate the provision of medical care to disabled infants. Courts, however, commonly defer to parental decisions in these matters, citing the constitutional rights of parents under the First and Fourteenth Amendments to make decisions for their children based on the parent's free exercise of religion and the right to bring up children, respectively.<sup>55</sup> In the absence of clear and convincing evidence of medical abuse or neglect, courts have favored the principle of family autonomy, and have generally scrutinized family decisions to terminate or withhold medical treatment only in cases involving incompetent minors or adults.<sup>56</sup>

The history of state protections for all children nicely illuminates the deferential treatment given to non-disabled infants and children under state law. And, the development of societal protections for children in general, preceded, and led to the possibility of heightened protections for infants with disabilities whose parents choose not to authorize medically necessary care. The state of New York paved the path toward increased protections beginning in 1875 with the formation of the New York Society of the Prevention of Cruelty to Children.<sup>57</sup> By the late 1880s, New York statutes prohibited negligence in providing food, clothing, sanitation, and medicine to children.<sup>58</sup> Further legal developments in 1922 led to statutory provisions allowing courts to mandate medical and surgical care for children.<sup>59</sup>

In recent years, state courts have routinely protected non-disabled children, ensuring they receive medically necessary care.<sup>60</sup> For example,

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<sup>55</sup> *In re Baby K.*, 832 F.Supp. at 1030.

<sup>56</sup> *Id.* at 1031.

<sup>57</sup> MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, *supra* note 12, at 57.

<sup>58</sup> *Id.*

<sup>59</sup> *Id.*

<sup>60</sup> *Id.* at 56.

under the doctrine of *parens patriae*, the state can limit parental authority over a child in certain circumstances where a court deems the limitation necessary to protect the well being of the child.<sup>61</sup> Even though great deference is given to parental authority, state intervention in these narrow circumstances guards a recognized public interest in protecting children. Moreover, courts have commonly utilized state child abuse and neglect statutes or *parens patriae* doctrine to order blood transfusions in life-threatening situations for children of Jehovah's Witnesses whose parents will not consent to transfusions on moral grounds.<sup>62</sup> In *Prince v. Massachusetts*, the Supreme Court opined, "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves."<sup>63</sup>

Although non-disabled children have been protected by state statute and by state courts, this has not been consistently true for children with disabilities. For example, even though the Child Abuse Amendments of 1984 stipulate that states receiving federal funding for child abuse and neglect programs must monitor and prevent doctors and hospitals from withholding medically necessary treatment from disabled infants, courts continue to defer to parental decisions regarding treatment in situations involving disabled infants.<sup>64</sup> If parents have been properly informed regarding the prognosis of their disabled infant, and have shown thought and the indicia of acting in the best interests of their infant, albeit with the harsh result of death due to non-treatment, courts have placed significant weight on the parents' decision of what was best for their child.<sup>65</sup> Therefore, despite statutory protections, parental autonomy reigns at the state level in medical treatment decisions for disabled infants, whereas it is often overruled in cases involving non-disabled children.

## 2. Tort Actions

Despite an infant's lack of autonomy in medical decision-making, state law provides remedies later in life for those who disagree with the treatment decisions made on their behalf. State law provides for tort

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<sup>61</sup> *Id.* at 57.

<sup>62</sup> *Id.* at 58.

<sup>63</sup> 321 U.S. 158, 170 (1940).

<sup>64</sup> MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES, *supra* note 12, at 56.

<sup>65</sup> See *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 627-28 (1986).

actions called “wrongful birth” and “wrongful life” suits to those seeking compensation for injurious existence.<sup>66</sup> Wrongful birth actions are brought in one of two forms by the parents of a child born as a result of an unexpected pregnancy. First, they can be brought against pharmaceutical companies and doctors who negligently performed sterilization procedures that resulted in the birth of a healthy, but unwanted child.<sup>67</sup> Second, wrongful birth actions can be brought against obstetricians and gynecologists in instances where children are born with serious congenital defects. In these cases, the parents allege that, had they been properly advised of the risks involved, they would have terminated the pregnancy.<sup>68</sup>

Most pertinent to the issue of an infant’s lack of medical decision-making autonomy, a child may bring a wrongful life action. In a wrongful life action, the child alleges that he or she would not have been born but for the defendant’s negligence.<sup>69</sup> In many cases, these suits are brought by severely handicapped children who claim they have experienced great suffering because a doctor or medical laboratory acted negligently in informing his parents about the risks of defects.<sup>70</sup> These children seek damages for their existence, as a result of the wrongful preservation of their life, based on their expected life span.<sup>71</sup>

Wrongful life actions have rarely succeeded in court. These types of suits, however, have caused courts to contemplate whether infants always benefit from receiving neonatal medical treatment. Interestingly, “[m]ost courts to date have concluded that impaired existence is preferable to nonexistence and that devising a fair procedure for computing the damages brought about by wrongful life is an impossible task.”<sup>72</sup> Some courts, in contrast have granted damages to child plaintiffs, deciding both that life is not always preferable to nonexistence, and that damages are calculable in these types of cases.<sup>73</sup> Regardless of this difference in opinion, it remains that each neonatal treatment decision has case-specific facts and case-specific implications. Moreover, each child’s experience with his or her disability differs in both personal perception and intensity. At the time the treatment/nontreatment decision becomes final, the number of variables in each instance makes it impossible to predict the ultimate

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<sup>66</sup> ROBERT F. WEIR, *SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE* 117 (Oxford Univ. Press 1984).

<sup>67</sup> *Id.*

<sup>68</sup> *Id.*

<sup>69</sup> *Id.*

<sup>70</sup> *Id.*

<sup>71</sup> *Id.*

<sup>72</sup> *Id.* at 123.

<sup>73</sup> *Id.* at 124.

outcome in any given situation. The potential remedies in tort allow those children, who disagree with the decisions made, the opportunity to voice their disagreement and possibly to receive compensation for their suffering.

#### IV. WHO SHOULD DECIDE?

Given that parents are the primary decision-makers when questions of medical treatment of disabled infants arise, should they be? The complicated issues involved in making treatment/nontreatment decisions may surpass the capabilities of parents to act in an infant's best interests in these difficult situations. Some factors complicating medical decision making for disabled infants include; the serious nature of the decision, the inherent uncertainty of proxy decision-making for infants who have never been competent, the pressure of time constraints, the severe emotional stress on parents who face the unexpected reality of the serious nature of the condition of their newborn infant, moral conflicts between parents concerning the appropriate course of action, conflicts between doctors and parents regarding the appropriate treatment, the difficulty of accurately predicting outcomes for disabled infants, and inadequate or confusing communication between the parties involved.<sup>74</sup> Any combination of these complexities may hinder the decision-making adeptness of even the most concerned, well-meaning parents. If parents may not always proffer the best treatment decisions when faced with these circumstances, who exemplifies a better alternative?

To determine the best alternative to parents in making medical treatment decisions for disabled infants, the qualities of an able proxy decision-maker must be defined. Proxy decision-makers for disabled infants must act to promote the best interests of the infant in treatment/nontreatment cases. In order to perform this duty effectively, a proxy decision-maker must necessarily possess pertinent knowledge and information. Relevant knowledge includes, either medical training, or clear and understandable communication from the infant's doctors regarding the medical circumstances involved in the case.<sup>75</sup> Second, a proxy decision-maker should possess information concerning the infant's familial setting, including information about the parents' emotional strength, financial circumstances, other children, and the disposition of family members regarding the care and acceptance of the disabled infant.<sup>76</sup>

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<sup>74</sup> *Id.* at 254.

<sup>75</sup> *Id.* at 255.

<sup>76</sup> *Id.* at 255-56.

Third, proxy decision-makers should know about alternatives to non-treatment, such as adoption of handicapped infants, and institutions that provide long-term care for disabled children.<sup>77</sup>

In addition to possessing relevant knowledge and information, an able proxy decision-maker should be an impartial decision-maker that can objectively evaluate the situation and come to a conclusion based on the best interest of the infant involved.<sup>78</sup> Objectivity presupposes a certain degree of emotional stability on the part of the proxy decision-maker as well. When faced with the confusing, saddening, and unexpected reality of their child's disability, parents may often lack the requisite emotional stability to ensure sound treatment choices.

Lastly, an able proxy decision-maker should reach the same treatment decision given identical circumstances.<sup>79</sup> This requirement of moral decision-making may not always apply, in that no two cases pose identical circumstances, however, general patterns of consistency in similar medical situations most likely fulfill the consistency requirement.

Establishing the desirable characteristics for an able proxy decision-maker makes it possible to evaluate the potential candidates against the outlined criteria. Parents possess several favorable characteristics for this role. First and foremost, parents possess the most complete and intimate understanding of the infant's familial setting, financial circumstances, other children, and the disposition of family members regarding the care and acceptance of the disabled infant. Parents, however, fall short in many of the other categories that represent favorable traits for proxy decision-makers. Notably, parents may not possess the requisite understanding of the medical complications present in their child, nor understand viable treatment options and their projected outcomes, even if presented with the relevant facts. Furthermore, parents may be unaware of the alternatives of adoption or long-term care for their infant, and may instead focus on the psychological or financial best interests of the family unit, rather than the best interests of the disabled infant. Lastly, since each set of parents possesses the autonomy to make a treatment determination for their own child, this eliminates the possibility of consistency.

Numerous alternative proxy decision-makers exist, however. The doctor involved in the care of the disabled infant is one example. His or her strength as a proxy decision-maker includes superior medical knowledge and the ability to assess prognoses for disabled infants based

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<sup>77</sup> *Id.* at 256.

<sup>78</sup> *Id.*

<sup>79</sup> *Id.* at 257.

on prior experiences and the results of empirical study data. Doctors possess more objectivity than the infant's parents, and possess the ability to consistently make treatment decisions based on their exposure to numerous cases.

Doctors, on the other hand, do not possess some of the favorable characteristics found in parents, such as an intimate connection to the infant's family situation. Undeniably, their vast medical knowledge can only *predict* outcomes and *attempt* to develop appropriate diagnoses – medicine, especially in developing fields, has many enigmatic qualities that may never be mastered. Moreover, possession of superior medical knowledge does not of necessity relate to a doctor's moral strengths, which may also differ from the morals of the infant's parents. This prospective weakness highlights another conflict of interest doctors may face in becoming proxy decision-makers - a lack of impartiality. Many pediatric doctors, for instance, have a bias in favor of normal, healthy children.<sup>80</sup> Other doctors may possess research interests that overcome their ability to advocate for the best interests of the infant when that infant represents a rare opportunity to advance neonatal medicine as a science.<sup>81</sup> And, in some situations, a conflict of interest may arise when doctors succumb to external pressures such as demanding parents, changing legal pressures, or financial considerations relating to lack of insurance coverage, for example. In sum, doctors while superior to parents in some aspects of medical proxy decision-making for disabled infants, face a variety of conflicts and issues of their own that hinder their ability to become ideal candidates for this role.

A hospital committee represents another potential proxy decision-maker for disabled infants. Hospital committees offer the benefits of diverse membership. This quality allows debate among individuals with expertise in varied fields and helps mitigate the possibility of harm to the decision-making process presented by the shortfalls discussed above which doctors or parents, acting in isolation, possess. In this manner, hospital committees potentially represent, in composite, the ideal proxy decision-maker for a disabled infant. Hospital committees typically utilize more formalized procedures, and therefore, a disabled infant may also benefit from due process protections.<sup>82</sup>

Hospital committees may protect infants in other ways as well. Aside from formalized processes, committees may arbitrate conflicts arising between doctors and parents, and can also safeguard an infant's

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<sup>80</sup> *Id.* at 262.

<sup>81</sup> *Id.*

<sup>82</sup> *Id.* at 263.

best interests in cases where the other parties involved have not demonstrated their willingness to do so.<sup>83</sup> Since hospital committees typically contain at least one member with a background in ethics, committees uniquely qualify to make the challenging decisions that doctors and parents unsuspectingly confront. An ethics-based approach can also lead to consistent moral reasoning among similar cases.

A major shortcoming of hospital committees relates to the structure by which they function. Since treatment decisions concerning disabled infants often take place within a short period of time, committees, which require consensus, debate, and input from a variety of members, can potentially fail to meet the necessary timelines involved in infant care decisions. Furthermore, a committee setting implies a degree of compromise. This characteristic may result in the formation of a group decision that completely satisfies none of the members.<sup>84</sup>

Finally, hospital committees reduce parental autonomy with respect to a very intimate decision-making process. Since committees exist remotely from the treatment setting, the lack of emotional closeness to the situation can detract from the effectiveness of their final decision. They may have external influences depending on whether the hospital is a for profit entity, and depending on the overall financial stability of the organization at the time the treatment decision needs to be made. Again, despite the many positive aspects of committee decision-making, various set backs, many based on the structure of the committee, exist with the use of hospital committees as proxy decision-makers for disabled infants.

Courts typify a fourth type of potential proxy decision-maker for disabled infants. Unlike the entities mentioned above, courts have the ability to use well-established procedures to facilitate their decision-making. For instance, courts may appoint a guardian *ad litem* to advocate on behalf of the infant's best interests. They may also summon witnesses, question experts, ensure the complete exposition of opposing views, and provide consistent reasoning across cases.

As with hospital committees, courts have procedural inadequacies that do not conform well to the short time frames necessitated by critical infant care decisions. More importantly, however, when courts act as proxy decision-makers, the myth that the "right" decision is made in any particular, personal, fact-specific circumstance may be promulgated.<sup>85</sup> This fault especially has merit because courts often have no personal contact with the case. This shortcoming can render judges less sensitive to

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<sup>83</sup> *Id.* at 264-65.

<sup>84</sup> *Id.* at 265.

<sup>85</sup> ETHICS OF NEWBORN INTENSIVE CARE, *supra* note 1, at 124.

the individuals involved. Finally, while courts may promote consistency within each jurisdiction, the personal opinions of judges across jurisdictions may certainly collide due to the highly sensitive and morally charged decisions made. Courts, therefore, also experience many obstacles to becoming ideal proxy decision-makers for disabled infants.

One potential solution to the dilemma of who is best suited to serve as a proxy decision-maker for disabled infants has been suggested by individuals who have closely studied the complexities of disabled infant treatment decisions. The two proposed solutions rest on a combination of the above-mentioned possible proxies. Robyn S. Shapiro and Richard Barthel suggest a state statutory model under which final treatment decisions result from a series of steps. In the first step, if a disabled infant's parents/guardians, doctors, and the hospital ethics committee all agree that necessary life-sustaining treatment should be withheld from the infant, the treatment should not be administered, and no civil or criminal liability ensues.<sup>86</sup> The second step, if applicable, concerns cases in which parents/guardians refuse consent for life-sustaining medical treatment, but either the doctor or ethics committee disagrees with this decision. In this situation, the model statute calls for a hearing before a Medical Treatment Panel.<sup>87</sup> At the hearing, the Panel appoints a guardian *ad litem* for the infant. Within in one week, the Panel meets to hear all arguments regarding medical treatment for the infant and is bound to render a decision within two days of the hearing.<sup>88</sup> The standard of proof required for the Panel to order withholding treatment from the infant is clear and convincing evidence that withholding the treatment is in the infant's best interest.<sup>89</sup> Finally, the model statute provides that a court may overturn the decision of the Panel if suit is filed within three days of the Panel decision. If no suit is filed, a court shall render final judgment in accordance with the Panel's decision. Alternatively, James Childress suggests a serial or sequential ordering of decision makers, in which the parents make the initial treatment determination.<sup>90</sup> The attending physician can then appeal this decision to a hospital committee and decisions of the committee can be appealed and overridden by a court.<sup>91</sup>

The most obvious flaws in either of the two proposed solutions lie in their high potential for timeliness problems. While the decisions

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<sup>86</sup> Robyn S. Shapiro & Richard Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827, 859 (1986).

<sup>87</sup> *Id.* at 859.

<sup>88</sup> *Id.* at 859-60.

<sup>89</sup> *Id.* at 860.

<sup>90</sup> WEIR, *supra* note 66, at 268.

<sup>91</sup> *Id.*

reached by either of these suggested processes might be more “right” than if any one of the other four suggested proxies (parents, doctors, hospital committees, courts) represented the best interests of the infant, the delay in reaching the decision may render it worthless.

#### V. CONCLUSION

No perfect proxy decision-maker exists for disabled infants. No perfect treatment decision exists either, for the outcome of every available treatment option in each circumstance can never be known. But if a society desires to treat each life with the same dignity and respect as each other life, consistency must exist among end-of-life decision-making options for all. Thus, the current options utilized for incompetent adults must be extrapolated for use by infants to the best extent possible.

Under current law, each state regulates the procedures to be followed for end-of-life decisions for adults. In Missouri, for example, an incompetent adult cannot be removed from life support absent a showing of clear and convincing evidence that, when competent, she expressed a desire that life sustaining treatment would not be continued if she reached a persistent vegetative state with no hope of recovery.<sup>92</sup> Missouri and other states, then, define the best interests of an incompetent patient as what the patient would have desired to do, were she competent.

Parents come closest to the best option for proxy decision-makers for disabled infants because they can most accurately predict the best interests of their infant. Since parents teach children their own morals and values, it follows that, if a disabled infant possessed competency, its parents would have shaped its ideas and values, and therefore, its decisions would have been based on these values. Of course, this hypothesis contains flaws, including the inevitable truth that many children think and act quite differently than their parents do. Assuming, however, that parents would most often make treatment decisions in harmony with the disabled infant’s wishes, were she capable of expressing them, the other shortcomings of placing parents in this role would be addressed most effectively through state statutory regulation.

In this respect, a proactive approach, rather than the reactive approaches currently in place, would be best. Just as many couples receive and benefit from pre-marital counseling prior to marriage, expectant individuals and couples may benefit from education concerning the alternatives to withholding life-sustaining treatment from a disabled infant *prior* to giving birth. This approach would help ensure that

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<sup>92</sup> *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. at 268-69.

alternatives such as adoption or long-term care were thoroughly communicated in a less emotional atmosphere. An awareness of the potential alternatives to caring for a severely disabled child could also assist in mitigating any conflict of interest present because of the couple's financial or familial situation.

A statutorily mandated discussion regarding potential medical complications with infants and their projected outcomes could also be communicated in the same manner. Of course, an infant could be born with any number of anomalies never discussed with the parents, but the prior discussions may offer a reference point in which a couple could make more informed treatment decisions based on their own infant's medical difficulties.

One shortcoming of parents as proxy decision-makers for disabled infants that may never be adequately addressed relates to the consistency of decisions across cases. This shortcoming is inevitable, and arguably desirable, in a model that allows for parental autonomy, as each family will possess differing values and morals that shape their decisions.

As noted previously, Congress lacks the power to directly federally regulate treatment decisions pertaining to disabled infants. It would, therefore, be left to the states to provide statutory mandates to would-be parents regarding pre-delivery counseling and decision-making. Although no ideal proxy decision-maker and no ideal treatment decision exist, further assisting parents to reach informed decisions in the best interests of their infants may offer the best possible solution to a difficult dilemma.