United States Commission on Civil Rights – Medical Discrimination against Children with Disabilities: An Abstract

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ADMINISTRATIVE COMMENT

UNITED STATES COMMISSION ON CIVIL RIGHTS — MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES: AN ABSTRACT

FUNDAMENTAL RIGHTS: AN INTRODUCTION TO MEDICAL DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES

The United States Commission on Civil Rights recently released a report which examines the practice of withholding lifesaving medical treatment from critically ill newborns. The report is the result of two Commission hearings, as well as staff research and contributions from outside experts. The report attempts "to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government." Findings of the report suggest that "decisions to withhold medically indicated treatment from infants born with disabilities continue to occur despite being prohibited by the Child Abuse Amendments of 1984."

The report provides a comprehensive review of this controversial and complex issue. Among the topics discussed in the report are: 1) the phys-
cian-parent relationship and its effect on decisionmaking; 2) quality of life assessments; 3) the Rehabilitation Act of 1973; 4) the Child Abuse Amendments of 1984; 5) constitutional issues; 6) Child Protection Services and the enforcement of the Child Abuse Amendments; 7) role of infant care review committees. The report concludes with several recommendations, including one urging the executive branch to consider the resumption of investigations into allegations of medical nontreatment and a concomitant enforcement of section 504 of the Rehabilitation Act. This Administrative Note is not a replacement for reading the detailed report itself, but is merely a review of its major findings, recommendations, and political viewpoints.

Federal attention became focused on this issue as a result of the "Baby Doe" case. On April 9, 1982, an infant afflicted with Down syndrome was born in a Bloomington, Indiana hospital. The child, who became known as Baby Doe, suffered from a blockage of the esophagus and needed corrective surgery so food would reach the stomach. The parents consulted with their obstetrician, who emphasized that even if the child survived surgery, a "normal" life would not be possible. The obstetrician advised the parents that they could choose not to act, in which case, the child would probably only survive a few days. After the consultation, Baby Doe's parents refused to consent to the surgery and the infant died six days later.

The Baby Doe case highlights a common, but frightening, attitude that is prevalent in our society. Traditionally, disabled individuals have been viewed as a menace, incapable of self-support, and a burden on society. Armed with this mindset, one noted authority on child abuse and neglect urges that a state should intervene to save the life of a child only when the child would have a "life worth living or a life of relatively normal healthy

7. Id. at 2-3, 26-31.
8. Id. at 3-4, 32-47.
9. Id. at 5-7, 61-77.
10. Id. at 7-8, 79-82.
11. Id. at 8, 93-101.
12. Id. at 8-9, 111-17.
13. Id. at 9-10, 118-29.
14. Id. at 151.
15. Id. at 21-22 and accompanying notes.
16. Id. at 21.
17. Id. at 21 n.17.
18. Id. at 21.
19. Id.
20. Id. at 21-22.
21. Id. at 23-25.
growth."\textsuperscript{22} The report makes clear that the complex issue of whether or not to treat disabled children must be approached "with sensitivity to the effect of this background of dehumanizing attitudes concerning people with disabilities."\textsuperscript{23}

**Physician-Parent Relationships and Treatment/Nontreatment Decisionmaking**

The birth of a disabled infant is a strenuous and emotional time for parents. In shock and ill-informed about their child's disability, parents turn to their physician(s) to determine what treatment, if any, should be provided for their child.\textsuperscript{24} The influence of medical personnel is great, with physicians typically taking the first step by approaching parents with a recommendation regarding treatment.\textsuperscript{25}

If parents have had no interaction with other disabled persons, their thoughts and emotions might reflect the "stigmatization of people with disabilities to which they have been persuasively and sometimes subconsciously subjected for most of their lives."\textsuperscript{26} This preconceived notion of their child's condition may not be grounded in fact. Moreover, there is often misinformation among physicians regarding advances and alternatives for children with disabilities and unclear communication between physicians and parents.\textsuperscript{27} These problems raise the question of whether a parent's decision not

\textsuperscript{22} Id. at 25 n.7.

\textsuperscript{23} Id. at 25.

\textsuperscript{24} Id. at 26-27.

\textsuperscript{25} Id. at 27-30. "There seems to be near unanimity, from health care personnel who support as well as those who oppose denial of treatment, that in all but a handful of cases the manner and content of the medical provider's presentation of the issue will be decisive in determining the parental 'decision.'" \textit{Id.} at 29.

\textsuperscript{26} Id. at 32-33.

\textsuperscript{27} Id. at 30-31. For example, one special education professor testified that health care personnel and bioethicists do not have the latest information about progress made in rehabilitative services. "Regrettably, reports of the advances in special education, habilitation and rehabilitation have not yet received wide dissemination in either the popular media or the literature of other professions. . . ." \textit{Id.} at 30 (quoting \textit{Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 97} (1986)(vol.II) (testimony of Professor Ruth Luckasson, Department of Special Education, University of New Mexico).

According to the Task Force on Technology-Dependent Children, this lack of communication may continue if the child survives.

Professionals have traditionally controlled the delivery of services with little or no input from the parents. In this environment, parents have often felt disenfranchised and incapable of influencing their child's care. . . . Some parents are influencing how, when and where services are provided. . . . For other parents, relationships with professionals may be less than supportive, as these parents often lack the confidence to assume a prominent role and/or may be excluded from care decisions by professionals. This lack of parental involvement in the decision-making process may result
to allow treatment is based on informed consent.\textsuperscript{28}

Based on the evidence presented, the Commission concludes that treatment decisions are influenced by information given to the parents by their doctors. The Commission goes further to state that "doctors are often the prime movers in denying the treatment."\textsuperscript{29}

\textbf{ROLE OF QUALITY OF LIFE ASSESSMENTS IN DENIAL OF MEDICAL TREATMENT}

The justification often given for denying disabled children treatment is that "it is in the children's best interests to spare them a life of unacceptably poor quality."\textsuperscript{30} This assumption does not appear to be shared by disabled individuals.\textsuperscript{31} The report suggests that society's discrimination against disabled individuals is more harmful to them than their physical limitations,\textsuperscript{32} supported by extensive testimony that disabled persons are capable of leading full and rich lives when barriers to their full integration are removed.\textsuperscript{33}

The past two decades have seen tremendous gains in the quality of life possi-
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Medical discrimination, the improved special education programs developed subsequent to the passage of major legislation, increased support for parents, technological advances, and the deinstitutionalization and mainstreaming of individuals into the community have all greatly enhanced the quality of life possible for disabled individuals.

The ability of disabled individuals to lead full lives is evidence that the bleak prognosis made at the time of birth is often proven false. The Commission cites several examples, most notably the case of Baby Jane Doe in New York. Baby Jane Doe was born with spina bifida and fluid on her abnormally small brain, and her parents were given little hope by doctors. While the parents' original decision to forego treatment was upheld in court, they changed their minds and allowed surgery. As of 1987, Baby Jane, now known as Keri-Lynn, was talking, using a wheelchair, and going to school.

Addressing the question of why many negative prognoses never materialize, the Commission states that:

Considerable evidence points to a significant tendency among health care providers to underestimate the capacities of children with disabilities and erroneously to convey unduly pessimistic prognoses to parents about their projected quality of life.

Studies cited by the Commission reveal a tendency on the part of physicians to give negative prognoses. One explanation offered is that doctors usually

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at 229. In addition, thirty percent of the respondents addressed "[a] loss of confidence in the medical profession" and nine percent recognized "inaccurate medical prediction." Id. at 230.


35. MEDICAL DISCRIMINATION, supra note 2, at 34-35.

36. Id. at 39-42. Reports have also indicated that "individuals with Down syndrome can indeed learn to read, to communicate, and to interact positively with others, activities that contribute to the development of independence." Id. at 37. With early intervention and special education, a child with Down syndrome can become, as an adult, a successful employee. Id. at 37-39.

37. Id. at 39-41.

38. Id. One doctor stated that "the baby is so severely deformed that there is nothing that can be done." Id. (quoting Dr. Henry Jennison, Director of the American Academy of Pediatrics, in Pro and Con[.] Should Uncle Sam Protect Handicapped Babies? U.S. NEWS & WORLD REP., Jan. 16, 1984, at 63, 64). Another doctor who testified in court, said that the "malformations" of Baby Jane Doe were such that she "is not likely to ever achieve any meaningful interaction with her environment, nor ever achieve any interpersonal relationships." Id. (quoting Dr. George Newman, in Baringer, Meese Approved Intervention in Baby Case, Wash. Post, Nov. 16, 1983, at A16).

39. MEDICAL DISCRIMINATION, supra note 2, at 40.

40. Id.

41. Id. at 43.

42. Id. at 43-45. One study revealed that pediatricians perceived mentally retarded individuals to be "devoid of most human capabilities, including the ability to sustain friendships;
see these children when they are ill and in need of attention; not when they are at their best. On the other hand, "[t]hose who have contact with people with disabilities on a more regular basis, when they are not in an immediate medical crisis—such as their teachers, coworkers, and family members—tend to have much more positive views of their abilities."

How appropriate is the use of the quality of life assessments in making life-saving treatment decisions? The scope of quality of life assessments is not limited merely to the quality of life for the disabled individual, but is also imputed to the person's family or society in general. "In other words, the burden the person creates for others outweighs the benefits they experience because she or he exists."

In determining the appropriateness of quality of life assessments, the Commission makes an important distinction between "technical medical judgments" regarding the likelihood of a treatment's success and judgments about whether or not the treatment should be used on a particular person. "The first sort of judgment is one that is uniquely medical in nature. The second sort of judgment is not, properly speaking, a 'medical' one. It is a social judgment about the value or desirability of particular people's lives."

Advocates of disability rights view the consideration of burdens placed on family or society by the disabled person as discrimination. The Department of Health and Human Services (HHS), in its implementation of the Child Abuse Amendments of 1984, holds the view that the consideration of subjective statements regarding the quality of life are impermissible for the pediatricians believed they were unlikely to work in any setting or reside outside an institutional setting." Id. at 43 (quoting Wolraich, Siperstein & O'Keefe, Pediatricians' Perceptions of Mentally Retarded Individuals, 80 PEDIATRICS 643, 647 (1987)).

43. Id. at 44.
44. Id.
45. Id. at 45. Canadian commentators gathered data on such quality of life assessments. Certain doctors try to appraise the effect which addition of a deformed child would have on the particular family. These doctors know that parents of handicapped children experience high divorce rates; feel much guilt; and express mutual recriminations. Strain is produced on the family by uncertainty and long periods of hospitalization. Other children frequently react adversely. A neonatologist pointed out that it is senseless to ruin five people's lives in order to save a life of questionable quality. . . . Social welfare considerations are important. A minority of doctors surveyed have a heightened awareness of the economic burdens handicapped children impose on society. This perception creates a greater overall resistance to treatment. WITHHOLDING TREATMENT, supra note 32, at 22-23 (footnotes omitted).
46. MEDICAL DISCRIMINATION, supra note 2, at 45. Testimony cited in the Commission's report suggested that the initial negative attitude of parents toward their disabled child changes as interaction increases. Id. at 45-46.
47. Id. at 46.
48. Id.
purpose of making life-saving treatment decisions.\textsuperscript{49} The Commission concludes that quality of life arguments "are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities."\textsuperscript{50} Therefore, commitment to civil rights includes a commitment to the people with disabilities and their families, not by elimination, but through support, acceptance, and "defending their rights to accessible and integrated transportation, housing, education, health care, and employment."\textsuperscript{51}

THE ROLE OF ECONOMIC CONSIDERATIONS IN DENIALS OF MEDICAL TREATMENT

As stated previously, many view the costs associated with caring for the disabled as too great to be borne by society.\textsuperscript{52} Since society has limited resources, why not spend the money on "normal" children?\textsuperscript{53} Often, the cost of care is factored into the treatment decision. How one undertakes such a cost-benefit analysis varies, but the Commission views this analysis as discrimination:

Cost-benefit analysis as a justification for denial of treatment to people with disabilities implies discrimination based on disability, because such evaluations are not typically employed in other contexts. The Commission emphatically rejects the view that life-saving medical services should be provided or denied to any group of people based on their estimated economic worth to society.\textsuperscript{54}

It is generally believed that, the more disabled the child, the greater the cost of the care and the less likely the child will develop into a productive adult. This belief, however, can be a self-fulfilling prophecy. Institutionalization for the disabled individual with a concomitant limitation on the child's ability to become self-sufficient may be the result of this belief.\textsuperscript{55} The

\begin{itemize}
  \item \textsuperscript{49} Id. at 47.
  \item \textsuperscript{50} Id.
  \item \textsuperscript{51} Id.
  \item \textsuperscript{52} Id. at 48. Canadian commentators noted:
  \begin{quote}
  The economic position of the baby's family figures prominently in medical decision-making. Most doctors think that if the parents are well situated financially, it is more likely that they will be able to cope with a handicapped child. Consequently, in questionable cases, the child of economically comfortable parents has greater chances of receiving treatment.
  \end{quote}

  Withholding Treatment, supra note 32, at 23.
  \item \textsuperscript{53} Medical Discrimination, supra note 2, at 48. Cf. Timothy W. v. Rochester, New Hampshire School District, 875 F.2d 954 (1st Cir.), cert. denied, 110 S. Ct. 519 (1989) (holding that school districts must provide education to all handicapped children regardless of the severity of the handicap).
  \item \textsuperscript{54} Medical Discrimination, supra note 2, at 49 (footnote omitted).
  \item \textsuperscript{55} Id. at 55. Recognizing that a disability does require cost, the Commission noted:
  \begin{quote}
  The assumption has been that the level of severity of disability is the major determi-
Commission cites studies which show that the cost of residential services varied more by the setting than the needs of the client,56 that a trend has developed toward family style placements which are less costly,57 and that job training programs are increasing the productivity of severely and profoundly disabled individuals.58

In spite of the cost advantages of group and family home living arrangements, federal and state policies do not encourage such programs.59 The nant of lifetime costs. . . . Although this assumption is unfounded, it has resulted in a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and non-work environment that significantly limits that person’s capability and entails far more expense than necessary.

Id. 56. Id. (citing ASBAUGH & NERNEY, AN ANALYSIS OF THE COSTS OF SERVING PERSONS WITH MENTAL RETARDATION BY TYPE OF RESIDENTIAL ARRANGEMENT: MACOMB-OAKLAND REGION IN MICHIGAN, REGION V IN NEBRASKA, AND REGION V IN NEW HAMPSHIRE 14 (1988)). 57. Id. at 52 (citing interview with Thomas Nerney, coauthor and project coordinator for ASBAUGH & NERNEY study, supra note 56 (Nov. 29, 1988)).

The Task Force on Technology-Dependent Children stated:

Recent studies indicate that, for pediatric technology-dependent populations, a community-based care is generally cost-effective, as compared with hospital care. . . . Programs as diverse as a Medicaid model waiver program in Maryland; and community ventilator care program managed by Kaiser Permanente in Southern California; CHAMPUS’ two-year home health care demonstration project; and Blue Cross-Blue Shield’s individual benefits management program under its Federal Employee Program, have all reported substantial cost savings in community-based services for technology-dependent individuals as compared to hospital care. In some instances, savings in these programs have run as high as 50 percent.

TASK FORCE ON TECHNOLOGY-DEPENDENT CHILDREN, supra note 27, at 66. 58. MEDICAL DISCRIMINATION, supra note 2, at 53-55. 59. Id. at 52. One government group has examined ways to assist in reducing the barriers to home and community-based care for technology-dependent children. The Task Force for Technology-Dependent Children defines these children between the ages of birth to twenty-one with a chronic disability that requires the “routine use of a specific medical device to compensate for the loss of life sustaining body function.” In addition, they require “daily, ongoing care or monitoring by trained personnel.” TASK FORCE ON TECHNOLOGY-DEPENDENT CHILDREN, supra note 27, at vii-1.

Authorized by section 9520 of the Consolidated Omnibus Reconciliation Act of 1985, P.L. 99-272, the Task Force analyzed “barriers that prevent the provision of appropriate care in a home or community setting to meet the special needs of technology-dependent children.” Id. It also “recommend[ed] changes in the provision and financing of health care in private and public health care programs, including appropriate public-private initiatives, in order to provide home and community-based alternatives to the institutionalization of children.” Id.

The report outlined three approaches for the provision and payment of services to technology-dependent children. Id. The first approach would utilize existing public and private health insurance provisions and suggest the “financing [of] selected incremental policy changes.” Id. at vii-3-vii-4. In the second approach, “each State Medicaid agency . . . would arrange for the delivery by qualified systems of excellence of pre-authorized medical, developmental, and support services specified in the individual care plan for a child certified as technology-dependent.” Id. at vii-4. The third approach would utilize a “public-private
Commission recommends that changes be made in Medicaid in order to provide funding to family and group homes. If incentives are provided for use of such living situations, the alleged "cost" of a disability will drop significantly.

**REHABILITATION ACT OF 1973**

At the time of the Baby Doe case, no federal law expressly prohibited withholding of medical treatment from critically ill infants. President Reagan, however, directed the Department of Health and Human Services to take administrative action on behalf of handicapped infants who had been denied medical treatment. Initially, HHS gave notice to health care providers that Section 504 of the Rehabilitation Act was applicable to the withholding of medical treatment from disabled infants. The Secretary of Health and Human Services issued an interim final rule on March 7, 1983. The rule established procedures for enforcement of section 504, requiring hospitals to post a notice that failure to feed and care for handicapped infants was a violation of federal law. The rule also established a toll free "hotline" number which would receive reports of infants being discriminatorily denied care and authorized federal investigators twenty-four hour access to the infant's records.

The rule was immediately challenged by hospitals and medical groups. In *American Academy of Pediatrics v. Heckler*, the court invalidated the rule on the grounds that it should have been published for public comment.

In July 1983, HHS published a new "proposed" rule, essentially the same as the old one. HHS conducted negotiations with the American Academy...
of Pediatricians (AAP) in exchange for the AAP's agreement not to sue over the Final Rule.\(^7\)

The Final Rule, published on January 12, 1984,\(^71\) provided model guidelines for the establishment of infant care review committees.\(^72\) The Final Rule redrafted the informational notice required to be posted and provided two alternative notices.\(^73\) Child Protective Services (CPS) agencies were required to implement reporting procedures for immediate review of reports, investigation, and the provision of protection where necessary.\(^74\) The CPS agencies were also required to notify HHS of these reports.\(^75\) HHS could have immediate access to records when it judged such access necessary to protect life or health.\(^76\)

Again, the rule was challenged.\(^77\) The Supreme Court's plurality decision in *Bowen v. American Hospital Association*\(^78\) invalidated the Final Rules. Justice Stevens stated: "A hospital's withholding of treatment when no parental consent has been given cannot violate section 504, for without the consent of the parents or a surrogate decisionmaker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap."\(^79\) The Commission noted that this statement sparked its analysis of the parent-physician relationship.\(^80\)

Justice Stevens also based his opinion on the lack of sufficient evidence in

\(^70\). *MEDICAL DISCRIMINATION*, *supra* note 2, at 70.


\(^72\). *MEDICAL DISCRIMINATION*, *supra* note 2, at 70 (citing Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, 49 Fed. Reg. 1,622, 1,651 (1984)).

\(^73\). Id. at 71.

\(^74\). Id. at 71 (citing 45 C.F.R. § 84.55 (c)(1)(i), (ii), (iii), (iv) (1987)).

\(^75\). Id. at 71 (citing 45 C.F.R. § 84.55 (c)(1)(v) (1987)).

\(^76\). Id. at 71 (citing 45 C.F.R. § 84.55 (d) (1987)).

\(^77\). United States v. University Hosp., 729 F.2d 144 (2d Cir. 1984). The Second Circuit addressed the validity of the Final Rule in the context of the Baby Jane Doe case. The court perceived the requirements of the Final Rule as inapplicable to such complicated medical decisions and held that the reach of section 504 did not extend to the investigations required under the Final Rule. *MEDICAL DISCRIMINATION*, *supra* note 2, at 72-73 (citing *University Hosp.*, 729 F.2d at 156-61).

\(^78\). 476 U.S. 610 (1986). This case was the consolidation of an existing complaint amended by the American Hospital Association and a separate suit by the American Medical Association. Prior to the Supreme Court decision, the district court had concluded that the rules were issued without statutory authority and prohibited HHS from regulating treatment decisions under section 504. American Hosp. Ass'n v. Heckler, 585 F. Supp. 541, 542 (S.D.N.Y.), *affd* without opinion, 794 F.2d 674 (2d Cir. 1984). *MEDICAL DISCRIMINATION*, *supra* note 2, at 73-74.

\(^79\). Id. at 74; *Bowen*, 476 U.S. at 630.

\(^80\). *MEDICAL DISCRIMINATION*, *supra* note 2, at 74.
the administrative record to support regulation. The Commission interprets the opinion:

The plurality opinion leaves a puzzling gap between the logic of its analysis and the apparent breadth of the plurality's description of the Court's injunction. Nothing in Justice Stevens' analysis suggests that HHS should be prevented from investigating instances in which it is alleged that a recipient of Federal financial assistance is failing to report medical neglect solely because the victim has a disability, only that HHS had provided insufficient evidence of the prevalence of discriminatory nonreporting to provide an administrative justification for the Final Rule.

The Commission claims that section 504 can provide enforcement advantages "not present in the Child Abuse Amendments alone." It maintains that its hearings and research supply the information that the Supreme Court claims was lacking in the administrative record leading to Bowen. The Commission recommends, in a way it perceives will not violate the Bowen decision, "that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which the allegations are found to be justified."

THE CHILD ABUSE AMENDMENTS OF 1984

After debate and negotiation which lasted over two years, the Child Abuse Amendments of 1984 were signed into law on October 9, 1984. This legislation allowed HHS to develop regulations and model guidelines for infant care review committees. The model guidelines regarding committee formation were intended to be voluntary and the amendments became effective on October 9, 1985.


81. Id. at 74-76 (citing Bowen, 476 U.S. at 626).
82. Id. at 76 (footnote omitted).
83. Id. at 77.
84. Id. at 78.
85. Id. at 78 & n.141.
86. See id. at 79-81.
88. MEDICAL DISCRIMINATION, supra note 2, at 81.
89. Id. at 82 (citing 42 U.S.C. § 5103 note (1983 and Supp. 1989)).
90. Id. at 82 (citing Child Abuse and Neglect Prevention and Treatment Program, 45 C.F.R. pt. 1430 (1987)). Forty-six states, the District of Columbia, and Puerto Rico receive funds under the Child Abuse Prevention and Treatment Act and therefore, must comply with the Child Abuse Amendments. California, Indiana, Ohio and Pennsylvania, however, did not
As the Commission noted, a large number of children in states which do not receive federal funds are not protected. Moreover, the minimal funding received by most states does not provide a great financial incentive for compliance with the Child Abuse Amendments.91 Because of these concerns and the controversy surrounding the legislation, the standard of care was executed carefully.92

The required standard of care may be divided for the purpose of convenient analysis into nine elements: (1) a disabled (2) infant (3) with a life-threatening condition (4) must always be given nutrition, hydration, and medication (5) and must normally be given the treatment most likely to correct or ameliorate the condition (maximal treatment) (6) based upon the reasonable medical judgment of the treating physician, (7) but the maximal treatment rule is not applicable in three situations: when the child is “chronically and irreversibly comatose,” (8) when maximal treatment would be futile in saving the child’s life for long, and (9) when “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.”93

While the Commission discusses several other definitions,94 the terms “nutrition, hydration, and medication” are crucial because “appropriate amounts” of each must be supplied even if an exception to the required max-

receive these funds as of December 1988 and are not bound to implement the Child Abuse Amendments. Id. at 82.

91. Id. at 82. Every state has a statute allowing authorities to act to protect a child who is threatened by abuse or neglect. Id. at 56. In the forty-six states receiving federal funds for their child abuse and neglect programs, those statutes must be used to prevent the withholding of medical treatment from infants with life-threatening conditions in order to comply with the Child Abuse Amendments of 1984. Id.

92. Id.

93. Id. at 83 (citing 42 U.S.C. § 5102 (3) & § 5103 (b)(2)(K)(West Supp. 1988). The Commission notes that the term “disabled” is not defined in the Amendments, its attendant regulations, or the Interpretive Guidelines. It offers the definition developed by the American Bar Association’s Commission on the Mentally Disabled and the National Legal Resource Center for Child Advocacy and Protections and based on the implementing regulations for section 504 of the Rehabilitation Act of 1973:

“Disabled infant” means an infant with a physical or mental impairment which substantially limits or hold the reasonable prospect of in the future substantially limiting one or more major life activities. “Major life activities” include functions such as, but not limited to, breathing, seeing, hearing, walking, caring for one’s self, performing manual tasks, learning and working.

Id. at 83 (citing Nicholson, Horowitz & Parry, Model Procedures for Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment From Disabled Infants With Life-Threatening Conditions, 10 MENTAL & PHYSICAL DISABILITY L. REP. 220, 228 (1986)).

94. MEDICAL DISCRIMINATION, supra note 2, at 84-88.
The Commission notes that many courts have rejected the distinction between nourishment and treatment. In spite of the courts' rejection of this distinction, however, the Commission looks to the intent of Congress and the HHS Interpretive Guidelines and declares that "[i]t is difficult to contend, therefore, that under the Child Abuse Amendments it can ever be appropriate to withhold nutrition or hydration from a child with a disability who is capable of assimilating it." In addition, this same requirement applies to "pain-relieving and other palliative medicine."

The Commission contends that the phrase "treatment most likely to be effective in ameliorating or correcting all life-threatening conditions . . . [is] the centerpiece of . . . [the] standard of care." The Interpretive Guidelines set forth the precise dimensions, which include a complete potential treatment plan, diagnostic procedures, and palliative measures. "Children covered by the law must be provided the treatment 'most likely to be effective,' not just the level of treatment that would be provided to their nondisabled counterparts."

There are three exceptions to the treatment requirement: "the comatose exception," "the futility exception," and "the virtually futile and inhumane exception." Under the comatose exception, maximal treatment may be withheld (although not appropriate nutrition, hydration, and medication) when a child is "chronically and irreversibly comatose."

As to the second exception, the Commission recognizes that "[w]hen life is inevitably ebbing away, and dying cannot be halted but only prolonged, the interest in preserving life can no longer be satisfied. This exception was designed to ensure that in such circumstances there would be no requirement that life-prolonging treatment be employed to eke life out for a brief

95. Id. at 85.
96. Id. at 85 & n.57.
97. Id. at 86.
98. Id.
99. Id.
100. Id. at 87 (citing 45 C.F.R. pt. 1340 App. Interpretive Guideline 7 (1987)).
101. Id. at 87.
102. Id. at 88-89.
103. Id. at 89-90.
104. Id. at 90.
period longer." This exception is not applicable "where many years of life will result from the provision of treatment, or where the prognosis is not for death in the near future, but rather the more distant future." If one untreatable condition will result in death, then treatment for other life-threatening conditions that could be cured is not required.

The third exception requires two criteria to be met. First, the provision of treatment must be "virtually futile." The difference between "futile" and "virtually futile" is found in the "degree of probability or uncertainty in determining the futility of the treatment." Second, treatment itself must be inhumane under the circumstances. Treatment is inhumane when there exists "significant medical contraindications and/or significant pain and suffering for the infant that clearly outweighs the very slight potential benefit of the treatment for an infant highly unlikely to survive."

After discussing the enforcement of the Child Abuse Amendments, the Commission concludes that the Child Abuse Amendments of 1984 "set out a detailed and, for the most part, unambiguous but nuanced standard of care." The Commission views the Amendments as "provid[ing] strong protection" upon adequate enforcement.

Constitutional Issues

In finding that decisions to withhold medically indicated treatment from disabled infants still occur, the Commission raises two questions implicating

106. Medical Discrimination, supra note 2, at 89.
108. Medical Discrimination, supra note 2, at 89-90 (citations omitted).
109. Id. at 90.
110. Id.
111. Id.
112. Id. (quoting 45 C.F.R. pt. 1340 App. Interpretive Guideline 9 (1987)).
113. Medical Discrimination, supra note 2, at 90-92. Under the implementing regulations, the State agencies must contact health care facilities on an annual basis to ensure that individuals have been designated as liaisons, with the authority to report suspected treatment withholding and assist with investigations. Id. at 91 (citing 45 C.F.R. § 1340.14 (c), (d) (1987)). In addition, state agencies must detail their access procedures for medical records in the case of an investigation and provide for a court order when an independent medical examination is needed. Id. at 117.
114. Id.
115. Id.
the principles of federal constitutional law. The first is whether any constitutional rights were in jeopardy; the second, whether "adequate substantive and procedural safeguards (including a forum)" are available in the event that constitutional rights are in jeopardy.

The Commission, recognizing that "Congress retains the ability to mandate a minimum level of additional protection which is not otherwise inconsistent with the Constitution," begins its analysis of equal protection by examining various laws affecting disabled individuals. Next, the Commission reviews the Supreme Court's decision in *City of Cleburne v. Cleburne Living Center*. In *Cleburne Living Center*, the Supreme Court prohibited zoning which would exclude mentally retarded individuals from living in a group home located in a neighborhood. While refusing to employ more than a minimum rationality standard, the Court reviewed the "real reasons behind the challenged unequal treatment and . . . analyz[ed] whether the discriminatory policy is actually related to a legitimate government purpose." The Court found irrational fear and prejudice to be at the root of the ordinance, as opposed to a legitimate government purpose, and invalidated it.

Integrating the testimony of a witness who views the lives of disabled children as "hopeless" with the outlook of the Supreme Court as expressed in *Cleburne Living Center*, the Commission contends:

Thus, when medical care decisionmaking is based on little more than personal experience and hearsay regarding the capabilities of problems of persons with disabilities and their families—that is, on deeply ingrained stereotypes that relegate persons with disabilities to a perpetually subordinate status—there can be no question that the equal protection clause forbids government action that either rests on such stereotypes or affirms them.

Analyzing the second issue, the Commission concludes that disabled infants needing treatment often were not receiving procedural protection.

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116. *Id.* at 93.
117. *Id.*
118. *Id.* at 95 n.11.
121. *Id.* at 450.
122. MEDICAL DISCRIMINATION, supra note 2, at 96 (citing City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 442-43 (1985)).
123. *Id.* at 96 (citing Cleburne Living Center, 473 U.S. at 448-50).
124. *Id.* at 97.
125. *Id.*
Since the record supports the finding that predictions regarding the future effects of a disability were often wrong, the Commission maintains that the “careful and informed evaluation of each case by independent and disinterested decisionmakers is required.”

The Commission emphasizes the important distinction between policymaking based on a “constitutional right to parental autonomy” and a “common law or statutory right of parents or guardians to refuse medical treatment.” While a common law or statutory right addresses the “best interests” of all concerned, “[c]onstitutional rights to privacy (autonomy), however, operate as limits on the power of the government to make any regulation at all regarding the subject matter.” A decision based on constitutional underpinnings places the issue out of legislative or executive jurisdiction, which “finds little, if any support in the case law.”

The Commission concludes that the refusal to treat disabled newborns on the basis of their disability and quality of life assessments threatens their constitutional rights. “The principle of equal protection of the laws is offended when disability is the basis of a nontreatment decision. Procedural protection for the interests of both child and parents is often absent completely or is woefully inadequate to the task of sifting the facts.”

Since recent Court decisions have not protected newborns with disabilities, Congress and state legislatures must step in and provide the necessary

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The due process clauses of the 5th and 14th amendments require, among other things, that certain procedural protections must be provided before the government may deprive individuals of life, liberty or property. Known as procedural due process, the doctrine is most frequently interpreted as providing an opportunity to be heard on the issue of fairness and lawfulness of the proposed deprivation.

Id.

126. Id. (footnote omitted) (citing Mathews v. Eldridge, 424 U.S. 319, 335 (1976)). The Commission recognizes that a significant constitutional issue does not arise where there is a “medically defensible difference of opinion” regarding the treatment in question. Id. at 99. Rather, the issue arises where there is misinformation about the disability or prejudices about the disabled child’s quality of life. Id. (footnote omitted).

127. Id. at 99.

128. Id. at 99-100 (footnote omitted). What role does privacy play in decisions to refuse medical treatment? The Commission distinguishes between two types of privacy: “(1) the inviolability of one’s person, home, or things from unreasonable governmental intrusions; and (2) individual autonomy or liberty with respect to certain matters important to one’s person or the course of one’s life (e.g., marriage, sex, childbearing).” Id. at 98 (citing Whalen v. Roe, 429 U.S. 589 (1977)). Parents have the constitutional right to make decisions regarding how to rear their children, but the government can step in when a child becomes endangered by those decisions. MEDICAL DISCRIMINATION, supra note 2, at 98.

129. Id. at 100 (citing Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1976); Prince v. Massachusetts, 321 U.S. 158 (1944)).

130. Id. at 101-02.

131. Id. at 102.
THE INCIDENCE OF DISCRIMINATORY DENIAL OF MEDICAL TREATMENT

How often is treatment denied to children because they have a disability? According to the Commission, the answer to this question is important in determining how the implementation of the Child Abuse Amendments could be improved and what new measures, if any, should be administered.\(^\text{133}\)

A primary problem with determining the frequency of discrimination is the difficulty with quantification.\(^\text{134}\) "When health care personnel and parents agree to reject a course of life-saving medical treatment for a child with a disability, they typically do not announce it to the world at large or report it in those terms to statisticians or public officials."\(^\text{135}\)

Since denial of treatment cases are rarely reported, they are usually brought to light by a family member or health care professional.\(^\text{136}\) "Whistleblowing" often results in serious consequences for the person who chooses to go public with the information. Studies indicate that many people lose their jobs, suffer retaliation, or manifest physical symptoms of depression and anger.\(^\text{137}\) The negative consequences associated with whistleblowing, combined with the dearth of public information, suggest that "[i]t is probable that such [reported] cases represent only the tip of the iceberg."\(^\text{138}\) Therefore, the Commission examines other ways to compute the incidence of medical discrimination.\(^\text{139}\)

First, the Commission turns to "[s]urveys of physician attitudes."\(^\text{140}\) Based on surveys,\(^\text{141}\) the Commission concludes that "a significant proportion of them [physicians] would participate in denial of treatment in certain circumstances . . . [and] contemporary denial of treatment is not
The Commission then reviews the statement submitted by H. Rutherford Turnbull, which documented various polls, data, and trends in ethical literature. Dr. Turnbull concluded that earlier data supports the fact that discrimination against newborns with disabilities occurred, causing needless deaths. Based on more recent literature, he found considerable support for the denial of treatment based on quality of life assessments.

The Commission also summarizes the investigative work of Carlton Sherwood, the testimony of individuals with disabilities and their families, and recent literature. The Commission concludes that, in spite of implementation of the Child Abuse Amendments, "the likelihood of widespread denials of lifesaving treatment to children with disabilities" has continued.

ENFORCEMENT OF THE CHILD ABUSE AMENDMENTS OF 1984

Since federal efforts to prevent medical discrimination have been thwarted, the responsibility for enforcing the Child Abuse Amendments rests with state CPS agencies. The Commission's study shows that, of the forty-eight states receiving federal funds under the Child Abuse Prevention and Treatment Act, fourteen of these states defer to the decisions of hospital infant care review committees or the staff when there is a case of suspected

142. MEDICAL DISCRIMINATION, supra note 2, at 104.
143. Id. at 106-07. Professor Turnbull is a professor of Special Education and Law at the University of Kansas. His report was prepared for the Commission and is found in appendix B, id. at 219-32.
144. Id. at 106; App. B, at 219-21.
146. Id. at 107-08. Mr. Sherwood traveled extensively and "interviewed more than 250 physicians, nurses, lawyers, hospital officials, and parents who, at one time or another, were directly involved in Baby Doe cases... [we] reviewed upward of 700 cases where there was a probability that infants died as a result of decisions to withdraw medical treatment." Id. at 107 (quoting Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 45-46 (1986) (vol. II) (testimony of Carlton Sherwood)).
147. Id. at 108-09. Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc., testified to comments made by physicians: "I can find good things in practically everything, even dying, but birth defects are roaring tragedies. Death doesn't bother me, but the living do." Another physician said, "I don't really enjoy a really handicapped child who comes in drooling, can't walk, and so forth. Medicine is here to perfect the human body. Something you can't do anything about challenges the doctor and reminds him of his own inabilities." Id. at 109 (quoting Protection of Handicapped Newborns: Hearings Before the United States Commission on Civil Rights 181 (1986) (vol. II)).
148. Id. at 109.
149. Id. at 110.
150. Id. at 111.
treatment denial.\textsuperscript{151} The Commission cited the close working relationship between CPS workers and health care professionals as one reason for the surrender of responsibility by CPS agencies.\textsuperscript{152} According to federal regulations, however, the CPS agency is responsible for the treatment determination regardless of the existence of an infant care review committee.\textsuperscript{153} The Commission found that CPS agencies who do not abdicate their reviewing responsibility to committees often rely on "the same organized elements of the medical profession who have strongly objected to the Child Abuse Amendments."\textsuperscript{154}

In addition, the Commission finds that "[t]here have also been a number of indications that some state CPS agency personnel are unsympathetic to the principles of treatment embodied in the Child Abuse Amendments."\textsuperscript{155} The agency personnel, mostly comprised of social workers, view these decisions as more appropriately made by the physician and the parent(s).\textsuperscript{156}

A conflict of interest may also exist between the CPS agency and other agencies within the state government.\textsuperscript{157} "CPS agencies are part of the State government, often in the same department that runs hospitals and other in-

\textsuperscript{151} Id. at 111-12 (footnote omitted). These states include Alabama, Alaska, Arizona, Delaware, Florida, Georgia, Hawaii, Maine, Michigan, Nevada, New Mexico, Washington, and West Virginia. Id. at 112 n.4.

\textsuperscript{152} Id. at 113. CPS agencies appear to rely much more heavily on the views of the medical community than those of disability advocates. One estimate indicated that thirty-four of thirty-seven states responding contacted members of the medical community during the decision making process; 11 had contacted disability groups. Id. at 114 (citing interview with Dr. Leon Burke, ISSUES L. & MED. (Nov. 30, 1987)).

\textsuperscript{153} Id. at 113. The Commission cited Kansas and Arkansas as two examples. Kansas allows the state chapter of the American Academy of Pediatricians to evaluate denial reports. Id. Arkansas allows the Arkansas Children's Hospital to handle such matters. Id.

\textsuperscript{154} Medical Discrimination, supra note 2, at 113. The Commission cited Kansas and Arkansas as two examples. Kansas allows the state chapter of the American Academy of Pediatricians to evaluate denial reports. Id. Arkansas allows the Arkansas Children's Hospital to handle such matters. Id.

\textsuperscript{155} Id. at 114. "A majority of states are not even clear in their policies concerning who is covered by the standards of treatment in the act." Id.

\textsuperscript{156} Id. at 115. A 1987 report by the Inspector of HHS revealed that at eleven of forty-nine CPS agencies, employees felt that their agency should not be responsible for Baby Doe cases, due to the existence of medical and ethical issues. In addition, ten other agencies would not respond as to where the responsibility should lie. Id. at 116 (citing U.S. DEP'T OF HEALTH AND HUMAN SERVICES, OFFICE OF THE INSPECTOR GENERAL, SURVEY OF BABY DOE PROGRAMS 11 (1987)).

\textsuperscript{157} Id. at 117.
stitutions that provide medical treatment to children with disabilities."158 As a result of this conflict, and the other factors discussed above, the Commission concludes that CPS agencies have failed to "effectively enforce" the Child Abuse Amendments.159

ROLE AND PERFORMANCE OF INFANT CARE REVIEW COMMITTEES

The Child Abuse Amendments of 1984 and the accompanying regulations encourage the establishment of infant care review committees.160 Use of these committees, in the context of "Baby Doe" cases, became more widespread largely as a result of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research report entitled Deciding to Forego Life-Sustaining Treatment and the promotional efforts of the American Academy of Pediatricians.161 The Commission views these discussions, as they apply to the specifics of decisionmaking, as "vague" and "designed less to enforce the treatment standards of the law than to protect doctors and hospitals from 'intrusion.'"162

The much disputed and overturned "Baby Doe" rule designed to implement section 504 contained a model for an infant care review committee.163 This model had been the result of much debate between HHS and AAP. Model guidelines were also included in regulations promulgated pursuant to the passage of the Child Abuse Amendments.164 These guidelines reflected the view of HHS that the Child Abuse Amendments "settled" ethical debates regarding "what circumstances justify withholding of treatment."165

Thus, the HHS guidelines assumed that the particular cases that came before a committee would not involve relitigation of the ethical and social debates about the propriety of treatment that preceded the enactment of the law, but would instead focus on an

158. Id.
159. Id.
160. The Commission defined infant care review committees as "internal hospital committees that consider instances in which life-preserving medical treatment is being or may be withheld from infants with disabilities." Id. at 118.
161. Id. at 118-19.
162. Id. at 120. "Central to the rationale for reliance on such committees was the position, taken by both the President's Commission and the Academy of Pediatrics, that precise substantive rules about when treatment should be provided or withheld are inappropriate." Id.
164. MEDICAL DISCRIMINATION, supra note 2, at 121 (citing Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, 50 Fed. Reg. 14,893 (1985)). These guidelines "have no mandatory force." Id. at 122 n.34. See supra noted 89-90 and accompanying text.
165. Id. at 122.
analysis of how the law should properly be applied to the facts of the case.\textsuperscript{166}

Alternatively, the model suggested by the President's Commission and the AAP emphasized the role of bioethics and an autonomous decisionmaking role for the committee.

With the role of these Committees at issue, the Commission investigates the use of the infant care review committees: are they "prognosis" committees determining whether the case falls under the Child Abuse Amendments or "ethics" committees making treatment judgments on quality of life assessments?\textsuperscript{167} The Commission cites instances where judgments have centered on the perceived quality of life for the child, in direct contravention of the Child Abuse Amendments.\textsuperscript{168} It is unclear, however, as to how often these deliberations resulted in the denial of treatment.\textsuperscript{169} Following from that premise, the Commission's review of the cases involving the withholding of treatment\textsuperscript{170} reveals that "it is impossible to determine whether any of the treatment denials violated the standards established by the Child Abuse Amendments."\textsuperscript{171}

The Commission, reviewing the procedures of four committees,\textsuperscript{172} a 1987 report of the HHS Inspector General, and the 1986 AAP/University of Connecticut survey, concludes that

the vast majority of committees convene only to deal with disagreements and do not attempt to scrutinize most denial of treatment decisions to see whether they comply with the law. This implies that many hospital infant care review committees seem more attuned to diffusing and resolving conflict in a way that keeps any controversy as much as possible within hospital walls than to ensuring that children with disabilities receive the lifesaving treatment to which they are entitled under the Child Abuse Amendments.\textsuperscript{173}

\textsuperscript{166} Id.
\textsuperscript{167} Id.
\textsuperscript{168} Id. at 123.
\textsuperscript{169} Id. at 126. Note that the Child Abuse Amendments, as interpreted by HHS, provide an exception to the required treatment when "the treatment itself involves significant medical contraindications and/or significant pain and suffering for the infant that clearly outweighs the very slight potential benefit of the treatment for an infant highly unlikely to survive." Id. at 125 (quoting 45 C.F.R. § 1340, 15 app. (1987)).
\textsuperscript{170} Id. at 125-26.
\textsuperscript{171} Id. at 126.
\textsuperscript{172} Children's Hospital of Wisconsin, Albert Einstein College of Medicine-Montefiore Medical Center, University Hospitals of Cleveland, and St. Joseph's Hospital (Denver). Id. at 122-27.
\textsuperscript{173} Id. at 127 (footnote omitted).
The Child Abuse Amendments require known and "suspected" instances of medical neglect to be reported to the state by designated individuals at health care facilities.\textsuperscript{174} This reporting requirement encompasses instances of treatment withholding.\textsuperscript{175}

Based on the report of the HHS Inspector General, the Commission concludes that most infant care review committees only report cases to the authorities where no agreement regarding treatment has been reached.\textsuperscript{176} This failure to report is especially serious since most committees appear to adopt a model more closely aligned with the ideals of the AAP.\textsuperscript{177} Furthermore, the combination of a lack of disability group representation on the committee, the lack of specific knowledge on the part of some committee members, and the reluctance of medical colleagues to criticize one another leads to the question of whether the committee is able to effectively address the issues.\textsuperscript{178} The Commission states: "[A]n institution rarely does a good job of policing itself. . . . Outside oversight is needed."\textsuperscript{179}

The Commission recognizes the permanence of review committees in the medical setting.\textsuperscript{180} Based on the disagreement within the profession regarding standards of treatment, however, the Commission recommends that "there be independent, contemporaneous scrutiny of infant care review committee proceedings, preferably by medically knowledgeable and experienced disability advocates, and that the prompt reporting requirement be more vigorously enforced to make this possible."\textsuperscript{181}

\textbf{PERFORMANCE OF THE FEDERAL GOVERNMENT}

Federal involvement in the protection of children with disabilities has been centralized in the Child Abuse Amendments, as well as the regulations

\textsuperscript{174} Id.
\textsuperscript{175} Id.
\textsuperscript{176} Id.\textsuperscript{179} at 128.
\textsuperscript{177} Id.
\textsuperscript{178} Id.\textsuperscript{179} at 128-29.
\textsuperscript{179} Id.\textsuperscript{179} at 129 (footnote omitted).
\textsuperscript{180} Id.
\textsuperscript{181} Id. (footnote omitted).
promulgated under section 504 until they were struck down. Prior to the time that the "Baby Doe" regulations were enjoined, the HHS Office of Civil Rights (OCR) was responsible for their enforcement. OCR was criticized for its failure to promptly and effectively conduct investigations. Although OCR never officially found a violation of section 504, it warned those in noncompliance of their shortcomings and provided them the opportunity to remediate their practices in the future.

The Commission finds that many OCR employees viewed "Baby Doe" investigations as an invasion of family privacy. Significant delays were common and the choice of medical consultants was, at times, questionable. The Commission chronicled the Connecticut Senate investigation into the Yale-New Haven Hospital, the OCR investigation of Oklahoma Children's Hospital, and subsequent OCR investigations.

The investigation into the Oklahoma Children's Hospital has a lengthy history. The hospital had implemented a selective treatment program for children with spina bifida. Within forty-eight hours of the birth of a child with spina bifida, a hospital team evaluated the baby. Based on the severity of the condition, the team would decide on a treatment recommendation for the family. The recommendation would either be to provide "vigorous" treatment or "supportive" care. If "supportive" care was agreed upon, the lifesaving operation to close the spinal opening would not be performed and no "active treatment" for infection would be given. As part of its criteria, the team considered the family contribution "so that those families who had greater resources might receive a recommendation for treatment and those families with fewer resources would be more likely to receive a recommendation against it, even though the severity of the disability might be the same in both cases."

182. Id. at 130.
183. Id.
184. Id.
185. Id.
186. Id. at 131. Dr. Gordon B. Avery and Dr. George Little, both OCR medical consultants, participated in the suit to invalidate the 504 regulations by submitting affidavits on behalf of the plaintiffs. Id. at 131 & n.10.
187. The Yale-New Haven investigation took two years to complete, but the letter of finding was never issued because of the legal action challenging the 504 regulations. Id. at 135.
188. Id. at 131-35.
189. Id. at 135-38.
190. Id. at 135.
191. Id.
192. Id. (citing Gross, Cox, Tatyrek, Pollay & Barnes, Early Management and Decision Making for the Treatment of Myelomeningocele, 72 PEDIATRICS 450 (1983)).
193. Id.
194. Id. (footnote omitted). Sixty-nine infants were included in the "experiment." Thirty-
The publicity surrounding the Oklahoma program resulted in a complaint to HHS and the Department of Justice. No investigation resulted. The incident culminated in a suit filed by the American Civil Liberties Union and the National Center for Medically Dependent and Disabled on behalf of three of the children adversely affected by the treatment plans of several physicians at Oklahoma Children’s Hospital.

Regarding the lack of action on the part of the federal government in the Connecticut and Oklahoma cases, the Commission stated:

[C]onfronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in both States, the responsible Federal agency failed to act with the vigor and dispatch incumbent on it in light of the circumstances, its legal responsibilities, and its publicly stated position.

As to the federal enforcement of the Child Abuse Amendments of 1984, the Commission views HHS’ failure to find CPS agencies in noncompliance and discontinue federal funding as “significant.” The Office of Inspector General, in fulfillment of its legislative mandate, completed two studies. One study reviewed the CPS implementation of the Child Abuse Amendments and the other addressed hospital review committees. According to the Commission, these reports failed to reflect a substantive understanding of the Child Abuse Amendments on the part of Inspector General’s office, failed to review unreported cases, and inappropriately focused on review committees whose principles differed from those required by the law.

The HHS Office of Human Development did agree to further investigate the policies of the Federal program and eligibility of the States. While the Commission notes this fact in its conclusion, it expresses serious concern for the “extremely poor performance” of HHS.

six were recommended to receive “vigorous” treatment. All but one (who was killed in a car accident) survived. Thirty-three children were recommended for “supportive care.” Five families rejected this recommendation and received “vigorous” treatment. Three of these children survived. Of the twenty-four children receiving only “supportive care,” all died. Id. at 136-38.

195. Id. at 136-38.
197. Id. at 139.
198. Id.
199. Id. (citing U.S. DEPT. OF HEALTH AND HUMAN SERVICES, OFFICE OF INSPECTOR GENERAL, SURVEY OF BABY DOE PROGRAMS (1987); U.S. DEPT. OF HEALTH AND HUMAN SERVICES, OFFICE OF INSPECTOR GENERAL, INFANT CARE REVIEW COMMITTEES UNDER THE BABY DOE PROGRAM (1987)).
200. MEDICAL DISCRIMINATION, supra note 2, at 139-40.
201. Id. at 141.
202. Id.
Protection and Advocacy Systems (P & A) were established by Congress in 1975 to "ensure vigorous advocacy of the rights of persons with developmental disabilities." The P & A staff is comprised of lawyers, social workers, and advocates. While the P & A system has handled cases of discriminatory denial of treatment to people with disabilities in the past, the major responsibility for enforcement has rested with the CPS agencies.

The Commission believes that the P & A system should play a larger role in the prevention of discrimination against children with disabilities. It views the added involvement of the P & A as having several advantages. The P & A system is more skilled in handling cases involving the rights of those with disabilities. In addition, there is less potential for conflicts of interest since the special relationship found between the CPS agency and the medical profession does not exist between the P & A system and the medical profession. Finally, "P & A agencies are accountable to the populations they serve."

The Commission maintains that "certain tools are essential" in utilizing P & A systems. First, the State P & A should be notified when the State CPS agency receives a report that discriminatory denial may have occurred.
The P & A agency must have access to medical records upon receipt of such a report. In addition, “new mechanisms” for reporting are necessary. The P & A agency should be allowed to review medical records and meet with the physicians, relatives, and committees involved. The access to records should be retrospective to include those records of children who have died. In order to achieve these additional responsibilities, the Commission endorses more funding for the P & A system.

POLITICAL VIEWPOINTS

The Dissenting View of Chairman Allen

The Commission’s report, however, did not go uncriticized. Chairman William B. Allen dissented. Several of his concerns center on methodological flaws: “research incontinence,” “the failure to make as strong a demonstration as possible,” and “the steadfast refusal to vent the report among critics in advance.”

Chairman Allen presents substantive concerns as well as methodological ones. He states that “the organic law of our society” mirrors the Hippos.
Medical Discrimination: An Abstract

In spite of their rejection of the Hippocratic oath, physicians remain bound by constitutional standards.

What we are trying to do now is to measure whether and how the protections of law can make up for the loss of steady moral commitment. By presenting the plight of the handicapped newborn as the logical development of unbroken historical antecedents — the legacy of bigotry in America — instead of as a corruption of previous accomplishments, it depreciates not only the value of the Hippocratic standard but also the organic principles of our nation.

While agreeing with a condemnation of the eugenicist movement, Chairman Allen maintains that it is "nevertheless unsound to seek to derive the eugenicist movement from mere historical conditions or the cultural milieu." Looking to "the heart of the report," Chairman Allen disagrees with the assumption of rights as "defined" or "illustrated" by needs.

Chairman Allen concludes in his dissent by stating:

We have abiding confidence that a regime of equal rights is the surest relief for unmerited disadvantage. We reject the contention, however, that to relieve disadvantages is to guarantee equality of rights. Insofar as this report takes the opposite position on this crucial question, we should not approve it. The correct application of this principle to the handicapped is to assure that they suffer no further burdens (above all civil burdens) than are already intrinsic to their circumstances.

He stated his position more clearly, however, in a footnote:

[C]ivil rights guarantees the fair distribution not only of advantages, but also of burdens. Hence, so long as medical neglect may fairly affect any citizen, without regard to handicap, race, gender, or other prohibited grounds, it could not pose a civil rights problem. Thus the task of this report has been to prove not only that

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which our art or science point us." Id. at 155. Society views knowledge of humanity as dependent on knowledge of the arts, in direct contravention of Hippocrates' views, regardless of their viewpoint on the Baby Doe issue. Id. at 155-56.

221. Id. at 156.

222. Allen stresses that "today . . . physicians no longer subscribe to Hippocratic standards, and certainly not to the Hippocratic Oath." Rather, medicine has adopted the "Principles of Medical Ethics" which drop the opposition to abortion and suicide found in the Hippocratic Oath. Id. at 156.

223. Id.

224. Id. at 157.

225. Id.

226. Id.

227. Id.
the handicapped newborn is burdened, but unfairly so. That the report fails to establish even the threshold phenomenon in the post-1984 environment is a signal [sic] condemnation of the effort devoted to it and the taxpayer funds expended on it.  

Dr. H. Tristam Engelhardt submitted comments in support of Chairman Allen’s position. As one of the foremost experts in medical ethics, Dr. Engelhardt states: “The report does not appreciate that a major shift in attitude has taken place, which makes further Infant Doe cases such as that in Bloomington, Indiana, highly unlikely, but which has made child abuse through overtreatment more likely.” He maintains that there has been no evidence of significant undertreatment of disabled infants since 1985.

Dr. Engelhardt’s presentation can best be summarized by his three “maxims.” First, “avoid seduction by the therapeutic and technological imperatives.” The growth of technology leads to unrealistic expectations of medical treatment. Physicians and hospitals gain profits and notoriety from technological advancement and “their roles as heroic therapists.” According to Dr. Engelhardt, however, these are not sufficient justifications for treatment that may only offer “some benefit of preserving life.”

The second maxim is to “encourage responsible choices on the part of individuals and avoid the intervention of government bureaucracies, whenever possible, in individual life-and-death choices.” Dr. Engelhardt foresees new regulations as leading to “a bureaucratization of medical technology.” Instead of further bureaucratization, the family should play the central role in these decisions.

Finally, Dr. Engelhardt’s third maxim encourages society to “recognize that a treatment that has a chance of saving life may be appropriately declined, if the harms are likely to outweigh the benefits.” Parents should not be restricted in their decisions regarding such treatment: “There should be no obligation to provide inhumane treatment.”

228. Id. at 156 n.6.
229. Id. at 158.
230. Id.
231. Id. at 165.
232. Id. at 159.
233. Id.
234. Id. at 165. “The actual pain and suffering involved in a treatment must be taken into consideration when deciding what treatment, if any, is indicated for individuals who have a good chance of dying.” Id.
235. Id.
236. Id.
237. Id. at 162-63.
238. Id. at 165.
239. Id.
Commissioner Destro’s Response

Commissioner Robert Destro, the major force behind this report, stressed in his statement “the practical and political issues the Commission had to overcome in the course of its deliberations, and to suggest a wider context in which this report and its recommendations should be viewed.” The major problem, both conceptual and political, was to identify which issues were within antidiscrimination and neglect laws, which issues were governed by medical decisions or ethics, and which issues required parental choice.

According to Commissioner Destro, “neither child abuse and neglect nor discrimination on the basis of disability are ‘private’ matters.” Therefore, the question addressed by the report is: “whether medically indicated (i.e. necessary) treatment for a given condition becomes any less ‘necessary’ when the patient has a disability?”

Commissioner Destro likens the placement of the question in the hands of medical ethics to the shift in attitude of physicians in Nazi Germany. The attitude started with an acceptance of quality of life assessments for the “severely and chronically sick” and escalated to include “the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans.” According to Commissioner Destro, the same “subtle shift in attitude” has started.

Commissioner Destro, in an effort to rebut Chairman Allen, points to several reasons why the actual numbers of treatment denial cases are hard to calculate and can only be effectively obtained after the treatment is denied. First of all, governmental efforts to require the posting of information notices encouraging reporting have been struck down in the courts. The reporting of treatment denial cases by employees has led to disciplinary actions and firings. Finally, the HHS Office of Civil Rights opposed investigations and the Civil Rights Division of the Justice Department slowed investigations after the Bowen v. American Hospital Association case.

Commissioner Destro claims that the number of cases, is “almost beside

240. Id. at 207.
241. Id.
242. Id.
243. Id.
244. Id. at 208.
245. Id. at 208 (quoting Alexander, Medical Science Under Dictatorship, 241 NEW ENG. J. MED. 39, 41 & n.17 (1949)).
246. Id.
247. Id. at 208-09.
248. Id. at 208.
249. Id.
250. Id.
the point” because of two other problems.251 First, the boldness with which the discrimination is reported conveys the attitude that those involved see no problem with their behavior. Second, and more relevant to the Commission’s task, the fact that courts have, on occasion and on the face of great public scrutiny, authorized medical neglect of persons with disabilities means that discriminatory attitudes about the “quality” of their lives are shared by those whose obligation it is to enforce our civil rights laws.252 Commissioner Destro rejects any suggestion that these cases be “privatized” or “medicalized.”

In addition, Commissioner Destro discusses and rejects the opposing view that the report’s conclusion centers on “overtreatment.”253 He maintains instead that the report’s context belongs in a realm where “discrimination based on non-medical factors is occurring.”254 The “quality of life” standard is viewed as a “formula” to place a “scientific patina” on medical discrimination.255

Commissioner Destro describes the “most interesting, and personally frustrating” element of the Commission’s work.256 During the first hearing, discrimination issues were virtually ignored: “bioethics, medicine, and personal privacy” emerged on the forefront.257 In the second hearing, “balance” was struck with an emphasis on “disability and rehabilitation issues.”258 He notes, however:

But then, libertarians on the Commission’s staff took over. Firm believers in deregulation, they sat on the transcript of the 1986 hearing, refusing to release it even to this Commissioner, for nearly a full year. Considerable political capital was expended in an attempt to kill the report as late as August 1987. In short, the internal opposition of key staff members to the publication of this report largely accounts for its late release. For some, personal liberty was the motivating reason for their opposition; for others, it was the

251. Id. at 209.
252. Id.
253. Id.
254. Id.
255. Id.
256. Id. at 211.
257. Id.
258. Id.
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“abortion connection” which complicated an objective review of the record. Sadly, neither group ever stopped to consider whether there might really be discrimination going on.259

Commissioner Destro recognized a connection between the “Baby Doe” issue and abortion, not as political, but as “philosophical and moral.”260 Acknowledging the limitations of the law, Commissioner Destro concludes that the report “rejects” discrimination.261

Public Reaction

The Commission’s report drew predictable responses. A Justice Department spokesman defended the government’s position: “We’ve had an aggressive record on intervening on behalf of handicapped infants. We took a lot of heat for intervening in the Stony Brook [Baby Jane Doe] case.”262 Dr. James Strain, executive director of the American Academy of Pediatrics, maintained that the states and hospital ethics committees were fulfilling their responsibility to ensure the care of newborns; therefore, no federal intervention was needed.263

In defense of the report, Reed Martin, of the National Task Force on Integrated Special Education, stated that the report supplies the facts the Supreme Court declared missing in Bowen.264 Other groups supporting the Commission’s efforts included the Pratt Monitoring Group of the District of Columbia Association for Retarded Citizens, The Disability Institute, and Sick Kids Need Involved People (SKIP).

CONCLUSION

The issue of treatment withholding has reemerged. A jury trial in the Western District of Oklahoma recently resulted in a verdict for several doctors affiliated with the Oklahoma Children’s Hospital.265 The case was brought on behalf of three children born with spina bifida. One child, Carlton Johnson, was left untreated for thirteen months and has survived.266 The other two, left untreated, died.267 The case is on appeal to the Tenth

259. Id.
260. Id. at 212.
261. Id.
263. Id.
267. Id. One of the children, Stonewall Jackson Smith, was born without a brain. The
The fruit of the Commission's labor may be seen in the Johnson appeal. Certainly, the Commission's report provides a wealth of information for those concerned about the cases of Carlton Johnson and "Baby Doe." What effect, if any, the report will have in a courtroom remains to be seen.

More predictable is the effect of the report on the medical community. From the evidence gathered in the Commission's report, it is clear that many in the medical community strongly disagree with the Commission's recommendations. A formidable army exists, poised to block any intervention into the decisionmaking process.

Although strongly opposed to the structure of the overturned Baby Doe regulations, Canadian commentators succinctly enunciated the existence of ethical dilemmas. "Certain practices . . . cry out for comment and analysis from both legal and ethical points of view. . . . Broad categories of questionable intensive care practice need to be synthesized from the individual cases. It is those categories of questionable medical practice which require legal and ethical analysis; not individual cases of abuse." While it appears clear that regulations aimed at the identification of individual cases of abuse may continue to be criticized and overturned, the Commission's report should serve as a guideline for identifying "broad categories of questionable intensive care practice."

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judge dismissed the claims against the doctors on the premise that the child would have died anyway. Id.

269. WITHHOLDING TREATMENT, supra note 32, at 37.