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## Rescuing Baby Doe

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# RESCUING BABY DOE

Mary Crossley\*

## INTRODUCTION

The twenty-fifth anniversary of the Baby Doe Rules offers a valuable opportunity to reflect on how much has changed during the past two-and-one-half decades and how much has stayed the same, at least in situations when parents and physicians face the birth of an infant who comes into the world with its life in peril.

The most salient changes are the medical advances in the treatment of premature infants and the changes in social attitudes towards and legal protections for people with disabilities. The threshold at which a prematurely delivered infant is considered viable has advanced steadily earlier into pregnancy, and the interventions developed to ameliorate the effects of premature delivery have become more—but not fully—effective, as discussed by other symposium participants. During the same period, Congress passed the Americans with Disabilities Act (ADA)<sup>1</sup>, providing individuals with disabilities with broad protection against discrimination, and it recently reaffirmed its intent that the ADA be broadly construed in the ADA Amendments Act of 2008.<sup>2</sup> Despite the advances in medical treatment and in legal protections for and societal attitudes regarding people with disabilities, however, the law regarding treatment decisions for newborns with disabilities has remained remarkably static.

Changes in the past twenty-five years in neonatal medicine and in the legal and social discourse regarding disability have led to increased complexity in teasing out how medical treatment choices at the beginning of life implicate disability concerns. This Essay describes that increased complexity and how it relates to the

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1. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2006), *amended by* ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553–3559 (2008).

2. ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553–3354 (2008).

disability concerns that originally prompted the enactment of the Baby Doe Rules. It will then proceed to suggest how analogizing these decisions to rescue situations might inform our thinking about how to give disability concerns their due. The Essay will close by suggesting that a richer conception of the Baby Doe Rules as part of child welfare law may help us situate a role that disability advocacy might play in influencing—if not controlling—how these complex situations unfold. The Essay's purpose is not to provide answers to the questions that vex medical providers about the legal limits on parental and provider decision-making, but simply to offer a perspective on the nature of the questions we should ask.

### I. INCREASED MEDICAL COMPLEXITY AND THE BABY DOE RULES

Beginning with a brief recap of how disability concerns played a central role in the passage of the Baby Doe Rules is in order. In 1982 the national news media picked up the story of an infant in Indiana, referred to simply as Baby Doe.<sup>3</sup> The newborn had been diagnosed as having Down syndrome and as suffering from a life-threatening blockage of its digestive tract. Although the latter condition could be easily corrected by surgery, the parents chose not to have the surgery performed, and as a result the infant died in less than a week.

The portrayal of an infant being permitted to starve to death, apparently because it had Down syndrome, prompted a public outcry. The Reagan Administration responded initially by promulgating regulations that treated hospitals' failure to provide life-saving treatment to infants with handicaps as a violation of section 504 of the Rehabilitation Act of 1973,<sup>4</sup> which prohibits discrimination on the basis of handicap by recipients of federal funding. To make a long story short, this initial approach of deeming selective non-treatment to be a form of disability discrimination was struck down because, although the hospitals where disabled infants were born were subject

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3. See John A. Robertson, *Extreme Prematurity and Parental Rights after Baby Doe*, HASTINGS CENTER REP., July–Aug. 2004, at 33.

4. 29 U.S.C. § 794 (2006).

to section 504's anti-discrimination mandate, it was the parents—not the hospitals—who made the decision whether to authorize the surgery or other treatment.<sup>5</sup> The federal anti-discrimination law did not apply to parents' decisions.

In a second and more enduring effort to craft a legal response to Baby Doe's case, Congress set limits on parents' treatment decisions by amending federal child welfare laws that conditioned federal funding on state child welfare agencies' carrying out certain federally mandated responsibilities. The Child Abuse Amendments of 1984<sup>6</sup> are the Baby Doe Rules still in force today.

The essence of the disability rights case against permitting selective non-treatment in a case like Baby Doe's is straightforward. The choice not to treat that infant was based on the fact that the life saved would certainly be a life with a disability. The medical literature contained clear evidence that many doctors thought such choices appropriate because of the perceived low quality of life with a disability,<sup>7</sup> and presumably the medical treatment choices of parents were influenced by this professional devaluing of life with physical and cognitive impairments.

Today, the area of greater challenge involves medical decisions for infants born very prematurely, at the margins of viability.<sup>8</sup> Part of the challenge is to determine how the Baby Doe Rules should be interpreted to apply to these situations as a legal matter. But part of

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5. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 610–11, 630 (1986). In *Bowen*, a plurality of the Court held that the Department of Health and Human Services failed to justify the need for such regulations because the agency had not shown that hospitals were withholding medical treatment from "otherwise qualified" infants. *Id.* at 630. Because parents must consent to surgery or other treatment before medical providers could provide it, a lack of parental consent meant that disabled infants were not "otherwise qualified" to receive treatment and were not denied care "solely by reason of his handicap." *Id.* For a criticism of this reasoning, see Leslie Pickering Francis & Anita Silvers, *(Mis)framing Schiavo as Discrimination against Persons with Disabilities*, 61 U. MIAMI L. REV. 789, 797 (2007).

6. Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101–5106i) (2006).

7. See, e.g., Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890, 893 (1973); Anthony Shaw et al., *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (1977).

8. See, e.g., Robertson, *supra* note 3. See generally Sadath A. Sayeed, *The Marginally Viable Newborn: Legal Challenges, Conceptual Inadequacies, and Reasonableness*, 34 J. L. MED. & ETHICS 600 (2006).

the challenge is to discern how disability concerns are implicated in these situations, and this Essay will focus on that question.

As a factual and prognostic matter, important distinctions exist between the original paradigmatic case of selective non-treatment of disabled newborns and situations involving very premature newborns. In a case like Baby Doe's, the parents and physicians knew at the time of the non-treatment decision that the infant, if he or she survived, would survive with a lasting disability whose nature, if not extent, was known. The treatment at issue was known to be effective in ameliorating a life-threatening condition, but would not eliminate the disability-producing impairment. In short, if the parents choose to treat, the infant will survive with a known disability.<sup>9</sup>

As several of the presentations at this symposium highlight, however, prognostic confidence in cases involving extremely premature newborns is substantially less.<sup>10</sup> In many cases, it is uncertain whether the infant will survive even if treatment is provided. If the infant does survive, it may survive with little or no long-term deficit in physical or cognitive functioning, or it may survive with physical or mental impairments that are moderate or severe. Moreover, physicians and parents cannot forecast with any degree of certainty how prolonged, invasive, and painful the course of treatment will be to produce this uncertain outcome. In short, if treatment is provided, the infant may or may not survive, and if the infant does survive, it may do so with no disability or with a mild, moderate, or severe disability that may be either physical or cognitive in nature. This extreme prognostic uncertainty changes the nature of parental decision making and changes how disability concerns are implicated.

In the original Baby Doe scenario, the parents' refusal to consent to treatment that in all likelihood they would have consented to as a

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9. Admittedly, this statement overstates the certainty of any prognosis; the point is simply that parents in the archetypal Baby Doe scenario were presented with a choice whose implications seemed clear.

10. See Sayeed, *supra* note 8, at 600 (referring to marginally viable newborns as presenting "unparalleled uncertainty about outcomes").

matter of course if their infant had not been identified as having a disability appears clearly to have been discrimination based on disability, whether legally proscribed or not. To the extent the non-treatment decision was influenced by societal and medical biases toward people with disabilities and misperceptions regarding the quality of the lived experience enjoyed by people with disabilities and their families, it seems like the kind of disability discrimination that our society recognizes as objectionable.

The concerns from the disability perspective look a bit different in cases of extreme prematurity. For one thing, categorizing infants born at the margins of viability as being disabled is itself questionable. These infants, if they survive, are certainly at significant risk of being disabled, but their future disability is by no means certain. At the time that decisions must initially be made, everything about their future is speculative and uncertain.<sup>11</sup>

As a matter of strict legal definition, an infant delivered at twenty-three to twenty-four weeks may well fall within the ADA's definition of "individual with a disability" by virtue of having an impairment that significantly limits a major life activity, such as seeing or breathing.<sup>12</sup> It seems likely, however, that it is not the impairments existing at the time of delivery that actually give pause to parents and physicians deciding whether to provide resuscitative and subsequent treatment to marginally viable newborns. Instead, it is the prospect that the prematurity could result in one or more disabilities that—perhaps together with other factors—may lead parents to consider withholding treatment. So, parents seem likely to be influenced more by the expectation of possible disability than the existence of disability, as in the original Baby Doe case.

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11. Of course, if initial resuscitation and treatment are provided, over time the contours of an extremely premature infant's anticipated disabilities may become clearer and more definite. This evolution may change the nature of disability concerns implicated in a single case.

12. 42 U.S.C. § 12102(2)(A) (2006). This conclusion is particularly likely in light of Congress's revisions of the statutory definition in the ADA Amendments Act of 2008 to include within the definition of "major life activity" the "operation of a major bodily function," including neurological and respiratory functions, and to make clear that the definition of disability should be construed broadly. *Id.* § 12102(2)(B), (4)(A).

The other, more subtle point that strikes me is that decisions about an extremely premature newborn seem less like end-of-life decisions than beginning-of-life decisions. Without stepping into the morass of questions about when “life” begins as a constitutional or philosophical matter, framing the question as involving the beginning of the infant’s experience of life may remove it some from the core of disability concerns. The central motivating force behind the passage of the ADA and the disability rights movement has been improving the lived experience of persons with disabilities. Demanding that medical interventions be provided to reinforce whatever fragile wisps of sustainable life a marginally viable newborn presents at birth arguably has more to do with a vitalist’s commitment to preserving all life than with a disability rights advocate’s agenda.

Let me hasten to say that, by pointing out that decisions about treatment for very premature infants do not present the paradigmatic disability discrimination scenario, I do not mean to suggest a lack of concern about how bias might operate in this setting to diminish opportunities and welfare for people with disabilities. But the immense complexity of the issues presented by the birth of a marginally viable newborn requires us to consider the potential for bias thoughtfully.

## II. RESCUING THE MARGINALLY VIABLE NEWBORN

Might a different perspective on the question offer some fresh insights? Some commentators describe the medical interventions responding to the birth of a marginally viable newborn as a rescue operation of sorts.<sup>13</sup> The newborn emerges from the womb in immediate peril, and all is lost unless the medical team steps in in an effort to achieve a healthy outcome in spite of long odds. The question is whether a rescue effort is compulsory.

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13. See, e.g., Sayeed, *supra* note 8, at 607 (referring to “the odds-against opportunity to rescue” that medical technology offers for marginally viable newborns and to “decisions not to initiate rescue”).

Looking at two different aspects of our societal response to rescues may be informative. First, when in general terms does a legal duty to rescue another person in peril arise? Second, what role does the so-called “rescue imperative” play in the scenarios presented by extremely premature births?

A principle of tort law that first-year law students learn is the “no duty to rescue” rule, which basically means that an individual has no duty, enforceable by a claim in tort law, to take actions to assist another who is in harm’s way.<sup>14</sup> To give a graphic example, I have no legal duty to pull the playing toddler from the railroad tracks, even if I could do so without any risk of harm to myself.

But like most rules, the “no duty to rescue” rule has its exceptions. The contours of these exceptions are not precise, but they are often based on the existence of relationships that impose some kind of duty.<sup>15</sup> Sometimes a duty is founded on professional relationships, such as the established relationship between doctor and patient, while another time the basis may be a familial relationship, like the parent-child relationship. Thus, courts have found that a parent may have a duty to take reasonable steps to protect her child from harm at the hands of a third party,<sup>16</sup> and that principle can logically be extended to require a parent to take steps to rescue her child in a health or accident-related emergency situation.

That duty’s extent, however, is not unbounded, as parents will not be required to place themselves in grave danger to come to their children’s rescue. The extent of the parents’ duty is instead cabined by the concept of reasonableness, as is so often the case with the law. Parents must take *reasonable* steps to rescue their children from harm

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14. *Kaho’ohanoano v. Dep’t of Human Servs.*, 178 P.3d 538, 563 (Haw. 2008) (“The general rule is that a person does not have a duty to act affirmatively to protect another person from harm. The fact that the actor realizes or should realize that action on his or her part is necessary for another’s aid or protection does not of itself impose upon him or her a duty to take such action.”) (citing *Lee v. Corregedore*, 925 P.2d 324, 329 (Haw. 1996)).

15. *Id.* (“The exceptions to this general rule . . . arise when a ‘special relationship’ exists between the actor and the individual facing harm.”) (citing *Lee v. Corregedore*, 925 P.2d 324, 329 (Haw. 1996)).

16. *See, e.g., State v. Walden*, 293 S.E.2d 780, 785–86 (N.C. 1982) (holding that the parent-child relationship confers a duty upon a parent to rescue a child when he or she is in peril); *People v. Rolon*, 160 Cal. App. 4th 1206, 1215–19 (2008).



or risk being held civilly and even criminally liable for the resulting harm.<sup>17</sup>

While American law does not impose a general duty to rescue on individuals, scholars have recognized that a so-called “rule of rescue” or “rescue imperative” in fact often motivates a collective rescue effort to save the lives of identified individuals in peril. This “rule” highlights our society’s willingness to devote extensive resources to rescue identifiable individuals, even if we are not collectively willing to devote resources to protect people generally from encountering a risk in the first place.<sup>18</sup> A contrast often drawn is between the money spent and lives risked to rescue trapped miners by a society unwilling to devote significant resources to enforce mine safety regulations meant to prevent accidents. The phenomenon occurs in health care settings as well, where the contrast is drawn between the sense of obligation to provide expensive, “last chance” therapies that might save an individual’s life, even when funding for preventive care may be limited.<sup>19</sup>

So do these two perspectives on rescue offer any fresh insights for incorporating disability concerns into how we think about marginally viable newborns? If we think about the provision of medical treatment to these infants as a species of rescue, does that affect how we view the obligation to provide treatment that the Baby Doe rules seem broadly to mandate?

Discussions often describe the “rule of rescue” as reflecting a commitment to saving individual life regardless of cost. In other words, under the rule of rescue, cost poses no limit to the rescue efforts.<sup>20</sup> By contrast, in the exceptional cases when a legal duty to rescue is recognized, its extent is limited by the concept of

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17. *Walden*, 293 S.E.2d at 786.

18. See David C. Hadom, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 J. AM. MED. ASSOC. 2218, 2218–19 (1991). Cf. M. Gregg Bloche, *The Invention of Health Law*, 91 CAL. L. REV. 247, 304–06 (2003) (discussing the tension between the rule of rescue and the “pursuit of population-wide health maximization”).

19. Cf. Leonard M. Fleck, *Last Chance Therapies: Can a Just and Caring Society Do Health Care Rationing When Life Itself Is at Stake?*, 2 YALE J. HEALTH POL’Y L. & ETHICS 255, 275–76 (2002).

20. *Id.* at 275.

reasonableness. On first glance, both these points might suggest that providing treatment to rescue extremely premature newborns would be uncontroversial and obligatory. After all, the rescue attempt poses no risk of physical danger to the parents (as intervening during a physical attack on the child might) and under the “rescue imperative” the cost of treatment is irrelevant.

What seems to blunt the rescue imperative, however, are concerns about the very real possibility of future disability if the rescue attempt produces a survivor. The risk of disabled rescuees does not generally make it into public discourse about whether to engage in rescue efforts, even though it seems that a rescuee—whether a miner trapped in a mine or a child who has fallen down a well—may sometimes suffer an accident-related disability after a successful rescue effort. We don’t say that we shouldn’t try to rescue the trapped miner because he may end up disabled if we do get him out. By contrast, the anticipation of future disability features centrally in discussions about whether medical interventions are mandatory, optional, or futile for marginally viable newborns.

This suggests that the “rule of rescue”—the moral imperative to try to save lives regardless of cost—is less robust in cases involving marginally viable newborns because the specter of a lifetime of disability blunts that imperative. If that is the case, then perhaps these cases resemble the original Baby Doe case more closely than I suggested earlier. Maybe the decisions in these cases really are primarily about disability, even though the decision makers cannot forecast with certainty the existence, nature, or extent of future disability. If so, perhaps the law is justified in prohibiting parental choices that—in blunt terms—would prefer to accept infant death over the possibility of a disabled child.

I am skeptical, though, that the dynamics in these cases can be reduced to such stark terms, and returning to the law’s treatment of the parental duty to rescue proves helpful here. Recall that while the law imposes a duty on parents to act to protect their children from harm, parents are legally required only to take reasonable steps to rescue their offspring. And the modifier of reasonableness requires

considering the full context of the parents' decisions. The dangers that attempted rescue poses for the parents are relevant, and logically so are the dangers that attempted rescue poses for the infant itself and for other children in the family as well. So, to illustrate the broader concept, the law might recognize some kind of duty on the part of a parent who can swim to dive into a lake to try to rescue her toddler who has fallen from a boat. It is less clear, though, that the parent would have a duty to dive in if doing so meant leaving another toddler alone on the boat. More controversially, beyond the risks of physical danger to self and others, one could argue that parents' duty to rescue might be limited by risks of significant emotional or financial harm attendant on the rescue attempt.

If we look at parents' duty to rescue an extremely premature newborn through this lens, the question of what "reasonable" rescue attempts the law should require looks more complex. Moreover, the reasonableness of rescue attempts would be decided on a case-by-case basis in light of all surrounding circumstances. The Baby Doe Rules, however, explicitly reject a contextualized, case-by-case approach to parents' treatment choices.<sup>21</sup> In that rejection they depart not only from the tort rules regarding rescue to which I am analogizing them; they also reject the principles of the very body of law in which they are embedded. And they do so in a way that may ultimately detract from the flourishing of people with disabilities.

### III. THE BABY DOE RULES AND CHILD WELFARE LAW

Often ignored in discussions of the Baby Doe Rules is the larger body of law of which they are a part, namely child welfare law. Specifically, the Rules require states to incorporate in their laws regarding child abuse and neglect provisions for responding to instances of medical neglect, defined to include non-treatment of disabled infants.<sup>22</sup> Like the Baby Doe Rules, child welfare laws more

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21. Cf. 42 U.S.C. § 5106i(b) (2006).

22. *Id.* § a(b)(2)(B).

generally set limits on parents' treatment of their children. And if parents act in ways that fall within a state's definition of child abuse or neglect, the state can intervene to protect the child.

In defining what parental conduct will be considered abusive or neglectful, however, states must legislate with an awareness of constitutional limits on their authority in this realm. Courts have recognized that the U.S. Constitution protects parents' rights to make important decisions regarding their children's upbringing, decisions that deal with schooling, religious training, medical care, and discipline, among other matters<sup>23</sup>. This constitutional right of "parental autonomy" is part of a broader right of family privacy or family integrity.<sup>24</sup> It is premised on an understanding that, because parents generally seek to act in the best interests of their children, they should enjoy substantial discretion in making decisions for their children, with the state interfering only when necessary to protect the child from a significant harm.<sup>25</sup>

This is the framework under which most cases of alleged medical neglect are handled. Parents generally have the authority to make decisions for their minor children, but if they fail or refuse to consent to a treatment needed to prevent their child's death or long-term disability, the state may intervene,<sup>26</sup> typically by taking custody of the child for the limited purpose of authorizing treatment. An example is when a court orders a life-saving blood transfusion for the child of parents whose religious beliefs proscribe transfusions.<sup>27</sup> In some senses, these are the "easy" cases: the treatment is a one-time intervention with known efficacy and few risks, so it is easy for the

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23. *Troxel v. Granville*, 530 U.S. 57, 65–66 (2000).

24. See generally David D. Meyer, *Lochner Redeemed: Family Privacy After Troxel and Carhart*, 48 UCLA L. REV. 1125 (2001).

25. Cf. *Parham v. J.R.*, 442 U.S. 584, 602, 604 (1979) (explaining and referring to the "traditional presumption that the parents act in the best interests of their child").

26. See generally Walter Wadlington, *Medical Decision Making for and by Children: Tensions between Parent, State, and Child*, 1994 U. ILL. L. REV. 311 (1994).

27. See, e.g., *Crouse Irving Mem'l Hosp., Inc. v. Paddock*, 485 N.Y.S.2d 443 (N.Y. Sup. Ct. 1985).

state to step in, protect the child, and then step back out of the picture.<sup>28</sup>

Courts seem less inclined to support the state's intervention into family privacy when the stakes are lower for the child or when the proposed treatment's benefits are less clear. For example, one case involved parents who placed their three-year-old child, who had been diagnosed with non-Hodgkins lymphoma, in the care of a Christian Science practitioner rather than consenting to the chemotherapy recommended by a doctor. Because the chemotherapy was estimated to have only a 40% chance of success and carried with it the risk of significant side effects, the court found an insufficient basis for the state to override the parents' right to determine their child's treatment, even though doctors predicted that the child would die without medical treatment.<sup>29</sup>

Cases like this one highlight the delicate balancing of the parents' constitutionally protected right to make medical decisions for their children against the state's interest in protecting a child from serious harm. It bears emphasis that the state's interventionist authority in child neglect proceedings is limited to protecting children from serious harm; the state cannot override parental judgment simply because it would reach a different conclusion about what is "best" for the child when more than one reasonable option is available.<sup>30</sup> So understood, child neglect laws set a floor of minimally acceptable behavior for parents but do not generally establish a bright line rule about what parents must provide their children. For better or worse, child welfare laws often contain standards that are vague and that leave discretion in the hands of child welfare social workers and

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28. I use quotation marks for "easy" because these cases are anything but. See generally Armand H. M. Antommaria, *Jehovah's Witnesses, Roman Catholicism, and Neo-Calvinism: Religion and State Intervention in Parental, Medical Decision Making*, 8 J. L. & FAM. STUD. 293 (2006) (arguing that courts and bioethicists de-rationalize and thus marginalize parents' religious beliefs).

29. *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991).

30. The Supreme Court made this point in a different context in *Troxel*, where the Court held unconstitutional a court's ordering of grandparents' visitation with their grandchildren over the objections of the children's mother. The Court observed that "the Due Process Clause does not permit a State to infringe on the fundamental right of parents to make child rearing decisions simply because a state judge believes a 'better' decision could be made." 530 U.S. at 72-73.

courts as to how the laws apply to the facts of a particular family's life.<sup>31</sup> In short, most child welfare laws look pretty different from the Baby Doe Rules, which characterize a broad group of non-treatment decisions as medical neglect unless they fall into one of three specific (though not precise) categories and provide neither parents nor child welfare workers with discretion.<sup>32</sup>

What the Baby Doe Rules do not recognize—despite their laudable efforts to guard against death-dealing medical decisions based on bias and stereotypes regarding the value and quality of life with a disability—is that they are in tension with a competing good: the value of parental autonomy in making decisions regarding their children and their families. This tension is magnified in cases involving marginally viable newborns because of the uncertainty and complexity their cases entail.

Value may flow from harmonizing our understanding of the Baby Doe Rules with the broader body of child welfare law, even from a disability perspective.<sup>33</sup> The law should intervene to protect infants whose parents make choices that fall below what society deems minimally acceptable. When there exists a range of acceptable choices, though—or what tort law might call reasonable choices,<sup>34</sup>

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31. When insufficiently bounded, this discretion generates criticism that social workers and courts exercise too much power to make judgments about the existence of abuse or neglect, judgments that may be infected by bias or false assumptions. See Marsha Garrison, *Child Welfare Decisionmaking: In Search of the Least Drastic Alternative*, 75 GEO. L.J. 1745, 1759 (1987).

32. Federal law recognizes as much, dictating that state child welfare authorities should use discretion in exercising authority in cases involving medical decisions, “[e]xcept with respect to the withholding of medically indicated treatments from disabled infants with life threatening conditions.” 42 U.S.C. § 5106i(b) (2006).

33. By making this point, I am not arguing that child welfare law is necessarily the optimal legal framework for addressing the limits on parental decision making regarding marginally viable or disabled newborns. My more limited point is that, to the extent that Congress has chosen this framework by enacting the Baby Doe Rules, it may be helpful to understand those Rules as existing within—and cohering with—the larger framework. For an argument that child neglect law is an inappropriate framework for addressing issues regarding parents’ medical decisions for their minor children, see Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1 (2000). Although she rejects the child neglect framework, Professor Rosato agrees that a problem with the Baby Doe Rules is that they give insufficient deference to parental decisions regarding newborns. See *id.* at 20–24.

34. Cf. Sayeed, *supra* note 8, at 609 (suggesting the value of “allowing reasonable considerations other than the mere chance at life to enter our ethical calculus”).

parents should be able to make decisions that accord with their own values and their understanding of what is best for their infant and their family.

This suggestion takes inspiration from the contribution by disability scholar Adrienne Asch to the discussion regarding the disability critique of prenatal testing for the purposes of permitting abortion when testing reveals the fetus will have a disability.<sup>35</sup> While she decries prenatal testing practices as “justified by mistaken assumptions about the quality of life of people with disabilities, and are demeaning to existing people with disabilities,”<sup>36</sup> Asch does not argue that pregnant women should be prevented from using prenatal testing. Instead, she advocates for changes in the rhetoric and practices surrounding prenatal testing in order to facilitate “true reproductive choice for women.”<sup>37</sup> She asserts that for true reproductive choice to exist, prospective parents need to hear from counselors about the full experience—both the satisfactions and challenges—of raising a child with the disability diagnosable by prenatal testing.<sup>38</sup>

Similarly, parents facing the birth of an extremely premature newborn could be provided not only with information about the various possible medical and developmental outcomes for an infant who receives maximal treatment but also information about the abilities retained by children having various impairments resulting from prematurity and whether and how those children can be participants in family and community life. Of course, because so much is uncertain at birth and in the earliest days of these infants’ lives, this task may be more challenging than in the case where a specific disability is diagnosed prenatally. Nonetheless, parents who

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35. By drawing this analogy, I do not mean to elide the moral and legal relevance of birth. But both prenatally and postnatally, the interest in preventing the termination of life on grounds of disability or potential disability exists in tension with other, competing interests. Prenatally, the competing interest is the woman’s interest in bodily integrity and reproductive autonomy; postnatally, it is the interest of parents in family privacy and parental autonomy.

36. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 318 (2003).

37. *Id.* at 317.

38. *Id.* at 334–35.

are provided not only with medical prognoses, but also with information about the social experience of older children who were born very prematurely, will be better able to make thoughtful and informed decisions about what is in the best interests of an infant and their family. An approach that seeks initially to support parents' ability to meet their parental obligations is also consistent (at least in theory) with the general approach of child welfare law.<sup>39</sup> Even under this approach, some choices will fall below the minimally acceptable threshold. For example, a refusal to provide life-saving surgery to correct a minor defect in an infant with Down syndrome might well be judged to be medical neglect justifying state intervention.<sup>40</sup>

I recognize that, from a disability perspective, adopting this approach is a risky proposition. The 2007 Policy Statement from the American Academy of Pediatrics on Non-initiation or Withdrawal of Intensive Care for High-Risk Newborns refers to "acceptable" quality of life and "unacceptable" quality of life for high-risk infants who survive after receiving intensive treatment without once acknowledging that these are loaded terms from a disability perspective.<sup>41</sup> There remains good reason to believe that some parents facing the bewildering and emotionally volatile situation presented by an extremely premature birth may be influenced by medical professionals who are biased or who entertain misconceptions about living with disability. Efforts to educate parents, neonatologists, nurses, and social workers regarding the joys and challenges

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39. Cf. David J. Herring, *Inclusion of the Reasonable Efforts Requirement in Termination of Parental Rights Statutes: Punishing the Child for the Failures of the State Child Welfare System*, 54 U. PITT. L. REV. 139, 202–06 (1992) (arguing that, while legislation forcing child welfare agencies to continue to make "reasonable efforts" to rehabilitate abusive or neglectful parents once the state has decided to seek termination of parental rights may cause harm to the child involved, agencies should be required to make reasonable efforts in support of parent-child reunification at earlier stages of child protection proceedings).

40. I should acknowledge that, in arguing for a broader realm of parental autonomy than that recognized by the Baby Doe Rules, this Essay does not confront the remaining, tough question of what parental choices involving newborns—whether they are born extremely prematurely or with disabilities like Down syndrome or spina bifida—should be deemed under this approach not to meet the minimally acceptable threshold and thus to constitute medical neglect.

41. Committee on Fetus and Newborn, *Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns*, 119 PEDIATRICS 401 (2007).



experienced by parents whose children were born very prematurely, as well as self-reports of those children's quality of life, will need to be ongoing. And even with education, some parents will decide not to resuscitate or provide continuing intensive care because of their concern about what a potential disability, with its attendant psychic, social, and financial costs, will mean for their family's lives. From a disability perspective, these decisions may be troubling.

To disable parents from exercising parental autonomy on the question of how to care for a marginally viable newborn, however, may carry costs of its own. It diminishes respect for family integrity and thus may itself be risky from the disability perspective. Family support and advocacy can play an invaluable role in the flourishing of persons with disabilities, both individually and collectively, and so parents should be empowered to play a lead in decision making throughout the process. To be sure, any assertion about the value of family support and advocacy for persons with disabilities must be accompanied by the recognition that children and adults with disabilities are more likely than their non-disabled counterparts to be the victims of family violence. Moreover, the constitutional presumption that parents will act in the best interests of their children may be particularly weak in the case of newborns, with whom parents have not enjoyed the same opportunities for the bonding that typically leads parents to seek their children's best interests. These points reinforce the importance of establishing some limits on parents' medical choices for extremely premature newborns<sup>42</sup> but do not, to my mind, make desirable the Baby Doe Rules' approach of defining medical neglect broadly to include most instances of non-aggressive treatment for imperiled newborns. For all these reasons, I would suggest that advocates for the rights and welfare of people with disabilities should consider the value of supporting the

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42. For example, John Robertson suggests that only parents acting on "full information about the child's conditions and prospects" are entitled to deference and that, therefore, "parents' directions not to resuscitate at birth should not be given effect until a medical assessment of the child's condition and prognosis justifying nontreatment has been made." Robertson, *supra* note 3, at 38.

educated—and limited—exercise of parental autonomy in cases involving marginally viable newborns.

