

March 2012

Playing God with Baby Doe: Quality of Life and Unpredictable Life Standards at the Start of Life

Anita Silvers

Follow this and additional works at: <https://readingroom.law.gsu.edu/gsulr>

 Part of the [Law Commons](#)

Recommended Citation

Anita Silvers, *Playing God with Baby Doe: Quality of Life and Unpredictable Life Standards at the Start of Life*, 25 GA. ST. U. L. REV. (2012).

Available at: <https://readingroom.law.gsu.edu/gsulr/vol25/iss4/12>

This Article is brought to you for free and open access by the Publications at Reading Room. It has been accepted for inclusion in Georgia State University Law Review by an authorized editor of Reading Room. For more information, please contact mbutler@gsu.edu.

PLAYING GOD WITH BABY DOE: QUALITY OF LIFE AND UNPREDICTABLE LIFE STANDARDS AT THE START OF LIFE

Anita Silvers* and Leslie Pickering Francis†

INTRODUCTION

Elevated by the mountain of literature focused on them during more than a quarter century,¹ the fourteen words at the core of the so-called Baby Doe regulations loom large. To be eligible for federal funding for their child abuse and child neglect prevention programs, states must put in place procedures to receive reports of and respond to “instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions” and to pursue certain remedies if needed to prevent such medical neglect of a disabled infant.² This language addresses denial of medically indicated treatment, which the Child Abuse Prevention and Treatment Act (CAPTA) defines as “medical neglect” under the

* Professor and Chair, Department of Philosophy, San Francisco State University.

† Alfred C. Emery Professor of Law and Distinguished Professor of Law and Philosophy, University of Utah.

1. For reference to the volume of literature, see Sadath Sayeed, *Baby Doe Redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A Cautionary Note on Normative Neonatal Practice*, 116 PEDIATRICS 578, 584 (2005).

2. 42 U.S.C. § 5106a(b)(2)(B) (2006). The procedures required by the statute are as follows:

(B) an assurance that the State has in place procedures for responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), procedures or programs, or both (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 services 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[.]

definition of “child abuse and neglect,”³ and directs states—not physicians or medical facilities—to address such denials. Yet these words have been accused of requiring medical professionals to impose horrendous suffering on innocent infants and of intruding repulsively into private family decisions.⁴

The usual way of reading directives for protection against the denial of services to disabled people is as prohibitions against disadvantageously differential treatment. Read in this way, the words of the Baby Doe regulations say that infants with disabilities must not lack access to medically indicated treatment that would be offered to infants who have similar medical needs but are free of the shadow of disability. Thus understood, the language is a good fit for the cases that originated the call for protection for Baby Doe, an appellation which has come to stand for infants with disabilities. But the fourteen words are not embedded in regulations that address discrimination based on “handicap.”

In the early 1980s, federal strategy to protect infants against denial of medical treatment on the basis of disability initially relied on regulatory action by the Department of Health and Human Services (DHHS) under section 504 of the Rehabilitation Act of 1973.⁵ At that time, the medical establishment fought⁶ adding such protection to extant statutory prohibitions of disability discrimination by successfully filing suit against the DHHS effort to create applicable regulations under Section 504. We will suggest, however, that this opposition may have been short-sighted.

Congress proved all too ready to embed protective language directly into a statute which left no vagueness about legislative intent to provide for categorical intervention into the medical treatment of children with disabilities. Changing the context of Baby Doe

3. 42 U.S.C. § 5106(g)(4) (2006).

4. E.g., Loretta Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 191 (2007).

5. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (2006).

6. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 647 (1986). In this case, the plaintiffs included the American Medical Association and the American Hospital Associations. The American Academy of Pediatrics filed an amicus curiae brief urging affirmation of the lower court's decision for the plaintiffs.

protection by turning from regulatory language under the Rehabilitation Act of 1973 (Rehab Act) to statutory language in the Child Abuse Prevention and Treatment Act (CAPTA) changed conceptualization of the problem from disability discrimination to child neglect. The prevailing value applicable to infants with disabilities under Section 504 was access to equitable treatment, while in contrast under CAPTA the prevailing value became access to life itself. Consequently, the shift from the context of the Rehab Act to the context of the CAPTA, with a concomitant alteration in the language prescribing the relevant right, amplified rather than reduced the rationalization of governmental intervention into medical decision making.⁷

We do not, however, subscribe to a strategy of amending out some or all of the famous fourteen words from the current DHHS regulatory text, as these words are taken directly from the statutory language of CAPTA. To change them therefore would need political action to impel Congress to amend CAPTA itself. Yet there is no reason to believe that the value of sanctity of life⁸ is less vigorously embraced today by part of the public, and less divisive, than in 1984 when the Baby Doe protection was amended into CAPTA.

We also contend that amending references to parental rights, the Best Interests Standard, or quality-of-life assessments into the regulations does nothing but beg the original question about protecting infants considered to be at risk for disability from being subjected to disability discrimination. We propose instead that the first step in rethinking the Baby Doe rules calls for revisiting their original focus: the prevention of disability discrimination in making decisions about medical treatment for infants. The elucidation we call

7. For objections to government intervention see, for example, Loretta M. Kopelman, Thomas G. Irons & Arthur E. Kopelman, *Neonatalogists Judge the "Baby Doe" Regulations*, 318 NEW ENG. J. MED. 677 (1988).

8. For a brief explanation of the "sanctity of life" standard, see Ascension Health, *Sanctity of Life*, <http://www.ascensionhealth.org/ethics/public/issues/sanctity.asp> (last visited March 29, 2009). For a pro-sanctity-of-life position, see Press Release, George W. Bush, Proclamation of Sanctity of Life Day (Jan. 16, 2009), available at <http://www.lifesitenews.com/ldn/2009/jan/09011601.html>. For a con-sanctity-of-life position, see Posting of Peter Suber, Dept. of Philosophy, Earlham College, *Against the Sanctity of Life* (1996), <http://www.earlham.edu/~peters/writing/sanctity.htm>.

for would clarify the entitlement of disabled infants, showing it to be neither a right to life nor a right to substantive special treatment, but instead a right to meaningful procedural equality in deciding whether to provide a disabled infant with access to life-saving and other medical treatment.

During the past quarter century of experience with regulation of medical treatment for disabled infants, concern about distortions the Baby Doe rules may induce in clinical decision-making has shifted from cases of infants born with explicit disabling conditions to cases of extremely premature or extremely low birth weight neonates whose functioning may or may not turn out to be impaired. Variances of these cases from those of the infants whose situations originally prompted protective governmental action further cloud understanding of the ethics of defending patients from disability discrimination. We therefore will suggest that developing decision procedure guidelines to distinguish—and deflect—judgments distorted by disability discrimination would be helpful in facilitating stable community practice.⁹

I. PROTECTING DISABLED INFANTS FROM DISABILITY DISCRIMINATION

Although controversial, letting neonates with disabilities die for want of medical treatment was practiced overtly in the United States during most of the last century (and previously).¹⁰ Disabled infants'

9. John Robertson points out that there is marked variation in the practice among various hospitals. For example, surveys of hospitals in New York and Chicago found completely different attitudes toward the treatment of marginal cases, with some treating aggressively and others not. John A. Robertson, *Extreme Prematurity and Parental Rights After Baby Doe*, 34 HASTINGS CENTER REP. 32, 35 (2004).

10. For example, in 1915 the *New York Times* reported the refusal of Dr. Harry Haiseldon to operate on a neonate with disabilities. This baby died after the doctor convinced the parents not to seek treatment by invoking a duty to defend ourselves and future generations against the mentally defective. New Society for Women at NYU, *Most Doctors Let a Defective Live*, N.Y. TIMES, Nov. 19, 1915, at 22. Haiseldon said this had been his practice for at least ten years. Some physicians supported, and other physicians condemned, him. Martin Pernick describes both the practice and the portrayal of infant euthanasia in the United States, including Haiseldon's advocacy of euthanasia to further the eugenics campaign. MARTIN S. PERNICK, *THE BLACK STORK: EUGENICS AND THE DEATH OF "DEFECTIVE" BABIES IN AMERICAN MEDICINE AND MOTION PICTURES SINCE 1915* 3–18 (Oxford University Press

deaths sometimes were hastened by withholding common medical treatment, or even hydration or nutrition. Letting neonates die because they had disabilities was advocated by eugenicists as progressive policy, benefiting community and country, as well as humankind.

The practice was fueled by claims that individuals with disabilities are burdensome to themselves, their families, and society in general.¹¹ While never the gold standard treatment for infants with disabilities, infanticide by means of medical neglect openly was an option made available by some physicians when a child with an actual or prospective serious disability was born.¹² Even in 1996, the Committee on Bioethics of the American Academy of Pediatrics characterized the status of the controversy as follows: “Our society has been divided about extending the life of some patients, especially newborns and older infants with severe disabilities.”¹³

During the term of office (1982–89) of Dr. Everett Koop as Surgeon General, the federal government confronted the practice of withholding the life-saving treatment accorded to other children from infants diagnosed with a disability. Two cases of neonates denied treatment on the basis of disability captured national attention. The child in the original case (in Indiana) died for want of treatment of a repairable tracheoesophageal fistula, a common congenital anomaly

1996). To offer another illustration, in 1984 John R. Britton, M.D. Ph.D., writing in the *Western Journal of Medicine*, uses a similar locution, referring to the type of child whom the DHHS regulations were aimed at protecting as “defective newborns.” John R. Britton, *Baby Doe Rulings—Review and Comment*, 140 W. J. MED. 303, 303 (1984). Britton estimates that about three percent of infants born in the United States fall into this category. *Id.* For further examples of physicians’ characterizing infants with disabilities as faulty or broken, see Raymond S. Duff & A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890, 892 (1973), J. Lorber, *Results of Treatment of Myelomeningocele*, 13 DEV. MED. & CHILD NEUROLOGY 279 (1971), and I. David Todres et al., *Pediatricians Attitudes Affecting Decision Making in Defective Newborns*, 60 PEDIATRICS 197 (1977).

11. For a thorough examination of the rationales used to argue that having a disabled child is unacceptably burdensome to the family, society and the child itself, pursued in the context of prenatal testing, see David Wasserman & Adrienne Asch, *The Uncertain Rationale for Prenatal Disability Testing*, 8 ETHICS J. AM. MED. ASS’N: VIRTUAL MENTOR 53 (2006).

12. Jenny Morris, *Tyrannies of Perfection*, NEW INTERNATIONALIST, July 1992, at 16.

13. Committee on Bioethics, *Ethics and the Care of Critically Ill Infants and Children*, 98 PEDIATRICS 149, 149 (1996).

for which surgery likely would have been offered had he not had trisomy 21 and therefore also a prognosis of mental retardation. Similarly, in the second case (in New York), surgical closure of the spinal canal of a child born with spina bifida, a common procedure in such cases, likely would have been offered had the infant not also had microcephaly, indicative of mental retardation. Based on his experience as a pediatric surgeon, Dr. Koop took a stance on the appropriate medical response in these cases and attempted to intervene in the latter one.¹⁴ As a result of his effort, DHHS officials attempted to find a role for federal intervention where disability discrimination threatened the life of a newborn child.

Before the passage of the Americans with Disabilities Act (ADA) in 1990, federal protection against disability discrimination was available mainly through Sections 503 and 504 of the Rehab Act.¹⁵ DHHS had been the lead agency in issuing regulations to implement the Rehab Act. As the federal government's initial policy response to the controversy occasioned by nationwide debate over the Indiana and New York cases, the Secretary of Health and Human Services invoked Section 504 (the section of the Rehab Act requiring nondiscriminatory access to programs and services), attempting to apply it to authorize stipulating that recipients of federal funds were prohibited from withholding nourishment or medically indicated treatment from a handicapped child solely because of the handicap. Subsequently, attempts to issue regulations to implement anti-discrimination protection for infants with disabilities were enjoined by the courts, at first because DHHS did not conduct the requisite public comment period and later, in a case that went to the Supreme Court, because various features appeared to inject the federal government into medical decision-making about individual patients, including providing the federal government with the powers to

14. See The C. Everett Koop Papers, National Library of Medicine, *Congenital Birth Defects and the Medical Rights of Children: The "Baby Doe" Controversy*, <http://profiles.nlm.nih.gov/QQ/Views/Exhibit/narrative/babydoe.html> (last visited Mar. 29, 2009).

15. 29 U.S.C. §§ 793, 794(a) (2006).

investigate medical records and to influence states' decisions about their priorities for resource allocation.¹⁶

Specifically, the contested regulations required hospitals "to post notices that because of"¹⁷ Section 504's protection, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) "should not be withheld from [handicapped] infants [solely] on the basis of their [present or anticipated] mental or physical impairments."¹⁸ Second, the regulations required "state child protective services agencies to [use their full authority] to prevent unlawful medical neglect of handicapped infants,"¹⁹ and where parents refuse consent for treatment, health care providers to report on a timely basis known or suspected instances of unlawful medical neglect of handicapped infants to the state agency. The agencies were then to conduct immediate on-site investigations and pursue timely legal action to compel the provision of necessary nourishment and medical treatment--and report such cases to DHHS. Additionally, the regulations required the federal government to access hospital medical records without full notice and take immediate legal action where responsible DHHS officials believed this necessary to protect the health or sustain the life of a handicapped individual.

In *Bowen v. American Hospital Association*, the United States Supreme Court found each of these requirements problematic.²⁰ One problem had to do with the mistargeting of regulation. The cases DHHS advanced as evidence of the need for regulation were aimed at governing hospitals but were not situations in which hospitals were authorized to treat. Rather, they were instances in which parents had not consented to treatment. Hospitals are not authorized to treat an infant without consent from a parent or from a properly appointed surrogate. Consequently, regardless of the role the infant's disability

16. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 627-36 (1986).

17. *Id.* at 610.

18. *Id.*

19. *Id.*

20. *Id.* at 626-47.

might have played in the parents' refusal of consent, the hospital's reason for withholding treatment was not the child's disability but the absence of consent. But DHHS's regulations were aimed at hospitals, parents being beyond the regulatory reach under Section 504.

Of course, hospitals (that is, hospitals' agents) make decisions about the medical treatment of minors. They are not completely passive instruments of parents but are expected to ask for substitution of the decision maker where doubt is cast upon the presumption that the parents are the best judges and most devoted seekers of their children's best interest. Section 504 (and the ADA) calls for equitable access to programs and services for nondisabled and disabled recipients. Thus, if a review of parental refusal to consent to treatment would be sought where the child is not disabled, protection against disability discrimination calls for seeking a similar review for children with similar medical conditions who are disabled. To illustrate, because surgery for infants with tracheoesophageal fistulas ordinarily is indicated and parental consent ordinarily is granted, and because therefore a hospital staff ordinarily would question whether parents who withhold consent are being guided by the child's best interest, equal treatment for a child with trisomy 21 who has a similar tracheoesophageal anomaly appears to call for a similar question to be raised about the parents' basis for decision.

And so the Indiana hospital acted in the original Baby Doe case. The delay in treatment resulting in that baby's death is attributable to a legal proceeding in which the lower court upheld the parents' right to decide.²¹ Consequently, the Supreme Court found DHHS unable to demonstrate that hospitals generally were at fault in cases of refusal to treat infants based on their having disabilities. The cases adduced by DHHS to show the need for federal intervention to rectify disability discrimination typically were ones in which hospitals went to court for permission to treat when faced with parents' refusal to

21. *In re the Treatment and Care of Infant Doe*, No. GU8204-004A (Ind. Cir. Ct., Apr. 12, 1982), *cert. denied sub nom.*, *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

consent to treatment. Consequently, DHHS had failed to show that hospitals appeared to be in violation of Section 504 by denying equal access to treatment on the basis of handicap.

A second reason addressed the remedial power DHHS had based on Section 504. Citing the majority opinion in *Alexander v. Choate*,²² the Court reiterated that Section 504's approach to disability discrimination is comparative, concerned about programs that offer less access or less meaningful access to people with disabilities than to other people. The Court reiterated that Section 504 does not confer any categorical entitlement to particular services and benefits.²³ Therefore, Section 504 could not authorize the actions mandated by the Secretary's rules.

On this reasoning, Section 504 cannot command state agencies to give investigation of cases of infants with disabilities priority over investigation of other kinds of child neglect or abuse. Nor can Section 504 warrant commanding hospitals to offer special resources or priority in the allocation of resources to children with disabilities. As the *Bowen* Court observed, "[t]he Rules effectively make medical neglect of handicapped newborns a state investigative priority, possibly forcing state agencies to shift scarce resources away from other enforcement activities—perhaps even from programs designed to protect handicapped children outside hospitals."²⁴ Subsequently, CAPTA eligibility language had just this effect. CAPTA statutory language succeeded in imposing priorities for resource allocation by the states, where Section 504 regulatory language could not, because CAPTA employed the indirect strategy of offering states child protection program funds in exchange for state commitments to establish a program to protect abused or neglected children, including infants and children experiencing medical neglect. Congress thus clearly signaled the intent to direct the states in the use of funds within the Congress's discretion, namely, federal funds.

22. 469 U.S. 287, 304 (1985).

23. *Bowen*, 476 U.S. at 640–41.

24. *Id.* at 639.

Parenthetically, the *Bowen* majority made no comment itself on what sort of standard should prevail in determining whether or not to treat a disabled infant. Nevertheless, because the DHHS regulatory endeavor that the *Bowen* Court rejected aimed at affecting medical decisions about individual patients, the Court's discussion has been subject to being misleadingly mined for guidance about how individual treatment decisions about disabled infants should proceed. It sometimes is contended, for example, that in overturning DHHS's claim to derive regulatory power over medical decision-making from Section 504, the *Bowen* Court also endorsed the Best Interests Standard. The *Bowen* Court's observation that "the degree of disability is relevant to making good life-sustaining medical treatment decisions"²⁵ has been cited in the literature about the Baby Doe regulations as evidence that, according to that Court, the value of the patient's best interest is in sharp opposition to the value or values embedded in the federal regulatory proposal the Court rejected.²⁶

In making this observation, however, the *Bowen* Court was not concerned to establish that disabled infants' best interests should be determinative of their treatment, but only that reference to an infant's disability was not necessarily discriminatory and might allowably be a factor in deliberating about medical treatment in the case. About the relevance or importance of the Best Interests Standard the majority of the *Bowen* Court was mute. Invocation of the Best Interests Standard appeared nowhere in the majority decision, but was introduced in a discursive footnote written by Justice White as part of his dissent.²⁷

Justice White's dissent supported the DHHS effort to apply Section 504 regulations to individual treatment decisions for disabled infants (although not every detail of the proposed rulemaking). In his view, hospitals and physicians typically benefited patients who lack competence to consent by advancing their best interest through advice to whoever will make the medical treatment decisions for

25. Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797, 798 (2005).

26. *Id.*

27. *Bowen*, 476 U.S. at 653 n.7.

them. Therefore, he reasoned, protection against disability discrimination might be needed to ensure that advising practice by hospitals and physicians equitably advanced the best interests of nondisabled and disabled patients alike.²⁸

Specifically, in his *Bowen* dissent Justice White adverted to the Best Interests Standard in addressing a court of appeals' analysis in a prior case, *United States v. University Hospital*.²⁹ In *University Hospital*, the Second Circuit concluded that Congress had not clearly intended Section 504 to apply to treatment decisions, and that therefore courts should not take that interpretive step absent a clear Congressional directive.³⁰ In his dissent, Justice White explicitly opposed this reasoning. He argued that hospitals provide benefits that ought to be offered equitably to nondisabled and disabled patients alike free of disability bias. He hypothesized that "one benefit provided by hospitals and doctors to patients who cannot make their own medical treatment decisions may be medical advice in those patients' best interest to those who must ultimately make the relevant medical treatment decisions."³¹ That is, he characterized application of the Best Interests Standard as integral to services hospitals and physicians provide, such service provision by federally funded entities being subject to Section 504. Thus Justice White's dissent portrayed the Best Interests Standard not as an alternative that excluded DHHS's attempt to regulate medical treatment in Baby Doe situations under Section 504, but rather as compatible with and sustaining those regulations.

II. FROM DISABILITY DISCRIMINATION TO CHILD ABUSE AND NEGLECT

While the challenge to the Secretary's invocation of Section 504 moved through the courts, advocates of protective federal

28. *Id.*

29. 729 F.2d 144 (1984).

30. *Id.* at 157.

31. *Bowen*, 476 U.S. at 653 n.7.

intervention turned their attention to Congress, which in 1984 amended the CAPTA to include the protections for infants with disabilities referenced at the beginning of this article.³² By doing so, the Congress created statutory protection for disabled infants independent of the Rehab Act, at least when states choose to apply for federal funding for their child abuse prevention programs. The thrust of the amendment is to classify withholding life-saving treatment from infants based on their being disabled as child abuse or neglect.

The difference between deriving the authority for federal protection of infants against disability discrimination from the Rehab Act, and deriving the authority from CAPTA, however, is a crucial one. Congress's express intention in enacting both the Rehab Act and the ADA was to move individuals with disabilities into the mainstream of civic and commercial life, and especially to ensure equal opportunity for them to be self-sufficient, productive citizens.³³ The Rehab Act and the ADA are directed at organizations with discriminatory practices, whether these are businesses, universities, or hospitals, not at individuals who discriminate against family members with disabilities.

In the initial Baby Doe cases (and in the eugenics practice which these cases reflect), the decision to treat the patients differently, on the basis of diagnoses of cognitive disability, from other infants with the same life-threatening but surgically repairable condition was a family decision. Although the parents may have been advised to withhold consent by some physicians, medical judgment was far from uniform. At bottom, whether withholding treatment was based on the

32. See *supra* note 2.

33. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 2(1), (3), (8) (emphasizing the importance of employment opportunities for people with disabilities); Americans with Disabilities Act, 42 U.S.C. § 12101(a)(1) (2009) (“[P]hysical or mental disabilities in no way diminish a person’s right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination.”).

prospect of having a disabled child, or had some other basis, was a question about parental judgment, not medical judgment.

Yet parents whose judgment is swayed by disability bias cannot for that reason be relied on to be governed by the best interest of their child. If their decision making is suffused with negative assessments about the lives of disabled people and the burden they place on family members, they will not be judging from the standpoint of the child's best interest. To view one's self with such negative self-assessment is not in anyone's interest, and surely not in the best interest of a disabled child.

And to cast the shadow of burdening the family over a disabled child subordinates the child's interests to those of other family members. The parental decision process is further strained because parents are charged with protecting the best interests of all their dependents, even when there may be severe conflicts of interests. When such considerations affect parental decision making, therefore, they compromise the presumption that parents are best positioned and most appropriately trusted to advance the best interest of the child.

The role of the physician is conflicted in such a context. Advice such as "the clinician should manage the situation while taking into account . . . what is in the best interests of both the infant and the mother"³⁴ is unhelpful, and even misleading, whenever the infant's and mother's interests do not perfectly match up. If both are considered to be patients, on what basis should physicians decide to which patient to assign priority? Except for triage, when one patient's prognosis for being benefited calls for aggressively speedy intervention while benefit for the other is achievable even when intervention is deferred, physicians are neither well placed nor well trained to adjudicate where the best interest of the infant patient is to be weighed against the best interest of its mother or entire family.

Further, when parents of a child with a disability who needs life-saving medical treatment diverge sharply from the decisions parents

34. K.N. Siva Subramanian, Aimee M. Barton, & Sepideh Montazami, *Extremely Low Birthweight Infant*, EMEDICINE, <http://emedicine.medscape.com/article/979717-overview> (last visited Mar. 29, 2009).

of similarly situated nondisabled children make, it is fair to wonder what has made the difference for them. Does their decision meet the Best Interests Standard, or have they failed to do so by embracing beliefs or assessments that controvert the child's interests? Mechanisms for addressing questions like these about when and how to defend infants against parental bias, maltreatment or neglect are put into play by CAPTA. The 1984 Baby Doe amendment to CAPTA thus cast disability bias as a cause of child abuse that can result in the death of a child.³⁵ What has not been widely noticed, however, is that CAPTA put a different set of regulations to protect infants with disabilities in place, despite continuing concerns from various quarters. The "Baby Doe" literature generally has treated the regulatory mandates proposed under Section 504, and the CAPTA statutory and regulatory mandates, similarly.³⁶ Yet even a brief comparison of the regulations for Section 504 of the Rehab Act, and the CAPTA rules, underlines the dissimilar purposes, presumptions

35. The abuse and neglect of children with disabilities is a familiar phenomenon. See, e.g., <http://blogs.bet.com/news/newsyoushouldknow/the-system-really-failed-disabled-teen/>; <http://chrisejasmemorial.blogspot.com/2007/05/death-puts-focus-on-cps.html>. Though individual cases usually are not labeled "disability discrimination," this is the account typically advanced to explain abuse of groups of disabled children. An example is the Willowbrook case, where institutionalized disabled children were left to wallow in each other's excrement despite some being diagnosed with hepatitis. See DAVID ROTHMAN & SHEILA ROTHMAN, *THE WILLOWBROOK WARS* (2005). Another example is the Nazi eugenics program that encouraged parents to send their disabled children to be killed to relieve their being burdens to their families, to the state, and to themselves. See MICHAEL BURLEIGH, *DEATH AND DELIVERANCE: "EUTHANASIA" IN GERMANY 1900-1943* 88-90 (1994).

36. See Kopelman, *supra* note 25. Kopelman claims that the criticisms neonatologists and other pediatricians made were "criticisms . . . akin to those of the courts in rejecting an earlier and similar set of Baby Doe regulations based on a Reagan Administration interpretation of civil rights law." *Id.* at 797-98. Were this the case (and we think it is not), however, the status of these complaints would diminish. In the referenced legal actions, the courts were concerned with the meaning and authority of Section 504 of the Rehabilitation Act, a complex matter about which pediatricians and neonatologists have little if any expertise. Specifically, Kopelman claims that the following criticisms were made by both the physicians she surveyed in 1988, and the Supreme Court in *Bowen* in 1986: (1) unnecessary to protect the rights of infants, (2) inadequate weighting of infant's suffering, and (3) interfering with parental rights. *Id.* at 798. But only (1) is a shared criticism. *Bowen* does not advert to the proposed regulations ignoring patients' suffering. Further, the point made in *Bowen* about the regulatory mandate to hospitals, relative to parental rights, is simply that hospitals cannot proceed to treat an infant if parents do not consent, absent a contrary directive from a state agency or court. The *Bowen* Court sums up its point this way: "Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children." *Bowen*, 476 U.S. at 646. Thus, the Court characterizes the proposed regulations for officiousness rather than for interference.

and practices of the regulations. These differences are characteristic of the disparate authorizing sources, that is, of the different aims of Section 504 and of CAPTA.

First, the regulations formulated under the Rehab Act, which proposed protection for disabled infants against disability discrimination, explicitly emphasized obtaining *beneficial* treatment.³⁷ They included a principle attributed to leading medical and prominent disability organizations, including the American Academy of Pediatrics and the National Association of Children's Hospitals and Related Institutions: "When medical care is clearly beneficial, it should always be provided."³⁸

In contrast, the CAPTA language aims at all instances of withholding medically indicated treatment for disabled infants with life-threatening conditions rather than withholding clearly beneficial treatment. The difference between "clearly beneficial" treatment and "most likely to be effective" treatment is a significant one. CAPTA defines medically indicated treatment as whatever is "most likely to be effective in ameliorating or correcting all such conditions."³⁹ By calling for whatever treatment most likely will be effective, regardless of whether the likelihood of benefit is low, the CAPTA prescription for treatment sets a lower bar for requiring treatment than did the proposed Rehab Act regulations, which called for clearly beneficial interventions if such existed, and not just for the most likely to be beneficial intervention, whatever the probability of benefit of that intervention happens to be.

Second, the regulations formulated under the Rehab Act proposed to bring neutral expert judgment to bear on whether withholding medical treatment from an infant constituted disability discrimination. As the Supreme Court observed in *Bowen* (citing its

37. 45 C.F.R. § 84.55(b)(3) (1984) (required notice describing federal law as requiring "beneficial treatment")

38. 45 C.F.R. § 84.55(f)(1)(ii)(B) (1984) (quoting the "Principles of Treatment of Disabled Infants" of the coalition of major medical and disability organizations, including the American Academy of Pediatrics, National Association of Children's Hospitals and Related Institutions, Association for Retarded Citizens, Down's Syndrome Congress, Spina Bifida Association, and others).

39. 42 U.S.C. § 5106g(6) (2006).

earlier decision in *Choate*⁴⁰, “Section 504 seeks to assure evenhanded treatment”⁴¹ and “Section 504 is essentially concerned only with discrimination in the relative treatment of handicapped and nonhandicapped persons and does not confer any absolute right to receive particular services or benefits under federally assisted programs.”⁴² In other words, protecting disabled infants from disability discrimination was a matter of reviewing community practice standards for medical treatment and addressing the provision of meaningful access to care offered under those standards for infants diagnosed with disabilities.

Health care providers were encouraged to create advisory Infant Care Review Committees (ICRCs) that would assist in the development of standards, policies, and procedures for providing treatment to “handicapped” infants, and in making decisions concerning medically beneficial treatment in specific cases.⁴³ From a perspective informed about the procedures for preventing disability discrimination under Section 504, the recommended formation of ICRCs seems far from threatening. During this period, across the nation institutions that received federal financial assistance, such as universities and municipalities, were forming advisory 504 compliance committees charged with assisting in the development of standards, policies, and procedures for offering equitable access to individuals with disabilities. These 504 advisory committees had much the same kind of representative membership as suggested for the ICRCs: staff members expert in the provision of the organization’s various services and individuals from disability organizations or groups.

An additional charge, not given to 504 advisory committees generally, was to be assigned to ICRCs—namely, decision making about beneficial treatment in specific cases. In such a circumstance, the ICRC was to appoint one of its members to act as advocate for the

40. *Alexander v. Choate*, 469 U.S. 287, 304 (1985).

41. *Bowen*, 476 U.S. at 640.

42. *Id.* at 641.

43. 45 C.F.R. § 84.55(f) (1984).

infant. But the ICRCs were merely advisory. They did not have *parens patriae* power, of course. They could recommend that the hospital board or administration go to the courts or to the state child protection agency, which do have such power. In this regard, ICRCs appear to have been conceived of as having a status similar to that accorded hospital ethics committees today. If treating physicians and an ICRC recommended such protective action and the parents disagreed, the regulations urged, the hospital should make every effort to prevent worsening of an infant's condition until the court or agency could resolve the matter.⁴⁴

Preventing the worsening of an infant's condition pending legal action to determine in whom the power should be vested to consent to medical treatment for the infant, as set forth by these regulations under the Rehab Act, differs notably from what CAPTA stipulates should be prevented. CAPTA does not call for a group of experts in medical treatment and in disability to consider referring cases for state decision making about the benefits of treatment. CAPTA's directive for state action is categorical: states are to prevent the withholding of treatments that might be effective in correcting or ameliorating a disabled infant's life threatening condition.⁴⁵ CAPTA's call for intervention thus is much more aggressive than that of the proposed Section 504 regulations.

Parenthetically, the Section 504 regulations also required that hospitals, as recipients of federal assistance funds, post either a notice stating that the hospital itself prohibited denying handicapped infants nourishment or medically beneficial treatment solely on the basis of their present or anticipated physical or mental impairments, or else that such inequitable provision of services, if on the basis of handicap, was prohibited by federal law.⁴⁶ These notices did invite reports of violation of federal anti-discrimination provisions, and

44. 45 C.F.C. § 84.55(f) (3)(ii)(F) (1984).

45. 42 U.S.C. § 5106b(2)(B) (2006).

46. The first version (Notice A) was for hospitals that explicitly agreed to comply with this interpretation of the Rehabilitation Act, while the second (Notice B)—simply a statement of the application of Section 504 protection to the medical services ordinarily provided infants, and containing no commitment from the hospital—was for hospitals that did not. 45 C.F.R. § 84.55(b)(3),(4) (1984).

promised protection against retaliation. But far from announcing the advent of a special federally backed campaign to spy on hospital delivery rooms, the posters fell within the federal directive that posters addressing compliance with statutory protection against discrimination on the basis of race, sex, religion and handicap be displayed by recipients of federal funds to inform organizations' employees of anti-discrimination law. They also referenced anti-retaliation protection for those who filed charges or otherwise complained about prohibited discrimination.

Third, because the regulations formulated to implement Section 504 of the Rehabilitation Act were proposed for protection against disability discrimination, they contextualized the delivery of medical services comparatively. They explicitly invoked the relevant context by quoting a sentiment expressed in the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: "[I]t is all too easy to undervalue the lives of handicapped infants; the Commission finds it is imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated."⁴⁷ The goal here was to achieve equitable valuation for infants with disabilities. Infants with disabilities deserve equally good treatment—as prompt and as strenuous medical interventions—as that accorded to similarly situated nondisabled infants. Here once again is the idea that community practice in regard to nondisabled infants was to be the reference point for nondiscriminatory treatment of disabled infants.

In contrast, the CAPTA directive is a categorical rather than a comparative one. Disabled infants (and, presumably, those who are expected to be disabled) with life-threatening conditions are to be provided with whatever the most promising life-saving intervention at the time may be, regardless of what the community standard of practice for infants without the prospect of disability may be. The prescription of these services appears defeasible only if the infant is

47. 45 C.F.R. § 84.55(f)(1)(ii)(C) (1984).

chronically and irreversibly comatose; or the treatment would do nothing more than prolong dying or would be ineffective in rescuing the child from death or otherwise futile in securing the infant's survival; or would be virtually—that is, for all practical purposes—futile and also inhumane.⁴⁸ To deny medical service that has even a small likelihood of effectiveness to a disabled infant with a life-threatening condition qualifies as abuse or neglect of a disabled infant with a life-threatening condition, but not of a nondisabled infant. In the case of the latter, abuse and neglect takes on more stringency, involving a parent's or caretaker's directly causing, either by acting or failing to act, death, serious physical or emotional harm, or an imminent risk of serious harm.

In sum, although federal officials sometimes appealed to the value of the sanctity of life in justifying federal intervention into Baby Doe cases, in their initial attempts to save Baby Does by applying federal anti-discrimination law to cases like those that came to national attention in the early 1980s there was only one circumstance in which Section 504 (and later the ADA) could have resulted in the categorical mandate called for by that value. For only if the lives of nondisabled infants are treated as unconditionally valuable and categorically worth saving, while the lives of disabled infants categorically are not, would disability discrimination law suffice to authorize categorical life-saving. CAPTA, on the other hand, is more supportive of categorical mandates because child abuse and neglect are not comparative notions. While harmfully depriving disabled children of services may be labeled discriminatory only if nondisabled children enjoy them, the deprivation may be labeled abusive even if no other children have access to the services.

III. DISABLED INFANTS AND TWO KINDS OF RIGHTS

Thus the comfortable reading of the words at the core of extant statutory (and regulatory) language regarding denial of medical

48. 45 C.F.R. § 1340.15(b)(2) (2009).

treatment to infants with disabilities is strained. The comfortable reading understands the mandate as protection against disability discrimination, to which infants with disabilities undeniably have been subjected in the past. But the context of CAPTA cannot help but give the words a very different aim, namely, to protect infants with disabilities directly against abuse and neglect regardless of the motivation for such disregard of and damage to them.

Rather than authorizing claims *against* inequality of medical treatment based on disability, and specifically against the withholding of necessary treatment based on disability, CAPTA assigns an entitlement *to* medical treatment based on disability.⁴⁹ That CAPTA mandates providing the prescribed life-saving treatment to infants with disabilities, and penalizes states that fail to do so, but is silent about the similar provision of life saving treatment to infants without disabilities, marks this allocation of medical resources as a special right based on disability. Thus, CAPTA's language establishes a special entitlement to certain services reserved for the disabled alone.

Although the Rehab Act is mainly a vehicle for providing special services to people with disabilities to enable them to participate in civic and commercial life, Section 504 is designed to secure equal access for them to programs that are supposed to serve everyone alike.⁵⁰ The Supreme Court's characterization of an acceptable goal under Section 504 is to give "meaningful access" to services and programs that nondisabled people enjoy, not to offer special benefits that place disabled people at an advantage.⁵¹ Consequently, Section 504 comes into play and calls for state or federal action only where

49. Amendments to Child Abuse Prevention and Treatment Act, Pub. L. No. 97-457, 97 Stat. 1749, § 121(3), 42 U.S.C. § 5102 (2009).

50. "Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive federal funds Section 504 provides: 'No otherwise qualified individual with a disability in the United States . . . 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 Federal financial assistance'" U.S. Dep't of Educ., Frequently Asked Questions About Section 504 and the Education of Students with Disabilities, <http://www.ed.gov/about/offices/list/ocr/504faq.html> (last visited Mar. 18, 2009).

51. See Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: "Meaningful Access" to Health Care for People with Disabilities*, 45 FORDHAM URB. L.J. 447, 447 (2008).

the disparate treatment of individuals with and without disabilities can be established and, further, disadvantageous differences in treatment can be accounted for by reference to the disabilities of those who suffer exclusion. The exclusionary actions need not be intentionally discriminatory. They can result from thoughtlessness, as when access to schools, hospitals, or federal offices is achievable only by climbing steps. Claiming that neglecting to build a level entrance to a health clinic was not meant to exclude wheelchair users, or testing students on subject matter available only in printed text form is not meant to disadvantage blind students, does not defend against charges of de facto discrimination by exclusion of disabled people from health care and educational services.

On the other hand, CAPTA's provisions generally are concerned with the deployment of various kinds of special services needed to protect children who are endangered in one or another way. Not surprisingly, therefore, CAPTA approaches its charge to protect infants with disabilities against exclusion from life-saving medical services as it does other threats to children's health, life, and well-being. CAPTA provides for states to develop mechanisms to get the needed services to the excluded children.⁵² The beneficiaries in this case are infants with disabilities, and within CAPTA's conceptual frame this group needs and deserves services whether or not the denial of services is based on disability, or results from something else. The first order of business when a child is neglected or abused is to negate the harm done, regardless of the reasons why the harm was incurred. This is another consequence of the categorical nature of CAPTA directives.

Under CAPTA, the prohibited act of withholding treatment includes refraining from offering whatever treatment the physician thinks will be most likely to be effective in ameliorating or correcting life-threatening conditions.⁵³ That is to say, if any treatment of a life-threatening condition is likely to be effective to some degree,

52. 42 U.S.C. § 5106a (2006).

53. *Id.* § b(2)(B) (2006).

however small the likelihood and however restricted the degree, the regulations seem to say that hospitals are required to provide it to infants with disabilities, regardless of what risks short of inhumane suffering are incurred. Further, among treatments likely to be effective, hospitals are required to offer those most likely to be effectively life-saving, regardless of other considerations such as side effects.

Hospitals are excused from offering treatments only if these will not be effective in securing survival, with some exceptions. Two categories of infants are denied the right to the most effective treatment for survival, those who in any case are going to die and those in irreversible coma who will never respond to other people or even to pain or light. In addition, physicians need not intervene (except for comfort care) when nothing but virtually futile treatment that occasions inhumane suffering is available.

IV. DISABILITY DISCRIMINATION AND CONSENT TO TREATMENT

CAPTA protection for infants with disabilities has been criticized for interfering with parents' rights to decide what is in the best interests of their child.⁵⁴ This objection begs the question, however, by failing to acknowledge that the impetus for developing protection for infants with disabilities arose from cases in which the parents' motivation appeared compromised, prompted by the prospect of disability to misjudge what was in the child's best interest, or to discount the child's interest for that reason. While parents have the right to shape their children, children are not their parents' property but are entrusted to them.⁵⁵ Both the regulations formulated under Section 504, and the CAPTA directives, aim at circumstances in which parents, either from ignorance or ill will, do not merit that trust.

54. See Kopelman, *supra* note 25, at 797.

55. See John Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV 426, 481 (1996).

Consideration of the fate of the original Baby Doe, as well as of the future open to him had he lived (a future his parents apparently were ignorant about, or else ignored), illuminates how disability bias operates and the importance of confronting it. This was a case in which the parents were influenced by the obstetrician who delivered the baby and also delivered a deeply gloomy prognosis about the quality of the child's future life. While their obstetrician advised the parents to withhold treatment, other physicians, including the family's doctor, as well as the hospital administration, disagreed.⁵⁶

As to which of these competing views would have survived the test of time, Kopelman writes in 2005 that "Baby Doe died in 1982; as more has been learned about trisomy 21, there has been greater agreement about the duty to provide life-saving treatments for infants with this condition."⁵⁷ Yet this way of putting the facts may be misread as suggesting that from 1982 to 2008, accurate judgment about the quality of life attainable by individuals with Down syndrome improved due to greater scientific understanding of the chromosomal anomaly, trisomy 21, which is correlated with Down syndrome. But this is not so.

No knowledge about the biology of trisomy 21 has caused the elevation of social status and expansion of opportunity that over the past quarter century has enriched the quality of life of people with Down syndrome now can enjoy in the United States. In earlier times, the inability of such individuals to read, to live independently, and to contribute as citizens, were claimed as incontrovertible fact. Today many citizens with Down syndrome engage in all these activities.

Instead, federal protection against disability discrimination during the past quarter century now offers more equitable opportunity to people with Down syndrome. We know that individuals with Down can learn to read only because those born after the middle of the 1970s were given full access to schooling where they were taught to

56. See The C. Everett Koop Papers, *supra* note 14.

57. Kopelman, *supra* note 25, at 798.

read.⁵⁸ Their generation was the earliest to be afforded an education equivalent to that offered to nondisabled children. Learning that people with trisomy 21 can read was not a matter of learning about trisomy 21 (no one has correlated any part of the triplicated chromosome with reading ability or its absence), but rather a matter of learning about (and eliminating) the effects of disability discrimination on educational opportunity. Ironically, had parents of children with trisomy 21 born in the early 1980s all made the same mistaken assessment of their children's potential as Baby Doe's parents did, greater knowledge about the capabilities of individuals with trisomy 21 likely would not have been achieved, nor would the greater agreement on the duty to save these children's lives that, according to Kopelman, now prevails.

The Section 504 regulatory approach was far more limited than the present course under CAPTA, for to contravene a parental decision to withhold treatment called for a showing that, in making that decision, disability bias held the parents in its sway. The Section 504 approach did not abandon consideration of the disabled infant's best interest but reasonably assumed that it is not in the best interest of any disabled individual to be subjected to decisions corrupted by disability bias. Nor did the Section 504 approach ban consideration of quality of life. But slanted quality-of-life measures, ones that stipulate lives lived with disability as necessarily being of lower quality than other kinds of lives,⁵⁹ incorporate a suspicious propensity for disability bias.

58. See U.S. DEP'T OF EDUC., OFFICE OF SPECIAL EDUCATION & REHABILITATIVE SERVS., HISTORY: TWENTY-FIVE YEARS OF PROGRESS IN EDUCATING CHILDREN WITH DISABILITIES THROUGH IDEA 1, available at <http://www.ed.gov/policy/speced/leg/idea/history.pdf>; see also NAT'L COUNCIL ON DISABILITY, BACK TO SCHOOL ON CIVIL RIGHTS: ADVANCING THE FEDERAL COMMITMENT TO LEAVE NO CHILD BEHIND (2000). Before 1974, more than a million disabled children were excluded from all schooling. *Id.* And another three and a half million were in segregated classes where they received little or no instruction. *Id.*

59. For an examination of disability bias in quality of life scales commonly used to judge the cost-effectiveness of medical treatment, see Anita Silvers, *Predicting Genetic Disability While Commodifying Health*, in QUALITY OF LIFE AND HUMAN DIFFERENCE 43, 43-66 (Jerome Bickenbach, Robert Wachbroit & David Wasserman eds., 2005).

Neither does CAPTA reject the Best Interests Standard. Sayeed quotes Kopelman to the effect that “federal law [does] not permit federally funded hospitals to . . . use quality-of-life considerations in deciding what interventions [are] futile or virtually futile.”⁶⁰ It is difficult to see how this can be, however. CAPTA explicitly applies what is known as the “pure objective” test to identify one of the circumstances in which failure to treat is not identified as neglect. As explicated by the New Jersey Supreme Court in the matter of Claire Conroy, where the question was whether to hasten the death of an elderly women at the end of life by withholding nutrition and hydration, the pure objective test is important where there is no trustworthy evidence about the patient’s wishes on which to base the decision.⁶¹ To warrant withdrawal of life-sustaining support under the pure objective test, the recurring, unavoidable and severe pain of the patient’s life with the treatment should be such that the effect of administering life-sustaining treatment would be “inhumane.”⁶² This standard for adults at the end of life is reiterated in the following CAPTA language:

The term ‘withholding medically indicated treatment’ means the failure to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) . . . except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician’s (or physicians’) reasonable medical judgment . . . the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.⁶³

60. Sayeed, *supra* note 1, at e585 (quoting Kopelman, *supra* note 25).

61. *In Re Conroy*, 486 A.2d 1209 (N.J. 1985).

62. Court and the End of Life—The Subjective, Limited-Objective, and Pure-Objective Tests, In the Matter of Claire C. Conroy, <http://www.libraryindex.com/pages/585/Court-End-Life-SUBJECTIVE-LIMITED-OBJECTIVE-PURE-OBJECTIVE-TESTS.html> (last visited Mar. 18, 2009).

63. 45 C.F.R. § 1340.15(b)(2) (2008).

To determine whether or not this condition holds, the physician is expected to make a reasonable medical judgment about the degree to which, as a result of the life-sustaining treatment, the infant will suffer recurring, unavoidable and severe pain, which surely is a quality-of-life judgment, propelled by a Best Interests Standard.

Merely invoking a Best Interests Standard begs the question, however, which is about who should make that judgment and what the criteria for determining best interest should be. Writing in *Pediatrics*, bioethicist Joel Frader expresses skepticism about this standard: “Best interests, similar to art or pornography, tends to mean whatever the beholder believes it to mean.”⁶⁴ We do not characterize the Best Interests Standard in the rampantly relativistic terms Frader chooses. Rather, we note that adjudicating conflicts between parents, physicians, and the state about whether living rather than dying is in the best interest of a disabled or potentially disabled infant requires careful reflection about how the specter of anticipated disability should be weighed.⁶⁵

We cannot say conclusively what would have transpired had the medical establishment’s response been less adverse and adversarial in regard to applying Section 504 of the Rehabilitation Act to giving disabled infants access to life-saving medical treatment, or if the plaintiffs in *Bowen* had constructed their legal strategy more narrowly, complaining about instances of federal intervention in actual cases that clearly exceeded the authorizing power of Section 504, rather than on the proclamation of any regulations at all under Section 504. On the one hand, under Section 504 hospitals would have had to review policies and practices to address disability discrimination, whereas under CAPTA both responsibility and penalties accrue to the states through their child protective services programs, rather than directly to hospitals or the health care

64. Joel Frader, *Baby Doe Rules: In Reply*, 116 PEDIATRICS 1602 (2005).

65. Another issue with quality of life scales is that people with disabilities often report a higher quality of life than is expected by nondisabled observers of their lives. For example, see Malcolm Kohler et al., *Quality of Life, Physical Disability, and Respiratory Impairment in Duchenne Muscular Dystrophy*, 172 AM. J. RESPIRATORY CRITICAL CARE MED. 1032, 1032 (2005).

professionals they employ. On the other hand, as we have pointed out, regardless of how CAPTA distances health care providers from responsibility for compliance, the CAPTA language creates a categorical and substantive obligation, whereas the obligation of hospitals and their employees to purge decision making of disability discrimination could not have been more than a comparative and conditional procedural one.

V. DIMINISHING DISABILITY DISCRIMINATION IN NEONATOLOGY

As to how onerous the obligation to review policies and practices under Section 504 might have been, in retrospect the burden surely was not as weighty as it might have seemed in prospect. Witness the progress, to which Kopelman attests, of agreement on the duty to provide medical treatment to save the lives of infants with trisomy 21. During the past quarter century, health care professionals have begun to commit to banishing bias from their reactions to disability. According to John Robertson, former Chair of the Ethics Committee of the American Society of Reproductive Medicine,⁶⁶ for example:

The norms of practice shifted: most physicians and hospitals were now more reluctant to defer automatically to parental wishes. Parents could no longer deny needed surgery to children with Down syndrome or spina bifida, as had occurred in the much publicized Baby Jane Doe case at Stony Brook Indeed, both the American Academy of Pediatrics and the American Medical Association, which had fought the Baby Doe rules, issued policies calling for equal treatment of newborns regardless of disability and low quality of life and recommended

66. See Univ. of Tex. at Austin, Faculty and Administration Profile of John A. Robertson, <http://www.utexas.edu/law/faculty/profile.php?id=jr43> (last visited Mar. 29, 2009).

the use of institutional ethics committees to review contested cases.⁶⁷

Undoubtedly, multiple factors contributed to this ethical evolution. Improved ability to ascertain early in pregnancy whether a child will have a tripled chromosome at 21 might be thought to have played a role because those prospective parents who most vehemently would reject a disabled infant now can terminate the pregnancy so no such child is born to them. Yet the extent to which the incidence of infants with trisomy 21 has decreased due to prenatal testing is not fully clear, nor has a continuing pattern of decline in their births been confirmed.⁶⁸ As argued in the preceding section, increased understanding of the biology of trisomy 21 does not appear to have played a role in improving parental and physician acceptance of such infants, while enlarged social opportunity for people with trisomy 21 very well may have done so.

Integral to their improved social acceptance and support is the diminution of hyperbolic warnings about the burdensome social cost of their survival. Consider the following erroneous prediction published twenty-five years ago by a physician who hyperbolically hypothesized that the lives of nondisabled infants would be threatened by regulation that helped disabled infants live:

Such expansion of health care supply to meet an increase in demand [from defective newborns] is likely to occur slowly, if at all, and in the interim other infants requiring intensive care may either be denied admission to an intensive care unit or receive compromised care by overextended staff. The institution of Baby

67. John Robertson, *supra* note 9, at 34; see also Am. Acad. of Pediatrics Bioethics Task Force & Consultants, *Guidelines for Infant Bioethics Committees*, 74 PEDIATRICS 306 (1984).

68. John Esterbrook, *Down Syndrome More Common: CDC Birth Defects Report Considered Most Reliable To Date*, CBS News, Jan. 6, 2006, <http://www.cbsnews.com/stories/2006/01/06/health/main1182961.shtml>.

Doe regulations could precipitate a health care shortage of crisis proportions⁶⁹

Published in 1984, this warning of potential danger posed by the very existence of disabled infants echoes the hyperbolic admonitions about social decline and degeneracy made earlier in the century in the name of eugenics by advocates of euthanizing neonates with disabilities. Whether made a hundred years ago or today, such exaggerated prognostication both expresses and further fuels disability bias by wrongly laying an existing or eventual social problem at disabled people's feet, portraying them as burdensome to themselves, their families, and society generally.⁷⁰

Hindsight makes clear that neither in 1915 nor in 1984 were such alarming auguries supported by facts and sound reasoning. Rather, they were exaggerations fueled by aversion to sharing society and its resources with disabled people. Yet, despite the extensive bioethical literature about the effects and effectiveness of current federal regulations protecting prospective Baby Does, forecasting the futures of infants threatened with disability, including their possible burdensomeness to society in general and their families in particular, has never been freed of the hyperbole that characterizes disability bias.

Hindsight into the baselessness of past prognostications of the social burdensomeness of disability does not seem to have led to nonbiased procedures for deliberating about medical treatment of anomalous infants today. Commentators agree that cases of extreme prematurity have replaced cases of congenital anomalies such as trisomy 21 or spina bifida in the center of debates about which infants should be treated aggressively.⁷¹ Diagnosed with trisomy 21, there

69. Britton, *supra* note 10, at 306.

70. At the Nuremberg Trials, the physician who administered the Nazi program for euthanizing disabled people claimed explicitly that the standard of practice among medical professionals in all nations understood disabled people to be burdensome to themselves, their families and society in general. See Morris, *supra* note 12, at 16–17.

71. See, e.g., Robertson, *supra* note 9, at 34.

was no doubt that the original Baby Doe was disabled.⁷² In contrast, there is much more variation in outcomes for extreme prematurity: an extremely premature or very low birthweight or extremely low birthweight infant may later be diagnosed with a disability, but the nature and degree of impairment, if any, may not be evident in the first hours, days or weeks of life. The conditions of these infants therefore should be less likely to lend themselves to incautiously pessimistic prognostications. Yet the opposite response to them seems to prevail, making them as subject to dire predictions about the value of their prospective lives as infants with traditional disabling conditions have been.

About 1.4% of U.S. babies are born with birth weights of less than 1,500 grams. Various reports show the incidence of cerebral palsy (CP) among this group as 7-10% of very low birth weight infants (1,250 to 1,500 grams) and 7-17% of extremely low birthweight infants (under 1,250 grams), with the effects of CP ranging from relatively mild below the knee lameness to quadriplegia. Different studies set the risk of major neurosensory or neurological disability at from 12% to 50% for extreme prematurity. About 40% of extremely low birth weight children have IQs of less than seventy, an outcome correlated as well with severe intraventricular hemorrhage. Various antenatal events may stimulate fetal inflammatory responses that can injure immature cerebral white matter. Further, there is evidence that certain therapeutic interventions are associated with adverse neurodevelopmental outcomes. Studies also suggest that extremely premature infants with parenting, social and environmental risk factors are at increased risk for neurodevelopmental disabilities.⁷³

Although extremely low birthweight babies sometimes suffer from conditions that may lead to disability (for example, patent ductus arteriosus, retinopathy of prematurity, respiratory distress syndrome)

72. See The C. Everett Koop Papers, *supra* note 14.

73. TUFTS NEW ENG. MED. CENTER EVIDENCE-BASED PRACTICE CENTER, AGENCY FOR HEALTHCARE RES. & QUALITY, SUMMARY—CRITERIA FOR DETERMINING DISABILITY IN INFANTS AND CHILDREN: LOW BIRTH WEIGHT 3 (2002), available at <http://www.ahrq.gov/clinic/epcsums/lbwdissum.htm>.

or worse, these conditions are not themselves diagnoses of disability, or disabling anomalies, as trisomy 21 and spina bifida (except sometimes for a low or incomplete lesion) are. These conditions may or may not lead to disability, as may other medical problems associated with prematurity. Thus neither extreme prematurity nor extremely low birthweight, nor diagnoses associated with prematurity such as those mentioned above, actually qualify infants as “disabled” and thereby as categorically entitled to the life-saving services designated by CAPTA’s famous fourteen words.⁷⁴ Although it was evident that the original Baby Doe would prove to be cognitively impaired, it was (and still is) impossible to tell at birth whether the disability of a baby with trisomy 21 will be mild, moderate or severe. Predictions about the future abilities and disabilities of premature neonates are even more tenuous, especially as the occasioning of disabling impairments in them is not very well understood.

For example, there is uncertainty about whether the rate of cerebral palsy is stable for extremely premature or extremely low birth weight neonates, or whether it has been or can be decreased. A study in Northern Alberta followed infants between 500 to 1,249 grams live born from 1974 to 2003. 48% survived past age two, and of these 14.2% had mild to severe cerebral palsy. The number of cases of cerebral palsy rose as the percentage of survivors did until the years 1992–1994, and then decreased although survival rates continued to increase.⁷⁵ These are a very few of many conflicting reports about rates of disability among extremely premature, very low birthweight, and extremely low birthweight children.⁷⁶

74. Mary Crossley makes a similar point in her article in this issue. Mary Crossley, *Rescuing Baby Doe*, 25 GA. ST. L. REV. 1402 (2009).

75. Charlene Robertson, Man-Joe Watt & Yutaka Yasui, *Changes in the Prevalence of Cerebral Palsy for Children Born Very Prematurely Within a Population-Based Program Over 30 Years*, 297 J. AM. MED. ASS’N 2733, 2734 (2007).

76. Some studies and reports have found that the proportion of disabilities among this group of children has declined, while others have found that it has remained steady. See F. Lefebvre, *Outcome of Very Low Birthweight Infants in a Sub-Arctic Population*, 87 ACTA PAEDIATRICA 360, 360 (1998). For examples of studies that claim that the incidence of disability has remained steady, see Subramanian et al., *supra* note 34, and Gabriel J. Escobar, Benjamin Littenberg, & Diana B. Petitti, *Outcome Among Surviving Very Low Birthrate Infants*, 66 ARCHIVES OF DISEASE IN CHILDHOOD 204, 204 (1991) (claiming that the incidence of disability among very low birthweight children is 25 percent).

What is evident is the imprecision of invoking such statistics to forecast the quality of life of an individual child. A telling illustration of the tenuousness of such predictions is the current commentary concerning the cost of supporting the Los Angeles octuplets. For example, a well-known physician told television audiences that “[t]here is a relatively small chance that all eight of th[e]se kids will grow up to be normal adults. There’s going to be a chance of cerebral palsy, developmental delays[—]emotionally, mentally[—]vision problems, hearing problems.”⁷⁷ In the context of questions about their mother’s relying on public aid, such a comment conjures up visions of extraordinary demands on the welfare system, imposed by the presence of (possibly eight more) disabled individuals brought into the world.

Yet the precise probability of the manifestation of any of this list of conditions is unclear, nor is there a perspicacious basis for the claim that they have just a relatively small chance of growing up nondisabled. Notice that this is a very different claim than that they have a higher than typical risk of not doing so. For one thing, as octuplets their risk of disability presumably should be calculated with some reference to the outcomes of other octuplet live births. The last octuplet birth in the United States was ten years ago, and the seven surviving ten-year-olds are not disabled.⁷⁸ Further, almost all birth weights of the recently born octuplets are greater than the birth weight of the largest octuplet of ten years ago, and unlike their predecessors all were weaned off ventilators soon after birth. As extremely low birth weight and ventilator dependence in neonates are correlated with ensuing disability, statistically speaking the new octuplets are much less likely than their nondisabled ten-year-old predecessors to have disabilities. Not to mention the improvements in medical care for preterm neonates that have been achieved in the past

77. Discussion of Nadya Suleman’s Octuplets, http://www.oprah.com/slideshow/oprahshow/20090219_tows_octupletgrandpa/10 (last visited Apr. 3, 2009) (quoting Dr. Mehmet Oz).

78. Jennifer Leary, *Famous Octuplets Reach Milestone*, HOUS. CHRON., Dec. 20, 2008, at B4. The eighth of the Houston octuplets weighed just a little more than half a pound and died about a week after birth. *Id.*

ten years. Yet even physicians who should understand these probabilities seem to issue hyperbolic warnings about the prospective burden of disability such infants may impose on society, nor are there professional guidelines or a standard of community practice to restrain them from doing so.

CONCLUSION

Current calls to rethink the complacency which the medical establishment accorded to the policy on life-saving treatment for disabled infants that Congress amended into CAPTA in 1984 often make it seem as if time has righted the wrongs that prompted attempts to create protective regulation a quarter century ago. Disability bias appears to have been rendered invisible to many of those who now write about discarding the Baby Doe rules. Contributors to the recent revival of concern about the impact of the rules typically do not discuss the role of disability bias in the events that prompted the rules' adoption, nor do they address alternatives to induce medical professionals themselves to protect against it.⁷⁹ Yet it would be a mistake to think that disability discrimination has been eradicated or rendered harmless just because the language of CAPTA has shifted attention from the comparative right to equality of meaningful access to medical treatment to the categorical right to life.

As we have pointed out, hyperbolic prognostication of social burdensomeness become stigmata that traditionally have marked the targets of disability discrimination. Yet such claims seem to surface almost as readily in current deliberations about premature infants as in past deliberations about whether infants with trisomy 21 or spina bifida should live. Statements such as "poor outcomes . . . are common,"⁸⁰ or "survival may come with varied disabilities"⁸¹ or

79. See, e.g., Frader, *supra* note 64, at 1601–02; Kopelman, *supra* note 25; Frank Clark, Letter, *Baby Doe Rules: In Reply*, 116 PEDIATRICS 1601 (2005). Sayeed believes that "public-policy concerns regarding discrimination against future disabled individuals . . . could [easily] tip a court . . ." but this observation suggests that turning to the courts, rather than relying on medical professionals, is the route to protection against disability bias. Sayeed, *supra* note 1, at e583e.

80. Escobar at al., *supra* note 76, at 204.

“preterm infants . . . have a higher incidence of cerebral palsy and mental retardation than the rest of the population,”⁸² are so vague as to be more alarming than informative. Ignoring the phenomenon of alarmingly nebulous prognostication thus obfuscates an old problem that has arisen in a new form. Nor is there a reasonably restrained and respectful gold standard of clarity for advising about the contingency of disability, without hyperbole or exaggerated foreboding, for such infants.

We do not, of course, suppose that all alarms about health risks for neonates, including those with extreme prematurity or extremely low birth weights, are hyperbolic nor do we identify references to health risks generally with disability discrimination. Nor do we think that the practice of hyperbolic prognostication exhausts the manifestation of disability discrimination in medicine. Still, a clear historical record exists to show how vagueness about risk encourages exaggerating the burdensomeness of living with disability and sometimes curtails disabled people’s access to social opportunity and even to life itself. Yet the ethics of incertitude in medical prognosis, applying statistics drawn from research on cohorts to make prognoses about individual cases, is not very well researched.

Compared to the volume of bioethics literature criticizing supposedly unfortunate influences of the Baby Doe rules on physicians’ freedom to judge, not a lot has been written about how, in doing so, physicians should deal with uncertainty about prospects of disability in Baby Doe cases without opening the door to the deleterious effects of disability discrimination.⁸³ Model guidelines for avoiding disability discrimination in deliberating about courses of medical intervention for extremely low birth weight or extremely premature infants thus would be helpful in facilitating ethical decision making. But the feasibility and success of such a program

81. Subramanian et al., *supra* note 34.

82. *Id.*

83. For exceptions to the drought of commentary, see D. Wilkinson, *Is It in the Best Interests of an Intellectually Disabled Infant to Die?*, 32 J. MED. ETHICS 454, 457 (2006), and Teresa Savage & Karen Kavanaugh, *Resuscitation of the Extremely Preterm Infant: A Perspective from the Social Model of Disability*, 4 NEWBORN & INFANT NURSING REV. 114, 118 (2004).

2009]

PLAYING GOD WITH BABY DOE

1095

depends on how far physicians and hospitals have progressed since the initial Baby Doe cases in distancing themselves from disability discrimination. In this regard, too, the prognosis for future Baby Does is obscure.

