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A Report of the
U.S. Commission
on Civil Rights
September 1989

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Medical
Discrimination
Against
Children
with
Disabilities

U.S. COMMISSION ON CIVIL RIGHTS

The U.S. Commission on Civil Rights is an independent, bipartisan agency first established by Congress in 1957 and reestablished in 1983. It is directed to:

- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, handicap, or national origin, or by reason of fraudulent practices;
- Study and collect information concerning legal developments constituting discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin, or in the administration of justice;
- Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, handicap, or national origin;
- Submit reports, findings, and recommendations to the President and Congress.

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LETTER OF TRANSMITTAL

The President
The President of the Senate
The Speaker of the House of Representatives

Sirs:

The United States Commission on Civil Rights transmits this report to you pursuant to Public Law 98-183.

Medical Discrimination Against Children with Disabilities examines the nature and extent of the practice of withholding medical treatment or nourishment from infants born with disabilities and makes recommendations to remedy deficiencies in existing law. The report is based on two Commission hearings and substantial staff research aided by experts and consultants.

Available evidence suggests 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. Discussed in the report is the effect of the relationship between parents and physicians on decisions to withhold medically indicated treatment, a major issue in the Supreme Court's invalidation of Infant Doe regulations in *Bowen v. American Hospital Association*. The report also examines the role of quality of life assessments and economic considerations in medical nontreatment decisions, whether the Child Abuse Amendments of 1984 have been properly implemented and enforced, enforcement of section 504 of the Rehabilitation Act of 1973 and efforts of the Department of Health and Human Services in that regard, whether child protective services agencies and hospital infant care review committees are fully complying with the Child Abuse Amendments, and whether medical discrimination against children with disabilities is part of a larger problem involving discrimination in the provision of medical treatment to persons with disabilities, of whatever age.

The many recommendations in the report include a recommendation that the Executive branch give careful consideration to resuming investigation of allegations of medical nontreatment based on handicap, and that it initiate enforcement of section 504 of the Rehabilitation Act where allegations are found to be justified. It is our hope that the extensive information and analysis contained in the report will be of assistance to you in the formulation of public policy.

William B. Allen, *Chairman*
Murray Friedman, *Vice Chairman*
Mary Frances Berry
Esther G. Buckley
Sherwin T.S. Chan
Robert A. Destro
Francis S. Guess
Blandina C. Ramirez

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Overall supervisory responsibility for the report rested with William J. Howard, General Counsel, and Brian D. Miller, Deputy General Counsel. Preparation of the substantive content of the report was carried out primarily by Commission attorney Thomas J. Balch and Assistant General Counsel Jeffrey P. O'Connell. Also contributing to the report were Commission attorneys Vincent A. Mulloy, Susan T. Muskett, and Joseph J. Piccione.

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Executive Summary

Introduction

In convening the first of two hearings held by the United States Commission on Civil Rights in connection with the subject matter of this report, the Commission announced that its purpose was to "attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government." Expressed otherwise, the subject of *Medical Discrimination Against Children with Disabilities* is the so-called Baby Doe issue.

The Commission's interest in the Baby Doe issue was sparked by events that began in the spring of 1982, when national attention focused on the increasingly desperate efforts of potential adoptive parents and a guardian *ad litem* in Bloomington, Indiana, to save the life of an infant boy born with a tracheoesophageal fistula, a failure of the esophagus and trachea to be properly connected. A child with this condition will starve without the necessary corrective surgery, which has better than a 90 percent chance of success.

Setting the Bloomington Infant Doe apart from most infants, however, was not so much the tracheoesophageal fistula but the presence of Down syndrome, a congenital disability that usually produces some degree of mental retardation. Even were the surgery successful, the attending obstetrician advised the parents, "this still would not be a normal child. . . Some of these children. . . are mere blobs." Declining to authorize surgery, the parents were upheld by the State trial and appellate courts,

and Infant Doe died while an appeal was being filed to the United States Supreme Court.

This and other cases of discriminatory denials of medically indicated treatment of infants with disabilities are recounted in *Medical Discrimination Against Children with Disabilities*. Though much has been said and written about the Baby Doe issue, the uniqueness of the Commission's report lies in the comprehensiveness both of the subject matter it treats and of the period of time it examines. For in addition to discussing Baby Doe incidents in this and in the last decade, separate chapters of *Medical Discrimination Against Children with Disabilities* examine:

- The relationship between physician and parents and its effect on decisions to withhold medical treatment from disabled infants. This was a major issue in the 1986 decision of the U.S. Supreme Court in *Bowen v. American Hospital Association*, invalidating the Department of Health and Human Services' Baby Doe regulations.
- The role of quality-of-life assessments in decisions to withhold medically indicated treatment from disabled infants, exemplified most notably by the quality of life formula, $QL = NE \times (H + S)$, which influenced a team of physicians at Oklahoma Children's Memorial Hospital in denying treatment to 24 out of 69 babies born with disabilities. In this formula, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.

- The role of economic considerations in decisions to withhold medically indicated treatment from disabled infants.

- The universal acceptance under State child neglect statutes of governmental intervention in medical treatment decisionmaking where the children at issue do not have disabilities.

- The Rehabilitation Act of 1973 and resort to section 504 of that act in the aftermath of the Bloomington Infant Doe case; the President's Commission's Report; the proposed Baby Doe regulations; and the Supreme Court's decision in *Bowen v. American Hospital Association*.

- The Child Abuse Amendments of 1984, the standard of care set forth therein, and the effectiveness of the amendments in addressing the Baby Doe issue.

- Constitutional issues.

- Child protective services agencies and their enforcement of the Child Abuse Amendments of 1984.

- The role and performance of hospital-based infant care review committees.

- The performance of the Federal Government in enforcing section 504 and the Child Abuse Amendments.

- Use of the protection and advocacy system as a means of strengthening enforcement of the Child Abuse Amendments.

Pursuant to its statutory mandate to "submit reports to the Congress and the President at such times as the Commission, the Congress or the President shall deem desirable," *Medical Discrimination Against Children with Disabilities* concludes with the Commission's findings and recommendations. These findings and recommendations are reproduced at the end of this executive summary, following a synopsis of each of the chapters upon which they are based.

The Physician-Parent Relationship and Treatment/Nontreatment Decisionmaking

Much of the debate over the question of denying treatment to children with disabilities assumes a conflict between the prerogative of parents to choose medical treatment for their children and the responsibility of government to intervene on behalf of the child where the parents decline to authorize treatment. Ignored, however, is whether, given the extent of physicians' influence on parents in the decisionmaking process, the parents' consent to

withhold medical treatment is, in fact, informed consent. In practice, doctors are often the prime movers in denying the treatment.

The period surrounding the birth of an infant is one of great stress and emotion for the infant's parents. The birth of an infant with a disability typically comes to them as a great shock, with feelings of depression, anger, and guilt. Because most parents have had little or no interaction with people who have disabilities, their assessments of their infants' conditions and prognoses may have little basis, and they thus turn to the attending physicians for information and recommendations. As one commentator noted, "[P]hysicians set the agenda. The person . . . who has the ability to set the agenda has to a large degree the ability to control the outcome." Physicians with a bent toward denial of treatment for persons with disabilities can be quite insistent in conveying negative information. There appears to be near unanimity from health care personnel who support treatment in a Baby Doe situation as well as those who oppose 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 the parental decision whether to authorize treatment.

Unfortunately, there also exists misinformation among many health care personnel and bioethicists advising parents on the advances and alternatives available to children with disabilities. As one witness at the Commission's hearings testified:

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. . . .

[O]ur review of the medical literature and the literature of the new bioethicists revealed that typical physicians and bioethicists have little or no familiarity with life possibilities or community resources available to individuals who are born with handicaps.

Medical Discrimination Against Children with Disabilities focuses solely on questions of discrimination, addressing medical services provided or required to be provided, that are withheld from individuals with disabilities precisely because of their disabilities. It is neither the province nor the purpose of the Commission to oversee, evaluate, or question the exercise of legitimate medical judgment inherent in decisionmaking concerning medical treatment. A civil rights issue appropriate for examination in this report arises

in the context of medical treatment decisionmaking only when such decisionmaking is influenced by factors extraneous to the science and art of medicine: when color, race, age, handicap, or national origin lead to a difference in treatment despite being irrelevant to the bona fide medical judgment.

Denial of Treatment to Newborn Children with Disabilities

The record of the Commission's inquiry leaves no doubt that newborn children have been denied food, water, and medical treatment solely because they are, or are perceived to be, disabled. The Commission concurs with the Senate Committee on Labor and Human Resources, which declared that there was a "sufficient body of evidence" indicating that infants with disabilities were being denied treatment, "not isolated to one or two instances." In some cases, the discriminatory denial of treatment was based on ignorance and false stereotypes about the "quality of life" of persons with disabilities and, in others, misconceptions about the nature of the particular disability the child would have if he or she were permitted to survive.

Attempts to quantify denials of treatment, now or in the recent past, are subject to inherent limitations. When a course of lifesaving treatment is rejected for a child with a disability, the decision typically is not reported to statisticians or public officials. Denial of treatment cases typically come to public attention when a family member or health care professional reports the case to a public agency or rights advocate. Isolated instances of treatment denials at major hospitals have been reported in medical journals in the 1970s and 1980s, written by physicians seeking open acceptance of treatment practices in the medical community. Attitudes of treating physicians and other health care personnel can help judge the prevalence of denial of treatment. Two highly significant surveys of pediatricians published in 1988 suggest that contemporary denial of treatment is not infrequent. As perceived possibility of mental retardation in an infant increased, the tendency of pediatricians to suggest surgery for unrelated medical problems decreased. These surveys supplement the underreporting of discriminatory denials of treatment. Appendix C of this report, moreover, provides evidence that underreporting of denial of treatment cases is a problem in hospital infant care review committees when all the parties in the review process are in agreement on the decision not to treat.

In these cases, State child protective services agencies are not notified, contrary to the requirements of the Child Abuse Amendments of 1984.

Quality of Life Assessments

The arguments typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities. A Nation committed to the equal protection of the laws should address the very real problems people with disabilities and their families face through fostering supportive services and social acceptance, and through defending the statutory rights of persons with disabilities to accessible and integrated transportation, housing, education, health care, and employment. To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission rejects the view that an acceptable answer to discrimination and prejudice is to assure the "right to die" to those against whom the discrimination and prejudice exists.

The Commission received extensive testimony documenting the possibilities that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Research indicates that a negative parental attitude tends to change over time, with increased interaction with the child.

Medical progress has been ongoing, making predictions based on past experience obsolete. Surgeon General C. Everett Koop, for example, testified before the Commission that: "My own lifetime has seen a complete reversal of success and failure. When I first began in the field of pediatric surgery in 1946, most of the things that now have a 95 percent survival had a 95 percent mortality, and indeed, some carried a 100 percent mortality." A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proven wrong. Why do many negative predictions about the future quality of life made at birth for a children with disabilities turn out to be wrong? Physicians may have a propensity for negative prognosis at least in part because they tend to see children with

disabilities at the time that the children are in the hospital and their conditions are at their worst. Those 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.

The quality of life argument extends beyond the life of the person with a disability. It is frequently argued that the continued existence of a person with disabilities will be a burden on the person's family or on society as a whole. In other words, the burden the person causes for others outweighs his or her legal and moral rights to lifesaving treatment.

There is an important difference between technical medical judgments over whether a given course of treatment is likely or not to preserve life or ameliorate an impairment and judgments about whether a person's life is worth preserving through lifesaving medical treatment. 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. The second judgment no more becomes a "medical" judgment by virtue of its implementation through the denial or provision of medical treatment than the decision whether to impose capital punishment becomes a "medical" judgment if execution is by lethal injection.

Recent decades have seen significant, although mixed, progress in dealing with the burdens on people with disabilities and in recognizing their rights and full humanity. At the Federal level, section 504 of the Rehabilitation Act of 1973 applies a general principle of nondiscrimination based on handicap to all programs or activities receiving Federal financial assistance; the Education for All Handicapped Children Act of 1975 promises to all children with disabilities a "free appropriate public education which emphasizes special education and related services designed to meet their unique needs"; the Developmental Disabilities Assistance and Bill of Rights Act gives the Nation's assurance "that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community"; and the Architectural Barriers Act of 1968 is intended to make public buildings physically accessible to people with disabilities.

Economic Considerations

Today, the real economic costs associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, persons considered most severely disabled. The assumption has been that the severity of the disability is the major determinant of lifetime cost and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency. This assumption is a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and nonwork environment that significantly limits that person's capability and entails far more expense than necessary.

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 lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society.

Evidence indicates that the average annual cost of residential services varies more by the type of residential option employed than by the level of need of the client. Group homes, apartments, and family-type homes have been found significantly less costly than institutions for individuals at all levels of disability, including the most severe levels. A clear trend in the direction of family-type placements, the least costly alternative, is developing, especially for children. It seems probable that in real terms the average cost of residential placement for people with disabilities is headed downward.

Despite the cost advantage and desirability of family placement, most contemporary Federal and State policies do not encourage it. Important, often unrecognized, historical reasons are responsible for this. In the early part of this century, the eugenics movement gave rise to the establishment of institutions to remove persons with disabilities from their communities and families because they were thought to be dangerous and responsible for society's ills.

Only recently has an attempt been made to change the Federal Medicaid legislation to give priority in funding to families and community homes. One attempt is the proposed Medicaid Home and Community Quality Services Act of 1987, which has yet

to be enacted. Because providing support for the family is the most cost-efficient way to provide residential services, changing the economic incentives to emphasize family placement rather than institutionalization would significantly reduce the cost associated with disability.

State Law

In popular debate, the question of whether children with disabilities should be denied lifesaving treatment has frequently been couched as though the issue were whether the government should intrude into matters of parental discretion. However, the universally accepted law has been that when parents make treatment decisions that will undoubtedly lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating lifesaving medical care. Only when children have disabilities has the claim of parental autonomy been given serious sympathetic consideration.

Every State provides a statutory basis for the civil authorities to act to protect a child whose life or well-being is threatened by abuse or neglect. In the jurisdictions that receive Federal funding for child abuse and neglect programs, this law must be applied to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions in order to comply with the Child Abuse Amendments.

Parens patriae is the legal doctrine which provides that the state has the authority, in proper circumstances, to intervene in the normal parent-child relationship for the protection of the child. Although primary authority is vested in the parent, that authority is restricted, or even abrogated in full, whenever that authority is abused.

The Rehabilitation Act and Section 504

Enforcement of section 504 of the Rehabilitation Act provides certain advantages not present in the Child Abuse Amendments alone. Section 504 reaches medical discrimination against people with disabilities of any age, while the coverage of the Child Abuse Amendments is limited to children. Additionally, the Child Abuse Amendments apply only to States that choose to accept Federal funding for their child abuse programs.

It creates a strange anomaly for the Federal Government, under section 504, to mandate that State agencies enforce detailed national standards

forbidding medical discrimination, while permitting Federal funds to be used for programs that are engaged in the same discrimination. The Federal Government enforces racial and sexual antidiscrimination standards for recipients of its funds; it should do the same to prevent medical discrimination against persons with disabilities.

Section 504 provides:

No otherwise qualified handicapped individual in the United States. . . shall, solely by reason of his handicap, 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. . . .

Section 504 has been called "the first major civil rights legislation for disabled people. In contrast to earlier legislation that provides or extends benefits to disabled persons, it establishes full social participation as a civil right and represents a transformation of federal disability policy." Modeled on legislation prohibiting race and sex discrimination by recipients of Federal financial assistance, section 504 may be enforced not only by cutting off such assistance but also through suits for injunctive relief by the Attorney General and by aggrieved private individuals.

Reacting to the Infant Doe case and the widespread negative response to it, President Reagan sent a memorandum to the Attorney General and Secretary of Health and Human Services in April 1982 on the enforcement of Federal laws prohibiting discrimination against individuals with a disability. The memorandum required HHS to issue an explanation to health care providers of section 504's applicability to the denial of treatment to newborn children with a disability. HHS was also to enforce section 504 and other appropriate Federal laws to prevent the withholding of potentially lifesaving treatment from children with a disability that would normally be provided to children without a disability. In May 1982, the Office for Civil Rights of the Department of Health and Human Services sent hospitals receiving Federal financial assistance a Notice to Health Care Providers which indicated that it was unlawful to deny nutrition or medical or surgical treatment to an infant with a disability if the denial was based upon the existence of a handicap and the handicap did not render treatment or nutritional sustenance medically contraindicated. Reflecting a concern that hospitals or their staff might attempt to do indirectly what could not lawfully be done directly, the notice

stated that hospital “[c]ounseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under Section 504.” In December 1982, internal guidelines for investigating complaints of discriminatory denial of treatment were sent to the regional divisions of the HHS Office for Civil Rights.

Regulations under Section 504

In March 1983, HHS published an Interim Final Rule. The Supplementary Information published with the Interim Final Rule stated that the purpose of the rule was to “acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to save the life of the infant.” Expressing concern that individuals with knowledge of actions violating section 504 did not have adequate opportunity to give immediate notice to governmental authorities, HHS designed the Interim Final Rule to increase public knowledge of the law, including the manner of bringing suspected violations to the attention of HHS, as well as increase the ability of HHS to investigate alleged violations promptly. In April 1983, a Federal district court judge invalidated the Interim Final Rule on procedural grounds, holding that the Interim Final Rule should have been published for public comment.

Shortly after the judicial invalidation, HHS published a proposed rule substantially similar to the Interim Final Rule. After intensive negotiations with medical organizations and disability rights advocacy groups, the Final Rule was promulgated with significant revisions and contained four mandatory provisions. The Final Rule established basic duties for State child protective services agencies receiving Federal financial assistance in dealing with reports to them of medical neglect of children with disabilities. Each such agency was obligated to establish and maintain procedures to ensure that the agency use its “full authority. . . to prevent instances of medical neglect of handicapped infants.” The procedures included requirements that health care providers report instances of known or suspected medical neglect on a “timely basis”; that a method be established for the agency to receive these reports; that there be immediate review, and where appropriate, onsite investigation, of such reports, and provision for the protection of “medically neglected handicapped infants,” including, if necessary, court

orders to compel necessary nourishment and medical treatment. Further, each State agency was to provide timely notification to HHS of every report of “suspected unlawful medical neglect of handicapped infants.”

Some medical organizations promptly challenged the new rule as unjustified by section 504. The Supreme Court struck down the mandatory provisions of the Final Rule by a 5-3 vote. Only four Justices, however, joined in the opinion, making it a nonbinding plurality, rather than a majority, opinion. The plurality opinion focused on the lack of evidence in the administrative record sufficient to support the regulation: “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.’”

A central problem with the *Bowen* plurality opinion is its suggestion that section 504 places no constraints on a Federal financial assistance recipient’s discriminatory denial of treatment to a person with a disability if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child’s medical treatment. (The logic of the plurality opinion applies equally to such authorizations by other surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities.) In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient’s involvement, would otherwise be prohibited discrimination. A recipient’s substantial involvement in a nonrecipient’s discriminatory practices should be held to violate section 504.

The Commission’s hearings and research supply information related to the issue that the Court considered not to have been satisfactorily addressed in the administrative record at the time *Bowen* was decided. The Commission believes that decisions nominally made by parents to deny treatment to children with disabilities often may in fact be

generated by health care personnel who act as the agents of health care facilities. In such cases, health care providers who do not provide lifesaving medical treatment to children with disabilities, which would be provided were it not for the disabilities, should be held to violate section 504 despite parental acquiescence in the treatment denial.

In light of this, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends 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.

Because there was no binding majority opinion, and because the plurality opinion is ambiguous, it might be appropriate for the Department of Health and Human Services to act to enforce section 504 in a well-documented instance of discriminatory failure to report as a way of ultimately obtaining clarification or adjustment from the Court.

Child Abuse Amendments

The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care that States which receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

Virtually all States receive funds under the Child Abuse Prevention and Treatment Act, and the Child Abuse Amendments therefore apply to them. Additionally, the District of Columbia, as well as Puerto Rico, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, and American Samoa receive such grants and are bound by provisions of the amendments.

Perhaps the best short statement of the medical standard of care established by the Child Abuse Amendments is found in the Supplemental Information HHS published with the Proposed Rule:

[F]irst, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication. Second, all such disabled infants must be given medically indicated treatment. Third, there are three exceptions to the requirement that all disabled infants must

receive treatment, or, stated in other terms, three circumstances in which treatment is not considered "medically indicated."

The centerpiece of the Child Abuse Amendments' standard of care is found in the phrase that treatment must be that "most likely to be effective in ameliorating or correcting all [life-threatening] conditions." It is the care that must be provided to all children covered by the law unless one of the three exceptions applies. This definition creates a high standard of care. 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. This places a responsibility on physicians to become knowledgeable about and employ the best available treatment rather than simply to avoid discriminating on the basis of disability.

Exceptions to Providing Treatment

The Child Abuse Amendments establish three exceptions to the requirement to provide the treatment most likely to correct or ameliorate a child's life-threatening conditions (maximal treatment)—although "appropriate nutrition, hydration, and medication" must always be provided. The exceptions are when in the treating physician's or physicians' reasonable medical judgment:

- (A) The infant is chronically and irreversibly comatose;
- (B) The provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or
- (C) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

State Programs and Authority

Under the statute as enacted, within 1 year after the act became law, State agencies desiring to receive the Federal funds had to have procedures and programs to permit coordination with the health care facilities, prompt notification by health care facilities for cases of suspected medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions), and authority, under State law, for the State child protective service system to pursue any legal remedies, including the authority to

initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.

Constitutional Issues

The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases where food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. 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 the Supreme Court's decision in *Bowen v. American Hospital Association*, it has been clear that judicial action is insufficient to protect newborn children with disabilities. The task of protecting such children from discrimination and neglect, whether based on ignorance or outright prejudice, thus falls to Congress and to the State legislatures.

Incidence of Discriminatory Denial of Medical Treatment

A significantly high incidence of medical discrimination against children with disabilities exists that is part of a much larger pattern of medical care discrimination against people with disabilities. This incidence largely persists despite 3 years of experience under the Child Abuse Amendments. The Commission relied on specific cases; testimony at the Commission's hearings, including the testimony of people with disabilities and their relatives; the repeatedly declared views of physicians set forth in professional journals; surveys of health care professionals; and investigative reporting.

Enforcement of Child Abuse Amendments by the Child Protective Services Agencies

Principal enforcement responsibility for the Child Abuse Amendments resides with State child protective services (CPS) agencies, the variously named entities that exist to administer each jurisdiction's child abuse and neglect laws. Under current law, the fate of children with disabilities who are threatened with denial of lifesaving medical treatment, food, and fluids largely depends on how effectively CPS

agencies carry out this responsibility. Alternative avenues of protection are scarce. Direct Federal efforts to prevent this type of medical discrimination to date have been stymied.

The close working relationship between some CPS personnel and members of the medical profession has resulted in the substantial failure of many State child protective service agencies to effectively enforce the child Abuse Amendments.

CPS Delegation of Investigative Responsibility

Virtually all jurisdictions receive Federal funds from the Department of Health and Human Services under the Child Abuse Prevention and Treatment Act. A review of their policies and procedures has shown that on their faces, the policies of 14 of these States explicitly abdicate to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is taking place when a report of suspected denial of treatment is received by the State agencies.

Under the Child Abuse Amendments, agencies must make the determination whether treatment is medically indicated. The existence of hospital-administered infant care review committees (ICRC) does not relieve a State CPS agency of its responsibility to investigate suspected cases of withholding of medically indicated treatment or to employ its legal authority to prevent such withholding. The widespread readiness of CPS agencies to surrender their arms-length oversight responsibility concerning medical neglect appears in part to be rooted in the special relationship that has developed between CPS workers and members of the medical profession. In dealing with traditional forms of child abuse and neglect, CPS agencies rely primarily on health care professionals for diagnosis and reporting.

In contrast to the receptivity of most CPS agencies to views from medical organizations, views from disability organizations—the groups representing those whom the amendments were designed to protect—are ignored in many cases. According to one survey of 37 responding jurisdictions, 34 said that they had consulted with medical representatives in formulating their implementing procedures, while only 11 said they had consulted with disability groups.

Failure to Comply with Federal Regulations

In direct contravention of Federal regulations, six States' CPS agencies have no written policy specify-

ing how they would obtain medical records to investigate a report of medical neglect. Four States' CPS agencies have policies that fail to provide for securing an independent medical examination of a child with a disability about whom a report of a suspected medical neglect has been filed. The impression that some States pay little or no attention to the standards of treatment embodied in the Federal law and regulations is reinforced by the fact that eight States' CPS agencies have policies that either misdefine the term "withholding of medically indicated treatment," do not define it at all, or define the term in such an abbreviated fashion as to invite ambiguity and uncertainty.

Many States are not even clear in their policies concerning who is covered by the standards of treatment in the act. Twenty-two State CPS agencies have policies that either do not define the term "infant" or—in direct contravention of the governing regulations—define the term to encompass only infants of less than 1 year in age.

CPS agencies are part of the State government, often in the same department that runs hospitals and other institutions that provide medical treatment to children with disabilities. This can create a direct conflict of interest.

Infant Care Review Committees

Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments, and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

At the same time, it is clear that such committees are here to stay. Therefore, the Commission believes there is a need to ensure 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.

The establishment of infant care review committees—internal hospital committees that consider instances in which life-preserving medical treatment is being or may be withheld from infants with disabilities—is encouraged by the Child Abuse Amendments, as it was by the section 504 Final

Rule. A 1986 survey found that 51.8 percent of hospitals with either a neonatal intensive care unit or over 1,500 births annually had established such committees, and an additional 8.9 percent were in the process of forming them. The proponents of ethics committees attempt to shift the question from the substantive one of whether treatment should be withheld to the procedural one of who should decide whether treatment should be withheld.

The Final Rule of section 504 includes a recommendation that hospitals establish infant care review committees. However, HHS recognized that the original rationale for ethics committees stood in stark contrast to the approach embodied in the nondiscrimination tenets of section 504. Inherent in reliance on section 504 was the assumption that the law establishes a societally defined basis for determining when life-preserving treatment must be provided to children with disabilities and when it may be withheld from them. In contrast, inherent in the original rationale for ethics committees was the assumption that such determinations should be decided on a case-by-case basis varying from hospital to hospital. Because of this dichotomy, the Final Rule explained that HHS revised a model proposed by the American Academy of Pediatrics "to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."

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 enactment of the law, but would instead focus on an analysis of how the law should properly be applied to the facts of that case. The "ethical issues" concerning what circumstances justify withholding of treatment would not be reconsidered on a case-by-case basis. The issues were to be regarded as settled by the Child Abuse Amendments.

Infant Care Review Committees in Action

Are the infant care review committees serving as prognosis committees, providing advice concerning whether or not the facts in particular cases bring them within the circumstances the Child Abuse Amendments define as requiring treatment? Or do they act as "ethics" committees, making quality of life judgments about whether or not treatment should be withdrawn without reference to detailed legal standards—the role originally envisioned for them by the President's Commission and the Ameri-

can Academy of Pediatrics? It appears that the vast majority of committees convene only to deal with disagreements and do not make an attempt to scrutinize most denial of treatment decisions to ascertain 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.

Even before the passage of the Child Abuse Amendments, the Federal regulations implementing the Child Abuse Prevention and Treatment Act required States receiving Federal funding for their child protective services programs to "provide by statute or administrative procedure that all other persons are permitted to report known and suspected instances of child abuse and neglect to a child protective agency or other properly constituted authority." The implementing regulations for the Child Abuse Amendments establish that States receiving Federal funds must ensure that health care facilities designate individuals with the duty to notify promptly the State child protective services agency of all "cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions)."

Because not merely known but also "suspected" instances must be reported, the health care facility's obligation to notify the State agency is not limited to cases in which, for example, the infant care review committee or the responsible hospital official makes a final determination that illegal withholding of treatment is occurring or about to occur. Nor is it limited to cases in which the infant care review committee or the responsible hospital official has attempted to obtain treatment but has failed and is turning to the civil authorities as a last resort.

Limitations of Hospital Self-policing

It is questionable whether most committees are constructed in a manner that permits searching scrutiny of proposed denials of treatment. Infant care review committees, although they upon occasion have "outside" members, represent an approach to the "Baby Doe" problem that relies essentially upon the internal self-regulation of the health care community. The Department of Health and Human Services and the American Academy of Pediatrics

recommend that committees include representatives of disability groups. A 1986 survey found that, of the responding hospitals, less than a quarter of the committees—23.9 percent—had a disability group representative.

A preponderance of medical personnel on committees does not necessarily mean that they are especially well equipped to serve as prognosis committees. Ethics committees are largely insular bodies, sharing the mores and limitations of knowledge of the local hospital. A reluctance to criticize one's colleagues, let alone report their decisions to a State agency, is only natural in such a setting. Resort to infant care review committees presents the same problem generally applicable to the creation of an internal body as a means of showing the public that the institution is serious about correcting abuses: an institution rarely does a good job of policing itself. Outside oversight is needed.

Federal Government

The Commission is dismayed at the extremely poor performance of the Department of Health and Human Services in fulfilling its responsibilities to protect children with disabilities from medical discrimination, first under section 504 of the Rehabilitation Act in the time period before its use was enjoined, and currently under the Child Abuse Amendments of 1984. That performance requires substantial improvement.

Although the Commission is encouraged by steps the Office of Human Development Services of the Housing and Human Services Department now states it will take in response to this report, it is too soon to determine whether this will result in a very significant increase in scrutiny of the performance of recipient State child protective services agencies that is essential if the Department is to fulfill effectively its responsibilities under the law.

Responsibility for enforcing section 504 rested with the Office for Civil Rights (OCR) in the Department of Health and Human Services. In none of the cases OCR investigated—even the Bloomington Infant Doe case—did it make a public finding that a section 504 violation occurred. If a discriminatory denial of treatment was found, OCR asked for assurances that practices would be changed to achieve compliances. If it received them, it did not make a public "finding of discriminatory withholding of medical care." In theory, OCR might detect noncompliance in fact and secure remedial action by

the discriminating party, thus fulfilling its role, without officially reporting a finding of noncompliance.

In at least two instances known to the Commission, OCR delayed taking action. Confronted 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, OCR failed to act with the vigor and dispatch incumbent on it in light of the circumstances, let alone consistent with its legal responsibilities and its publicly stated position.

Although several State Child Protective Services agencies failed to meet the standards and procedures required under the Child Abuse Amendments and their implementing regulations, the States have been certified by HHS for receipt of Federal funds under the Child Abuse Prevention and Treatment Act, without being advised that they are out of compliance or being given any deadline to bring their standards and procedures into compliance. The Commission considers this a significant failing on the part of HHS.

In a report on infant care review committees, the HHS Office of the Inspector General identified between 20 and 36 potential Baby Doe cases considered by 10 committees whose activities were monitored. Only three cases were reported to State CPS agencies. The Office of Inspector General did not review the facts in the unreported cases to determine whether or not they met the standards established in the Child Abuse Amendments. It is hard to see how, without doing this, the Department could accomplish its task of ascertaining whether the committees are fulfilling what HHS has described as "the role of the ICRC [infant care review committee] to review the case. . .and recommend that the hospital seek CPS agency involvement when necessary to assure protection for the infant and compliance with applicable legal standards."

The Protection and Advocacy System: A Resource for Enforcement

In 1975 Congress established structures called Protection and Advocacy Systems (P&A), originally attuned specifically to the need to ensure vigorous advocacy of the rights of persons with developmental disabilities. The Developmentally Disabled Assistance and Bill of Rights Act required that each State or similar jurisdiction receiving Federal funding for persons with developmental disabilities establish an

independent system with "authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of [persons with developmental disabilities]."

In 1984, in substantially expanding funding for the P&A systems, Congress recognized both their importance and their impressive track record. The Senate Committee on Labor and Human Resources Report noted that P&As are an expanding effort by Congress to assure disabled persons protection of their rights under law. In 1986 Congress chose "to build on the experience of the existing P&A System in investigating and resolving situations involving abuse and neglect" of persons with mental illness by adding responsibility for advocacy for this population to the P&As.

The Commission thinks that the P&A system affords an experienced and appropriate resource to remedy discriminatory denial of medical treatment, food, and fluids to people with disabilities. P&As currently have a general jurisdiction that encompasses such instances. The Commission believes that the P&A system should be brought into active involvement in efforts to prevent illegal denial of treatment to children with disabilities. In summary, the Commission envisions the following approach:

- Prompt reports of suspected or actual cases of withholding of medically indicated treatment would still go to CPS agencies, which would retain the authority and responsibility to investigate them. However, the State P&A agency would be notified by the CPS agency as soon as the report was received. The P&A would have access to records. As a representative of the interests of the child, the P&A agency would have independent authority, similar to that now held by the CPS agency, to obtain medical records and to obtain a court order.
- To catch cases not being reported to the CPS agency, any hospital that uses a committee to review a prospective withholding of treatment from a person with a disability would be required to notify the State P&A agency of meetings held to discuss the case. The P&A would be able to review the records and discuss the situation. A court order could be sought by the P&A.
- To provide a deterrent to physicians disposed to not reporting a case to the State CPS agency or a hospital committee, the P&A could conduct retrospective reviews of the medical records.

The Commission sees several advantages to involving the P&A systems more directly in the enforcement of the Child Abuse Amendments of 1984. First, the P&A system has more specialized experience in safeguarding the rights of persons with disabilities than the CPS system. While the CPS system deals with the abuse and neglect of all children, most of whom are not disabled, the P&A system since its inception has concentrated on protecting the rights of persons with disabilities. Second, the P&A system is less likely to be affected by conflicts of interest than the CPS system because the P&A system is statutorily independent of State agencies and hospitals. Third, unlike the reliance by the CPS agencies on the medical profession, P&A agencies have no special relationship with the medical profession that could impair their ability to be vigorous advocates. Fourth, P&A agencies are accountable to the populations they serve. They must provide an annual opportunity "to assure that persons with developmental disabilities have full access to services of the system." This provision for oversight, not present in most CPS agencies, is an important check on the danger of relaxing the vigilance and vigor essential to effective advocacy.

The Commission believes that appropriate additional funding for the P&As will be needed to implement these new responsibilities. It should be adequate both for State-by-State implementation and for supportive training and technical assistance, including resources for the rapid evaluation of medical conditions. With these powers and resources, the P&A system would be in a position to bring about what the Commission believes would be a significant improvement in enforcement of the medical treatment rights of persons, especially children, with disabilities.

Findings and Recommendations

Based on its hearings, research, and the report, the Commission adopts the following findings and recommendations.

General Findings

1. Surveys of health care personnel, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to persuade the Commission of the likelihood of widespread and

continuing denials of lifesaving treatment to children with disabilities.

2. The Commission is convinced that the evidence supports a finding that discriminatory denial of medical treatment, food, and fluids is and has been a significant civil rights problem for infants with disabilities. It is also persuaded that the available evidence strongly suggests that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

3. The grounds typically advanced to support denial of lifesaving medical treatment or food and fluids are based on erroneous judgments concerning the quality of life of a person with a disability or on social judgments that such a person's continued existence will impose an "unacceptable" burden on his or her family or on the Nation as a whole. These judgments are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities.

4. Many people, including members of the medical profession, hold negative attitudes about life with disability that affect not only children but also adults with disabilities. Moreover, direct testimony was provided at the Commission hearings that these attitudes exist and that discrimination in the provision of lifesaving and other medical treatment occurs with respect to adults with disabilities as well as in cases involving infants and children. Further fact-finding is needed to determine the extent of discriminatory denial of medically indicated treatment in cases involving adults with disabilities.

5. There is evidence that in many instances in which lifesaving treatment is denied to children with disabilities, their parents are only nominally making the decision to withhold the treatment. In practice the doctors are often the prime movers in denying the treatment.

6. The question of whether children with disabilities should be denied lifesaving treatment has frequently been couched in popular debate as though the issue were the wisdom of government intrusion into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental

autonomy is given serious sympathetic consideration. Thus, the decisions upholding putative parental decisions to deny lifesaving treatment to their children with disabilities are rooted less in a respect for parental authority than in a bias against disability.

7. There are substantial economic costs associated with some forms of disability. Many costs, however, are less a function of the disability or the severity of the disability than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled without even considering the alternative of providing social and economic support for the family. The assumptions influencing denial of treatment have often been: (1) that the level of severity of disability is the major determinant of lifetime costs; (2) consequently, that the more severely disabled a child may appear to be at birth the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency; and (3) therefore, the more expensive it will be to meet that person's basic needs. Although these assumptions rest on major fallacies, reliance on them has resulted in a self-fulfilling prophecy: a diagnosis of severe disability at birth leads to placements in residential and nonwork environments that significantly limit that person's capability and entail far more expense than necessary. The ultimate irony occurs when the expense that is the consequence of the original unfounded and stereotypical assumption becomes a basis for ending the lives of persons with severe, or what are thought to be severe, disabilities shortly after they are born.

8. The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases in which food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the law is offended when disability is the basis of a nontreatment decision. Procedural protections for the interests of both child and parents are often absent completely or are woefully inadequate to the task of sifting the facts.

General Recommendations

1. The Commission concludes that the Congress and the President should address the very real problems faced by people with disabilities and their

families. The President should take the lead in fostering the development of a climate of social acceptance of persons with disabilities and their families by speaking publicly on the issue. The President should instruct the White House Council on Domestic Policy to review the adequacy, as well as the coordination and development of, supportive services intended to assist such families. The President should order a review of the mechanisms designed for vigorous enforcement of the statutory rights of those with disabilities to accessible and integrated transportation, housing, education, health care, and employment. In addition, the appropriate committees of the Congress should schedule hearings to address these questions.

2. In considering legislation designed to prevent discrimination against persons with disabilities, Congress should take care to make clear that discrimination in the course of rendering medical treatment is precluded.

3. There is a need for factfinding activities by the Congress, the State legislatures, and Federal, State, and local agencies charged with the enforcement of civil rights laws and medical standards, to determine the extent to which adults with disabilities are subjected to discrimination in the provision of medical care and treatment, and to evaluate what remedies exist or are needed to prevent future discrimination of this kind from taking place. In particular, the new Secretary of Health and Human Services should direct the Department to undertake such a study.

Specific Findings Regarding Support for Families with Disabilities

1. The period surrounding birth is a time of considerable stress and emotion, and for nondisabled parents the birth of a child with a disability typically comes as a great shock. While beset by traumatic feelings of depression, grief, anger, and guilt, many such parents today have inadequate accurate information with which to make considered evaluations concerning the nature of life with a disability or the consequences for a family that includes a child with a disability.

2. One of the principal motivations for denial of lifesaving treatment to children with disabilities is the view that their continued existence will create too great a burden for their families. There is evidence that this concern has led to concurrence or

acquiescence in the death or elimination of these children.

Specific Recommendations Regarding Support for Families with Disabilities

1. Congress should amend the Medicaid Act or other appropriate legislation to require that recipients of Federal financial assistance for medical services provide specific information on support and resources to parents of newborn children with disabilities. This should include information on adoption and, when necessary, information on other supported family placement with resources necessary to care for the child.

2. Congress should amend the Medicaid Act or other appropriate legislation to lower the adjusted gross income ceiling that a family must spend on disability-related medical expenses before the family member with a disability becomes medicaid eligible.

Specific Findings Regarding Section 504 of the Rehabilitation Act of 1973

1. The hearings and research conducted by the Commission, and the findings based on them, especially General Finding 5, supply a factual record that was absent in 1986 when the United States Supreme Court decided *Bowen v. American Hospital Association*, striking down regulations intended to assist enforcement of section 504 in the context of discriminatory denial of treatment to children with disabilities.

2. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a recipient of Federal financial assistance responsible for the discriminatory denial of treatment to a person with a disability, if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment.

3. The Commission's findings suggest that parents who authorize denial of treatment to their children with disabilities are frequently substantially influenced in that decision by the views of their children's physicians and other health care personnel who frequently display inadequate awareness of the potential of these children.

4. In cases in which decisions nominally made by parents to deny treatment to children with disabilities are in fact generated by health care

personnel, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

5. The logic of the *Bowen* plurality opinion applies equally to authorizations for denial of treatment by other nonrecipient surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions.

6. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities. In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

7. The Commission's reading of the legislative history and plain meaning of section 504 of the Rehabilitation Act of 1973 persuade it that the provision does cover discriminatory denial of medical treatment to people with disabilities.

8. The Commission concludes that passage of the Civil Rights Restoration Act establishes that a hospital's practice of reporting to State agencies instances in which parents withhold consent for provision of lifesaving treatment to their children is covered by section 504. The act defines section 504's coverage to include "all of the operations of . . . an entire corporation, partnership, or other private organization. . . which is principally engaged in the business of providing . . . health care. . . ." If a hospital engages in reporting cases of medical neglect to the State child protective services agency, that practice of reporting is among the operations of a corporation that principally provides health care. Therefore, if any part of the hospital receives medicaid or medicare, discrimination in reporting based on handicap (such as a practice of reporting instances in which religiously motivated parents refuse consent for lifesaving treatment for nondisabled children to the authorities, but failing to report instances in which parents refuse consent for lifesaving treatment for children with disabilities) violates section 504.

9. During the period in which enforcement of section 504 in this context was not yet enjoined, the performance of the Office for Civil Rights of the Department of Health and Human Services in implementing it was poor. Confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities, evidence that suggested an ongoing threat to lives in two 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.

Specific Recommendations Regarding Section 504 of the Rehabilitation Act of 1973

1. In light of the record developed by this Commission, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends 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.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to make clear that withholding of medically indicated treatment, as defined in the Child Abuse Amendments of 1984, constitutes denial of the benefits of health care services for purposes of Title VI and section 504.

Specific Findings Regarding the Child Abuse Amendments of 1984

1. The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

2. Parents engaged in life and death decisions for their children are heavily dependent on the good faith of, and accurate information provided by, those advising them. Because advisors may be ignorant or prejudiced about persons with disabilities, there is a need for the establishment of a broadly based advisory process that includes members of the local

protection and advocacy system (P&As) and others with expertise in disability and rehabilitation. Establishment of a structured care review process or committee will ensure that the decision made is in compliance with the standards set forth in the Child Abuse Amendments, provided that any participant in the advisory process who is concerned with the well-being of the child has standing to invoke the remedies that are otherwise available under State law and the Child Abuse Amendments for dealing with child neglect.

3. Many State child protective services agencies rely heavily upon members of the medical profession for information and assistance concerning cases of parental child abuse. This close working relationship has also led to heavy reliance by many State child protective services agencies on the very medical care facilities and personnel whose actions, advice, or neglect are at issue in cases of suspected medical care discrimination. Taken together, such close working relationships among State child protective services agencies and members of the medical profession has resulted in the substantial failure of many such agencies to enforce effectively the Child Abuse Amendments of 1984.

4. It is questionable whether most hospital-based ethics or infant care review committees are constructed in a manner that makes them likely to conduct searching scrutiny of proposed denials of treatment. They represent an approach that relies essentially upon the internal self-regulation of the health care community. Few committees include representatives of disability rights groups; the majority convene only to deal with disagreements, rather than attempting to scrutinize most denial of treatment decisions to see whether they comply with the law. Instead of strictly applying the Child Abuse Amendment standards, many appear in practice to use more ambiguous criteria that include consideration of the projected "quality of life" of the child with a disability. Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

5. The Commission is dismayed at the poor performance of the Office of Human Development

Services of the Department of Health and Human Services in fulfilling its responsibility to ensure that State child protective services agencies receiving funds under the Child Abuse Prevention and Treatment Act comply with the Child Abuse Amendments of 1984 so as to protect children with disabilities from illegal discrimination in the provision of medical care. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

Specific Recommendations Regarding the Child Abuse Amendments of 1984

1. Because funds available under the Child Abuse Prevention and Treatment Act are apparently not sufficient to induce all jurisdictions to comply with the Child Abuse Amendments in order to qualify for them, compliance with the Child Abuse Amendments should be made an additional requirement for State eligibility for participation in medicare, so that the protections they afford will be made available to all children with disabilities in the United States.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to establish a mechanism to improve reporting of cases of suspected withholding of medically indicated treatment by requiring that any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability is required to notify the State protection and advocacy (P&A) agency of meetings held to discuss the case. The P&A agency should then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. It should have authority to obtain a court order for an independent medical examination, and if it concludes that medically indicated treatment would otherwise be withheld illegally, it should have the standing to institute a court proceeding to require that it be provided.

3. Hospitals without a specialized advisory process for dealing with the special needs of parents for information on disability and rehabilitation should be

required to establish a process in accordance with the provisions of the Child Abuse Amendments and the recommendation made above.

4. Representatives of the local protection and advocacy system should be included in the advisory process, both as advocates for the child's interests and as a resource for the information of the parents.

5. Congress should amend section 504 and the Child Abuse Amendments to require the establishment of such a care review process or committee within treatment facilities across the country.

6. Should any participant in a care review advisory process not be satisfied that the outcome of the process is in compliance with the standards set forth in the Child Abuse Amendments, that person should have standing to invoke such remedies, judicial or otherwise, that are available under State law for dealing with child neglect.

7. When a State child protective services agency (CPS) receives a report of suspected withholding of medically indicated treatment under the Child Abuse Amendments, it should be required promptly to notify the State P&A agency and to provide it access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency should have independent authority, similar to that now held by the CPS agency, to obtain medical records, to obtain a court order for an independent medical examination, to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency. The P&A agency should also have independent standing to initiate a court proceeding to authorize medical treatment for the child.

8. To create a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A agency should be given authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment are detected, the P&A agency should be able to seek appropriate action by licensing boards or Federal funding sources and, in extreme cases, to institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

9. Congress should afford P&A agencies appropriate financial and backup assistance to enable them to fulfill these roles capably.

10. The Office of Human Development Services in the Department of Health and Human Services should take corrective measures to ensure more rigorous scrutiny of State plans submitted for funding under the Child Abuse Prevention and Treat-

ment Act to remedy the current widespread failure of State child protective services agencies to comply with the requirements of the Child Abuse Amendments of 1984.

Fundamental Rights: An Introduction to Medical Discrimination Against People with Disabilities

The Chairman opened the first hearing the United States Commission on Civil Rights held on the subject matter of this report by setting forth the Commission's aim:

The purpose of this hearing is to attempt to determine the nature and extent of the practice of withholding medical treatment or nourishment from handicapped infants and to examine the appropriate role for the Federal Government.

Section 504 of the Rehabilitation Act of 1973, as amended, prohibits discrimination against qualified handicapped individuals under any program or activity receiving Federal financial assistance. In the spring of 1982, reports of the death of a Bloomington, Indiana, infant with Down's syndrome, from whom available surgical treatment to correct a detached esophagus was withheld, prompted widespread attention on the medical treatment of handicapped newborns. Following the Indiana incident, the Department of Health and Human Services [HHS] issued a notice to recipient hospitals reminding them of the applicability of section 504 to the treatment of handicapped infants. HHS then issued interim and proposed rules governing nondiscrimination in the treatment of these newborns, both of which were challenged in courts and struck down.

Last fall Congress passed the Child Abuse Amendments of 1984, requiring States seeking child protection funds from the Federal Government to take certain steps to protect handicapped newborns. HHS has issued rules and model guidelines under that statute which have been made final and will become effective in October of this year.

The primary focus of this hearing is the role the Federal Government should play. . . .¹

¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 1-2 (1985) (vol. I) (statement of Clarence M. Pendleton, Jr., Chairman, U.S. Commission on Civil Rights).*

One year later, the Commission held a second hearing to receive testimony concerning the Supreme Court's decision in *Bowen v. American Hospital Association*,² which invalidated regulations issued by HHS to implement section 504, and to examine the manner in which the regulations promulgated under the Child Abuse Amendments had been implemented in the period since the first hearing.

Underlying both sets of hearings, and thus this report, is concern about the appropriate role of the Federal Government in safeguarding the rights of children with disabilities under both section 504 and the Child Abuse Amendments of 1984 to be free of discrimination in the provision of lifesaving medical treatment. Three years have passed since the regulations implementing the Child Abuse Amendments took effect, and two and a half years have passed since the section 504 regulations were rendered unenforceable by *Bowen*. Thus, in evaluating the performance of the Federal Government in addressing the statutory rights of children with disabilities to lifesaving medical treatment, this report raises the question whether modifications to current laws and practices are desirable.

Included in the Commission's mandate is the responsibility to appraise the laws and policies of the Federal Government and to examine legal developments with respect to discrimination or denials of equal protection of the laws under the Constitution because of handicap.³ This report focuses solely on

² 476 U.S. 610 (1986).

³ 42 U.S.C.A. §1975c (West Supp. 1988).

questions of discrimination. It addresses medical services that are already provided or required to be provided to nondisabled individuals but that are withheld from individuals with disabilities precisely because of the disabilities.⁴ It is neither the province nor the purpose of the Commission to oversee, evaluate, or question the exercise of legitimate medical judgment that is inherent in decisionmaking concerning medical treatment. The Commission emphatically disclaims any competence or intention to judge whether particular medical treatments are more efficacious than others or at what times a medical treatment is effective or futile. Such judgments in individual cases may be correct or they may be mistaken. They may raise questions appropriate for examination through peer review, licensing boards, or malpractice cases; but they do not entail civil rights issues.

A civil rights issue appropriate for examination by this Commission arises in the context of medical treatment decisionmaking only when such decisionmaking is influenced by factors extraneous to the science and art of medicine: when color, race, age, handicap, or national origin lead to a difference in treatment despite being irrelevant to the bona fide medical judgment.⁵ If kidney dialysis, for example, is withheld from someone because it is medically contraindicated, such a judgment is outside the

⁴ Preexisting child abuse and neglect laws throughout the States create the obligation to provide children lifesaving medical treatment. See chap. 5. The statutory or constitutional rights of children with disabilities to receive equal treatment are found in section 504 of the Rehabilitation Act of 1973 (29 U.S.C.A. § 794 (West 1985)), the Child Abuse Amendments of 1984 (42 U.S.C.A. §§ 5101-03 (West Supp. 1988)), and the due process and equal protection clauses of the 14th amendment (U.S. Const. amend. 14 § 1). Section 504, considered in chap. 6, is explicitly an antidiscrimination statute; given a preexisting program or activity receiving Federal financial assistance, handicap cannot be the sole basis for someone's being excluded from the program, denied benefits under the program, or otherwise subjected to discrimination in the program. While the Child Abuse Amendments of 1984, considered in chap. 7, define an explicit standard of medical care for children with disabilities, they do so in the context of a system that has been universally applied to require similar care for children without disabilities. The equal protection clause, considered in chap. 8, creates a nondiscrimination standard applicable when a state actor that provides medical care or legal protection to those without disabilities unwarrantably denies it to those with disabilities precisely because of the disabilities. The constitutional procedural due process rights also considered in chap. 8 presuppose an existing substantive benefit which they ensure may not be denied by processes that fail to meet standards of fundamental fairness.

⁵ "A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant

scope of the Commission's purview. But if medically indicated kidney dialysis is withheld from a person with a disability precisely because of the disability (and the disability itself does not make provision of the dialysis ineffective or dangerous), that raises a civil rights issue suitable for consideration by the Commission.

A number of well-publicized cases has raised concern that discrimination based on disability may be occurring in the provision of health services.⁶ Reports of such cases convinced the Commission to undertake consideration of the laws that do and should govern, of the prevalence and context of discriminatory practices, of the effectiveness of past and present Federal Government activity in this field, and of options for future Federal Government policies.

Oklahoma Case

Denial of treatment practices at Children's Hospital of Oklahoma⁷ is currently the subject of a lawsuit brought by the American Civil Liberties Union and the National Legal Center for the Medically Dependent and Disabled on behalf of Carlton Johnson.⁸ The black child of a "welfare mother," he was allegedly left to die by hospital staff at a "children's shelter" after he was born with spina bifida.⁹

has Down's Syndrome is not a *bona fide* medical judgment." *United States v. Univ. Hosp., State Univ. of New York at Stony Brook*, 729 F.2d 144, 162 (2d Cir. 1984) (Winter, J., dissenting).

⁶ Some of these cases also raise the concern that, within the class of people with disabilities, discrimination may also be occurring based on economic status or social class. Frank Bowe, director of the American Coalition of Citizens with Disabilities, testified: "[I]t has been shown again and again. . . that persons who are disabled who are members of minority groups are denied an education or are denied medical care or denied any kind of opportunity to get vocational training." U.S. Commission on Civil Rights, *Civil Rights Issues of Handicapped Americans: Public Policy Implications* 39 (1980) at 28-29.

⁷ At the time of the alleged events that are the subject of the lawsuit, the hospital was named Oklahoma Children's Memorial Hospital.

⁸ Paulus, *Suit Filed in Oklahoma Alleging Twenty-Four Infants Died After Being Denied Beneficial Medical Treatment*, 1 *Issues in L. & Med.* 321, 324-25 (1986). Amended Complaint, para. 78, at 13, *Johnson v. Gross*, No. CIV-85-2434-A (W.D. Ok. filed July 14, 1987).

⁹ Spina bifida, also known as myelomeningocele or meningocele, is a congenital disability consisting of a gap or improper opening through the vertebrae of the spinal column. It results from a failure of the developing spinal cord to roll into a completely tubular structure during the early stages of pregnancy. Spina bifida manifesta, also called spina bifida aperta, results when the spinal cord or some of the nerve tissue lining surrounding the cord extend through the opening in the verte-

Carlton Johnson was evaluated by a medical team using a procedure under which, as described in an earlier medical journal article, 24 out of 69 babies analyzed were denied surgery and died.¹⁰ Infants born with spina bifida were evaluated by a "myelomeningocele team" shortly after birth. In this evaluation, the team members wrote, they were "influenced" by a quality of life formula: $QL = NE \times (H+S)$. In this formula:

QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.¹¹

Based on the assessment, the team recommended to the parents that the infant be given either vigorous or supportive care. Vigorous care involved, at a minimum, closing the spinal lesion. Supportive care, by contrast, consisted of a "regular follow-up . . . until death or until a decision to treat the child more aggressively is made."¹² The team members acknowledged that "treatment for babies with identical [degrees of mental and physical

brae. The protruding tissues often form a fluid-filled sac on the infant's back. In 96 percent of the cases of spina bifida manifesta, the spinal cord itself protrudes through the gap in the vertebrae. Spina bifida involves various degrees of (1) muscle weakness and paralysis below the opening; (2) sensory loss below the opening; (3) hydrocephalus [see note 14, *infra*] in about 70 percent of the cases; and (4) bowel and bladder incontinence. H. Swinyard, *The Child with Spina Bifida* 5 (1980).

According to Dr. David McLone, head of Pediatric Neurosurgery at Chicago Children's Memorial Hospital, "Spina bifida has been referred to as the most complex disease which is compatible with survival." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 6 (vol. I) (1985). At least 6,000 children are born with spina bifida each year in the United States. *Id.*

Dr. McLone testified concerning the typical technical context of treatment decisions concerning spina bifida:

The problem arises that if they are not operated on within a few days of life, they will acquire a potentially lethal infection, and if they are left unoperated on, approximately half of the children, in most studies, will die. If their back is repaired and closed, then about 90 percent of the children will go on to develop rapidly progressive hydrocephalus and require a second operation to install a shunt, a small tube to drain the fluid from their brain into another brain cavity.

Id. at 6. See note 14 *infra* for a discussion of hydrocephalus.

¹⁰ Gross, Cox, Tatyrek, Pollay, & Barnes, *Early Management and Decision Making for Treatment of Myelomeningocele*, 72 *Pediatrics* 450 (1983).

¹¹ *Id.* at 452.

¹² *Id.* at 454.

¹³ *Id.* at 456.

¹⁴ Paulus, *supra* note 8, at 324. Sherwood, *Who Lives, Who Dies?—Part I*, Cable News Network Documentary (Feb. 21, 1984).

disability] could be quite different, depending on the contribution from home and society."¹³

In the case of Carlton Johnson, the medical record stated:

"neurosurgery [was] not enthusiastic about shunting the child and closing the defect." The medical records stated that information was given to Sharon Johnson, his mother, and that she would make the final decision between treatment and nontreatment. Ms. Johnson, however, said that "the only thing they told me was about a shunt, and this, you know, after they told me about six months, that he would live six months without it, and then with it, a year, and I just figured, what's the sense in—he already suffers, so why should he suffer anymore?"¹⁴

Carlton was accordingly sent to a children's shelter, where he developed severe respiratory distress, periods of cessation of breathing, an ear infection, and dehydration. When he was returned to Children's Hospital of Oklahoma:

Physician's orders stated that there were to be no laboratory tests to monitor his condition, no intravenous fluids to correct the dehydration, and no antibiotics for the ear infection. If Carlton were to suffer a cardiopulmonary

Hydrocephalus—which can occur in combination with spina bifida or independently—is an abnormal accumulation of fluid in the ventricles (cavities) of the brain. It results from an imbalance between production and absorption of cerebrospinal fluid that flows through the brain and spinal cord. Normally the fluid is produced by cells in the ventricles, passes to the outer surface of the brain and to the spinal cord, and is eventually absorbed into the bloodstream. When the pathways for cerebrospinal fluid flow are obstructed or incomplete, production exceeds absorption and the fluid pressure can build up. Increased fluid pressure in the brain can cause enlargement of the head, compression of the brain, prominence of the forehead, mental deterioration, and convulsions. The compression of the brain can be so severe that an X-ray will show only a thin ribbon of brain tissue pressed up against the inside of the skull. Swinyard, *supra* note 9, at 18. Hydrocephalus without spina bifida has a mortality rate of 50 to 60 percent if untreated. March of Dimes Birth Defects Foundation, *Incidence of Selected Birth Defects* 2 (1984).

Shunting is the primary treatment for hydrocephalus. It consists of the implantation of a flexible tube (the shunt) into a ventricle of the brain to permit drainage of the excess fluid. The tube is passed through a small opening in the skull and then underneath the skin from the head to some other part of the body. The drainage end of the tube may be placed in the heart area, in the abdomen, or in some other body compartment. The most common shunting procedure links the ventricle to the abdomen; it is referred to as a ventriculo-peritoneal shunt.

The shunt contains a one-way valve to prevent a reversal of flow. A properly operating shunt is highly successful in channeling away excess cerebrospinal fluid and preventing the buildup of pressure in the head. The recovery of brain shape and size can be quite dramatic: within 2 weeks of installation, special X-rays may show the brain to have returned to a nearly normal shape. Swinyard, *supra* note 9, at 17-18.

arrest, he was not to be put on a respirator and no drugs were to be used.¹⁵

Nevertheless, Carlton managed to survive. Eventually, after a television investigation into denial of treatment at the hospital and children's shelter, he was given the lifesaving surgery he had been denied.

Bloomington, Indiana, Infant Doe Case

Probably more than any other single event, the Infant Doe case focused the attention of the Nation on denial of treatment to children born with disabilities. For one dramatic week in the spring of 1982, as the public followed the increasingly desperate efforts of the potential adoptive parents and the child's guardian *ad litem* to save his life, national newspapers wrote of the legal, ethical, and social ramifications of the withholding of lifesaving surgery, food, and water from a Bloomington, Indiana, baby.¹⁶

The child was born on April 9, 1982, with a tracheoesophageal fistula.¹⁷ The most significant aspect of the condition is that the child cannot take nourishment normally. Left without surgery, a child will die. This condition, clearly life threatening, may be corrected by an operation that, performed early, has better than a 90 percent chance of success.¹⁸ But Infant Doe differed from other children with a

tracheoesophageal fistula because he also had Down syndrome, a congenital disability usually producing some degree of mental retardation.¹⁹

Although pediatricians called into the case recommended immediate transfer of Infant Doe to a hospital equipped to provide surgery,²⁰ the obstetrician who had delivered the child:

insisted upon. . . pointing out to the parents that if this surgery were performed and if it were successful and the child survived, that this still would not be a normal child. That it would still be a mongoloid, a Down's syndrome child with all the problems that even the best of them have. That they did have another alternative which was to do nothing. In which case the child [would] probably live only a matter of several days and would die of pneumonia probably. . . .Some of these children. . . are mere blobs.²¹

Based on what the obstetrician told them, the parents of Infant Doe agreed not to authorize surgery, food, or water for the child. But nurses at the hospital protested,²² and the hospital agreed to place the matter before a court, while refusing to take any position on what course should be followed. A judge came to the hospital for a late evening session on Saturday, April 10, 1982. The hearing was not recorded,²³ and no guardian *ad litem* was appointed for the child.²⁴ The judge ruled

curve inward, short, wide feet with a gap between the first and second toes, short stature, sparse hair, low voice pitch, below-average muscle tone, a tendency to hearing impairments and respiratory disorders, and mental retardation. While persons with Down syndrome exhibit a combination of several of these characteristics, it is rare for any one individual to exhibit all of them. Mental development is usually retarded, generally in the moderate to severe range, although it is possible (albeit unusual) for an individual with Down syndrome to have average or even superior intelligence. R. Burgdorf, Jr., *The Legal Rights of Handicapped Persons* 39 (1980).

²⁰ *In re Infant Doe*, No. GU 8204-004A, slip op. at 2 (Monroe County Cir. Ct. Apr. 12, 1982), *petition for writ of mandamus and prohibition denied sub nom. State ex rel Infant Doe v. Monroe Circuit Court*, No. 482 S 140 (Ind. Apr. 14, 1982), *appeal dismissed sub nom. In re Infant Doe*, No. 1-782A 157 (Ind. Ct. App. Feb. 3, 1983), *cert. denied* 464 U.S. 961 (1983), *reprinted in* 2 *Issues in L. & Med.* 77, 78 (1986).

²¹ Dr. Walter Owens, *quoted in* *Petition for Writ of Cert.* at 8-9, *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

²² Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment and the Handicapped Newborn*, 52 *Linacre Q.* 45, 51 (1985).

²³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 72-73 (vol. II) (1986) (testimony of John G. Baker, Monroe County Superior Court, Bloomington, Ind.).

²⁴ *In re Infant Doe*, No. GU 8204-004A, slip op. (Monroe County Cir. Ct. Apr. 12, 1982), *reprinted in* 2 *Issues in L. & Med.* 77, 79 (1986).

¹⁵ Paulus, *supra* note 8, at 325.

¹⁶ See, e.g., McCormick & Tribe, *Infant Doe: Where To Draw the Line*, *Washington Post*, July 27, 1982, at A15; "Private" Death, *New York Times*, Apr. 27, 1982, at A22; Will, *The Killing Will Not Stop*, *Washington Post*, Apr. 22, 1982, at A29.

¹⁷ In about 1 of every 3,000 to 4,500 live births, the esophagus is incomplete, and the upper part of the esophagus is not connected to the lower part. This condition is called esophageal atresia. In about three-fourths of cases of such atresias, the incomplete esophagus (the tube connecting the mouth with the stomach) is linked to the trachea (windpipe). This latter condition is referred to as a tracheoesophageal fistula. Nelson, *Textbook of Pediatrics* 1041 (1979). It occurs in about 1 of 5,000 births. March of Dimes, *supra* note 14, at 3.

Atresia of the esophagus prevents food or liquids from getting to the child's stomach. A tracheoesophageal fistula can cause the aspiration of stomach juices if the lower part of the esophagus is joined to the trachea, and aspiration of food and liquids taken by mouth if the upper part of the esophagus is connected to the trachea. These conditions are somewhat more common in babies with Down syndrome than in other children. Each is lethal if untreated, and they are both considered surgical emergencies. Nelson, *supra*, at 1041.

¹⁸ Bannon, *The Case of the Bloomington Baby*, *Hum. Life Rev.*, Fall 1982, at 63, 67.

¹⁹ Down syndrome is characterized by the presence of three instead of the normal two of the human chromosomes designated as number 21. Consequently, Down syndrome is also called Trisomy-21. It is characterized by a small flattened skull, flat nose, unusual slanting of the eyes, a protruding, furrowed tongue, a short, thick neck, short broad hands with small fingers that

“that Mr. and Mrs. Doe, after having been fully informed of the opinions of two sets of physicians, have the right to choose a medically recommended course of treatment for their child in the present circumstances.”²⁵ The judge later wrote: “It is a harsh view that no life is preferable to life, but the great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was nonexistent. The physicians in attendance supplied the medical judgment.”²⁶ The Indiana Supreme Court refused to overturn the ruling, and the child died of pneumonia 6 days after birth while attorneys were en route to file a petition for review by the United States Supreme Court.²⁷

Commission Approach

This is not the first report in which the United States Commission on Civil Rights has dealt with medical discrimination against people with disabilities.²⁸ In its 1983 report, *Accommodating the Spectrum of Individual Abilities*, the Commission wrote:

Handicapped people. . .face discrimination in the availability and delivery of medical services. While occasional denials of routine medical care have been reported, a much more serious problem involves the apparent withholding of lifesaving medical treatment from individuals, frequently infants, solely because they are handicapped. Recently, widely publicized denials of medical treatment to handicapped infants have occurred in Indiana, Illinois, and California.²⁹

On May 1, 1984, the Commission approved in concept a hearing to obtain testimony from the legal, medical, and academic communities, from representatives of civil rights organizations, including those advocating on behalf of people with disabilities, and from the general public on the subject of medical treatment accorded to or withheld from newborn children with disabilities, with a special focus on the applicability of section 504 of the Rehabilitation Act of 1973.³⁰ In preparation for the hearing, staff conducted a literature review, legal research, and interviews with experts. The hearing took place

June 12–14, 1985, in Washington, D.C. Forty-three witnesses testified, including specialist physicians, representatives of medical organizations, parents who had been involved in treatment decisionmaking concerning their children born with disabilities, representatives of disability groups, ethicists, medical and other personnel involved in hospital ethics committees, hospital administrators and support personnel, and current and former staff of the executive and legislative branches of the Federal Government.

The Commission held a second hearing, also in Washington, D.C., on June 26–27, 1986. Testimony was received from attorneys and disability rights advocates assessing the then-recent U.S. Supreme Court decision limiting Federal investigations under section 504 of denial of treatment to children with disabilities,³¹ from academicians and an investigative journalist on the extent of discrimination and pervasiveness of discriminatory attitudes, from physicians and a judge who had been involved in denial of treatment about the context and rationales for that denial, from people with disabilities about their perspectives on denial of treatment, and from an academician and a Federal official about the potential that exists for people with disabilities.

Following the hearings, staff conducted significant additional research and examined agency documents and data.

The Commission employed a distinguished group of consultants, drawn from a variety of fields and perspectives in the area of disability, to assist it in providing research leads and in reviewing drafts of this report. They included Gunnar Dybwad, emeritus professor of human development at the Heller School, Brandeis University, and visiting professor at the University of Syracuse; James Ellis, professor of law at the University of New Mexico; Frank Laski, chief counsel for the Public Interest Law Center of Philadelphia; Reed Martin, professor of law at the University of Texas-Austin; Marguerite Mikol, president of Sick Kids Need Protection (SKIP), the national organization of parents of

²⁵ *Id.* at 3, 2 Issues in L. & Med. at 80.

²⁶ J. Baker, June 8, 1982, *Letter of Judge John Baker to Anonymous Person*, 2 Issues in L. & Med. 81, 82 (1986). See chap. 3 for an examination of the view that people with Down syndrome lack a minimally adequate quality of life.

²⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 204–05* (vol. II) (1986) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

²⁸ When referring to disabilities or to people with disabilities throughout this report, except in quotations or when making direct reference to legal or medical terminology, the Commission has sought to use language defined as appropriate in the standards issued by the Research and Training Council, Writing and Reporting About People with Disabilities (1986).

²⁹ U.S. Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 35 (1983).

³⁰ 29 U.S.C.A. § 794 (West Supp. 1988).

³¹ *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986).

technology-assisted children; Charles Rice, professor of law at Notre Dame University School of Law; H. Rutherford Turnbull, professor of law and special education at the University of Kansas; Colleen Wieck, executive director of the Minnesota Governor's Planning Council on Developmental Disabilities; and Robert Williams, deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens. The Commission also employed Thomas Nerney, president of the Disability Institute and currently executive director of the Autism Society of America, first as a consultant and later as an expert.

In accordance with statutory³² and regulatory³³ requirements, draft portions of the report which the Commission determined tended to defame, degrade, or incriminate persons or institutions were provided to them for comment. Verified answers received in response are reprinted as appendix D to this report. Commission policy also requires that relevant portions of its draft reports be provided to affected agencies for comment. Thus, relevant sections of this report were provided to State child protective services agencies; to the U.S. Department of Health and Human Services' Office of Human Development Services, Office for Civil Rights, and Office of Inspector General; and to the Civil Rights Division of the U.S. Department of Justice. Comments received from the Federal agencies are reprinted in appendix E to this report. Answers and comments were carefully reviewed and, when appropriate, modifications were made in the final report.

³² 42 U.S.C.A. §1975a(e) (West Supp. 1988).

³³ 45 C.F.R. §702.18 (1987).

³⁴ U.S. Commission on Civil Rights, *Civil Rights Issues of Handicapped Americans: Public Policy Implications* 230, 230 (1980) (statement of Judith E. Heumann, Deputy Director, Center for Independent Living, Berkeley, California). The International Center for the Disabled estimates that in 1985 there were approximately 27 million individuals in the general population who were age 16 or older and had a disability. The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream iii (March 1986), conducted for ICD—International Center for the Disabled, in cooperation with the National Council on the Handicapped, by Louis Harris and Associates, Inc. The U.S. Department of Education estimates that, in 1986–87, “4,421,601 children with handicaps from birth to age 21 were served” by the special education system. U.S. Department of Education, Tenth Annual Report to Congress on the Implementation of The Education of the Handicapped Act 3 (1988). In line with Ms. Heumann's testimony quoted above, in 1983 the Commission stated:

A Legacy of Discrimination

Treatment decisions resulting in the denial of lifesaving medical treatment to children with disabilities cannot be viewed in isolation. Together with discrimination in employment, barriers to access to transportation and physical facilities, and a tradition of institutionalization, these decisions may be viewed in the context of longstanding attitudes and practices toward people with disabilities.

Eight years ago, Judith E. Heumann, then deputy director of the Center for Independent Living in Berkeley, California, told the Commission:

I belong to the largest civil rights group in the country. The statistics, while they vary, go anywhere from 35 million to 47 million and up, and yet our civil rights group still has not yet received the status within the nondisabled community as a civil rights group representing a body of oppressed people in this country who have thus far been unable to achieve our place within this society, based on the failure to provide appropriate services and probably most importantly based on the failure of people in this country to believe that disabled individuals are in fact people who have the ability to achieve and have the desire to achieve. I think it is still all too common that disabled people in this country are perceived of as people who are sick and who are in need of being taken care of, as opposed to people who have different needs and whose needs, in fact, can be met, which will allow us to achieve our goals.³⁴

Historically, the notion that people with disabilities “are sick and . . . in need of being taken care of” has found outlet not only in paternalistic approaches that foster dependency but also in the view that such “sickness” imposes a burden too great to be borne either by the person with the disability or by society as a whole. As Frank Bowe, then director of the

Structuring society's tasks and activities on the basis of assumptions about the normal ways of doing things reflects the idea that there are “normal” people who can participate and there are people with physical and mental handicaps who cannot. When people are classified as either handicapped or normal, the only questions are who falls into which category and what criteria are used. A close examination of this handicapped-normal dichotomy, however, reveals fundamental flaws: it ignores the fact that abilities occur as spectrums, not as all-or-nothing categories, and discounts the importance of social context. The resulting distortion of reality is the wellspring of handicap discrimination.

U.S. Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 93–94 (1983). That is not to say that there is not a standard against which the health of individuals is measured. Rather, the point to be made is that categorizing persons based upon disabilities raises the very legitimate concern that it not obscure the extent to which such persons may in other respects have greater abilities than persons not in that category.

American Coalition of Citizens with Disabilities, told the Commission in 1980:

Within the Colonies, and later the States, community mores recognized indolence as a prime evil. Because popular perceptions equated disability with inability, existence of a disability appeared reason enough to deny a person the right to participate in societal life.³⁵

In the late 19th and early 20th centuries, acceptance of the purported science of eugenics resulted in the view that people with disabilities were a burden to be regarded as a menace. The American Coalition of Citizens with Disabilities has summarized this history in a brief submitted to the United States Supreme Court:³⁶

Th[e] stark history is . . . of the regime of segregation and degradation which by force of state statute deemed retarded people to be “unfit for citizenship.”³⁷ In every state in inexorable fashion handicapped persons were legislatively declared a “menace to the happiness. . . of the community,”³⁸ “unfitted for companionship with other children,”³⁹ a “blight on mankind”⁴⁰ whose very “presence”⁴¹ in the community was “detrimental to normal” people.⁴²

Official policy was to “purge society”⁴³ of these “anti-social beings,”⁴⁴ to “segregate [them] from the world,”⁴⁵ so that they “not. . . be returned to society”⁴⁶ since a “defect. . . wounds our citizenry a thousand times more than any plague.”⁴⁷ Disabled persons simply did not have

the “rights and liberties of normal people.”⁴⁸ The District of Columbia Board of Charity urged Congress, and it agreed, to authorize putting handicapped people away since they were “not much above the animal.”⁴⁹ Handicapped people were “not far removed from the brute,”⁵⁰ not quite persons, but “by-products of unfinished humanity”⁵¹ who were to be segregated for the benefit “of society,”⁵² “to relieve society of the ‘heavy economic and moral losses arising from the existence at large of these unfortunate persons.’”⁵³ It was important to find a “way of getting rid of these kinds of cases.”⁵⁴ Government reports labeled handicapped people “a parasitic predatory class,”⁵⁵ a “danger to the race,”⁵⁶ “a blight and a misfortune both to themselves and to the public”⁵⁷ whose role “in discounting social progress is by far the most potent influence for evil under which society is struggling today.”⁵⁸

As Justice Thurgood Marshall noted:

Fueled by the rising tide of Social Darwinism, the “science” of eugenics, and the extreme xenophobia of those years, leading medical authorities and others began to portray the “feebleminded” as a “menace to society and civilization. . . responsible in large degree for many, if not all, of our social problems.”⁵⁹

Attitudes toward individuals with a disability were harsh. One article in the Massachusetts Medical Society magazine in 1912 stated that “[t]he social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class, never capable of self

³⁵ F. Bowe, *An Overview Paper on Civil Rights Issues of Handicapped Americans: Public Policy Implications*, in U.S. Commission on Civil Rights, *Civil Rights Issues of Handicapped Americans: Public Policy Implications* 7, 9 (1980).

³⁶ Amicus Curiae brief for the American Coalition of Citizens with Disabilities, *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986). The text of footnotes 37 through 58 are reprinted as they appeared in the brief.

³⁷ 1920 Miss. Laws 294, ch. 210, § 17.

³⁸ 1919 Ala. Acts 739, No. 568, § 7.

³⁹ 1909 Wash. Laws 260, tit. I, subch. 6, § 2.

⁴⁰ Report of the Vermont School for the Feeble-Minded 17-18 (1916).

⁴¹ Report of the Rhode Island School for the Feeble-Minded 21 (1910).

⁴² California Board of Charities and Corrections, First Biennial Report 41 (1905).

⁴³ Wisconsin Board of Control, Biennial Report 321 (1898).

⁴⁴ Report of the Commission on Segregation, Care and Treatment of Feeble-Minded and Epileptic Persons in Pennsylvania 43 (1913).

⁴⁵ Thirty-Sixth Annual Report of the Indiana School for Feeble-Minded Youth 14 (1914).

⁴⁶ First Biennial Report of the Board of Commissioners of Nebraska Institutions 10 (1915).

⁴⁷ Fourth Biennial Report of the Board of Trustees of the Utah State Training School 3 (1938).

⁴⁸ Fourth Biennial Report of the South Dakota Commission for Segregation and Control of the Feeble-Minded 3 (1932).

⁴⁹ *District of Columbia Appropriations Bills: Hearings Before the Comm. on Appropriations*, 67th Cong., 2d Sess. 96 (Jan. 13, 15, 1932).

⁵⁰ Mental Defectives in Virginia: Special Report of the Board of Charities and Corrections to the General Assembly of 2926, at 20.

⁵¹ Baldwin, *The Causes, Prevention and Care of Feeble-Minded Children*, in Proceedings of the Texas Conference of Charities and Corrections at Its Second Annual Meeting 87 (1912).

⁵² See, e.g., 1919 Ga. Laws 379, No. 373, § 3.

⁵³ 1915 Tex. Gen. Laws 143, ch. 90, §§ 1, 2.

⁵⁴ *Connecticut School for Imbeciles: Hearings on H.B. No. 644 Before the Joint Standing Committee on Humane Institutions* 20 (typed transcript, Feb. 25, 1915) (statement of Mr. Kerner of Waterbury).

⁵⁵ Report of the Vermont School for Feeble-Minded Children 17-18 (1916).

⁵⁶ *Report of the Legislative Visiting Committee*, Wisc. Sen. J. 263 (48th Leg. Sess.).

⁵⁷ Thirteenth Biennial Report of the Kansas School for Feeble-Minded Youth 12 (1906).

⁵⁸ Mental Defectives in Indiana: Third Report of the Committee on Mental Defectives 6 (1922).

⁵⁹ *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 461-62 (1985) (Marshall, J., concurring) (quoting H. Goddard, *The Possibilities of Research as Applied to the Prevention of Feeble-mindedness*, in Proceedings of the National Conference of Charities and Correction 307 (1915)).

support or of managing their own affairs.”⁶⁰ A Chicago ordinance provided that no person “who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person” could be found “in or on the public ways or other public places,” and that no such person could “expose himself to public view.”⁶¹

In *Heredity and Human Progress*, a physician advocated that children with severe disabilities, including “idiots,” most “imbeciles,” and “epileptics” should be eliminated for the safety of the Nation through the use of a painless gas.⁶²

In 1941 a physician addressing a luncheon during the annual meeting of the American Psychiatric Association said: “[W]e have too many feeble-minded people among us. . . . The idiot and the imbecile seem to me unresponsive to the care put upon them. They are not capable of being educated; nor can such defective products ever be made to be so.”⁶³ He spoke “in favor of euthanasia for those hopeless ones who should never have been born—Nature’s mistakes,” urging that when a “competent medical board. . . acting. . . on the application of the guardians of the child, and after three examinations of a defective who has reached the age of five or more, should decide that that defective has no future nor hope of one. . . it is a merciful and kindly thing to relieve that defective—often tortured and convulsed, grotesque and absurd, useless and foolish, and entirely undesirable—of the agony of living.”⁶⁴ An editorial in the issue of the *American Journal of Psychiatry* that published the physician’s address suggested that the attitude of parents who opposed elimination of their “idiot” children was a fit subject for psychiatric analysis and correction:

It is difficult to conceive how normal affection can be felt for a creature incapable of the slightest response; and exaggerated sentimentality or forced devotion which can serve no possible purpose can hardly be looked upon as desirable. . . .

. . . .

[T]he psychiatric problem. . . [of] the “fondness” of the parents of an idiot and their “want” that he should be kept

⁶⁰ A.M. Clark and A.D.B. Clarke, eds., *Mental Deficiency: The Changing Outlook*, 16–17, quoted in Evans, *The Lives of Mentally Retarded People* 43 (1983).

⁶¹ Formerly Chicago, Ill., Mun. Cod. §36–34 (1966).

⁶² D. McKim, *Heredity and Human Progress* 189, 193 (1900).

⁶³ Kennedy, *The Problem of Social Control of the Congenital Defective*, 49 *Am. J. Psychiatry* 13, 13 (1942).

alive. . . we believe deserves study—the extent to which it exists, in fact and not merely as a generalization of opinion, what underlying factors. . . are discoverable, whether it can be assessed as healthy or morbid, and whether in the latter case it is modifiable by exposure to mental hygiene principles.⁶⁵

Although contemporary justifications for denial of treatment to children with disabilities are typically less harshly worded, a clear continuity of thought can often be found. Contemporary bioethicist Peter Singer writes:

When the death of a defective infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the defective infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second.⁶⁶

A noted authority on child abuse and neglect argues that the 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 growth.”⁶⁷

The complex and difficult questions surrounding treatment decisionmaking for children with disabilities must be approached with sensitivity to the effects of this background of dehumanizing attitudes concerning people with disabilities. Dehumanizing stereotypes are common to virtually every form of discrimination, including that based on disability.⁶⁸

This report thus begins with an examination of the context of such decisionmaking in a chapter that explores the parent-physician relationship and the sort of information about disability sometimes provided parents by physicians. The next chapters consider what the evidence suggests about the potential quality of life of people with disabilities in contrast to what are often inaccurate assumptions about their quality of life. The report then describes in detail the history and current status of legal standards governing medical treatment for those with disabilities. The degree to which these standards are being implemented and the performance of governmental and nongovernmental institutions in enforcing them are assessed. The report ends with findings of fact and recommendations for the future.

⁶⁴ *Id.* at 14.

⁶⁵ *Euthanasia*, 99 *Am. J. Psychiatry* 141, 143 (1942).

⁶⁶ Peter Singer, *Practical Ethics* 134 (1979).

⁶⁷ J. Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 *Yale L.J.* 645, 651 (1977).

⁶⁸ See generally U.S. Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 22 (1983).

The Physician-Parent Relationship and Treatment/Nontreatment Decisionmaking

Much of the popular and scholarly debate over the question of denying treatment to children with disabilities assumes a conflict between the rights of parents to make a choice concerning medical treatment for their child and whatever rights the child may have to lifesaving treatment despite the views of the parents. However, testimony before the Commission suggests that this is an artificial conflict, because it is normally inaccurate to assume that it is solely the parents of newborn children who actually decide whether to provide or withhold lifesaving medical treatment. In the words of Dr. Rosalyn Benjamin Darling: "In the decisionmaking situation, parents are likely to feel confused when confronted with a disability about which they know little. As a result, they rely heavily on the information and attitudes communicated to them by the physician. In most cases, the parents' decision reflects the physician's decision."¹

One Commissioner summarized the evidence heard by the Commission:

To the parents who testified, it was clear. . . that most parents are indeed influenced primarily by the recommendations of their physicians and that those recommendations can be and sometimes are based on a totally erroneous view of the child's abilities and future quality of life.²

¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 181-82 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc). *Accord id.* at 41-42 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas) ("I dispute the predicate. . . that parents make the decision. I think that kind of aseptic view runs contrary to the published literature in the health

Factors that Impair Independence in Parental Decisionmaking

It is important to understand the situation in which most parents suddenly confronted with a child with a disability find themselves. Assistant Secretary Madeleine Will pointed out:

A parent may have had no experience with a person with a disability, and suddenly, at a moment's notice, finds himself or herself at an existential cliff, and one is very much dependent on this physician who is in some way going to protect you, one imagines, from a cataclysm, and one is dependent on the quality of information that he or she provides.³

The period surrounding birth is one of considerable stress and emotion, and for nondisabled parents, the birth of a child with a disability typically comes as a great shock. It frequently produces feelings of depression, grief, anger, and guilt. Because most new parents of a child with a disability have had little or no interaction with people who have disabilities, their reactions are often dominated by the stigmatization of people with disabilities to which they have been pervasively and sometimes subconsciously subjected for most of their lives. This stigmatization may produce in their minds a picture of the child's condition and prognosis that has little basis in fact. The Spina Bifida Association of America (SBAA) emphasized the problems:

field and it also runs contrary to some of what I have been told by physicians who are neonatologists, pediatric surgeons, and pediatricians.").

² *Id.* at 5 (opening statement by Commissioner Robert A. Destro).

³ *Id.* at 92 (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

Parents of a newborn spina bifida child are expected to make rational life and death decisions when what was expected to be a joyous time has instead become an occasion for confronting the concerns of the unknown. The decisions must be made quickly and under great stress. Dr. Rosalyn Darling, a member of SBAA's Professional Advisory Committee, has written that decisions are often made by physicians and individuals who have very little contact with the disabled community; consequently, decisions concerning treatment are often "stacked" against the newborn with a problem.⁴

Because the parents typically lack knowledge and are in such a state of stress, they turn for information and recommendations to the physicians caring for their child. Medical sociologist Rosalyn Benjamin Darling has done several studies of the relationship between the physicians and parents of children with disabilities. She noted:

[P]arents are very vulnerable immediately after having given birth to a handicapped child. The hospital is not their natural habitat, and the medical milieu is frightening to them. They know very little about birth defects in general and their child's defect in particular. They turn readily to the "experts" who can help them understand what is happening to them. They have learned to trust physicians and to respect their opinions. Not surprisingly, they often defer to the physician's expertise in deciding whether their child is to be medically or surgically treated—or allowed to die.⁵

Evan Kemp, a lawyer with a disability who directs the Disability Rights Center, made a similar point:

I think that at time of birth, when parents are very distraught, when they find that they don't have a child that measures up to the children of their friends, they're very impressionable at that time and under a great deal of stress, and I think that doctors have tremendous power to influence them, and I think they do influence them. . . .⁶

⁴ Quoted in 49 Fed. Reg. 1649-50 (1984).

⁵ Darling, *Deck Often Stacked Against Defective Newborns*, American Medical News, Jan. 14, 1983, at 23. Cf. the description in an anonymous letter from a parent submitted for the record by Dr. Walter Owens:

[A]t delivery I just remember being shocked that I, as a young, healthy person who avoided all artificial ingredients during my pregnancy, ate sensibly, could have given birth to an infant with multiple deformities. I didn't know anything about spina bifida, its consequences for the baby or the family; I guess I must have looked very bewildered as to the correct choice to make regarding surgery for a shunt, etc. You told me that if it were your decision, you probably would not sign consent for surgery. You gave me a short, but complete description of what I could expect from surgery, quality of life. It was simply a presentation of facts. I decided against sustaining measures, the baby died in a short time. . . .

Influence of Physicians

Dr. Anne Fletcher, a neonatologist at Children's Hospital National Medical Center, told the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research:

[I]t is important, that we make a recommendation of what is to be done. That is not to say that we don't feel the parents have a decision to make, but it is a decision with us and not a decision on their own. And we usually have felt it is our duty to make a decision, and then have them agree with us, rather than to have them feel they made the decision completely on their own.⁷

Another physician, who specializes in the treatment of spina bifida, has written:

Invariably, in these circumstances, families make a decision based on information that is given to them by the pediatrician, pediatric neurologist, or neurosurgeon. The great likelihood is that any one of these physicians will have his/her own philosophy concerning what should be done and, therefore, whether intentional or unintentional, the information will be skewed. It is, therefore, the physician that is responsible for the immediate decision for or against surgery.⁸

Do parents or physicians typically initiate discussion of denying lifesaving treatment? In his team's study of approximately 150 cases of denial of treatment, investigative journalist Carlton Sherwood testified:

[N]ot one parent we interviewed—and we spoke with several dozen who were personally involved on both sides of the treatment issue—not one said they took any initiative in the decisionmaking process; invariably, it was the physician, often teams of physicians, who approached the parents and recommended, strongly and persistently sometimes, for a course of treatment or nontreatment.

Anonymous letter to Dr. Walter Owens (Aug. 20, 1983) (available in files of U.S. Commission on Civil Rights).

⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 29 (1986) (vol. II) (testimony of Evan J. Kemp, Jr., Director, Disability Rights Center).

⁷ Testimony of Dr. Anne Fletcher, Transcript, Sixteenth Meeting of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 17 (Jan. 9, 1982), quoted in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 210-11 (1983).

⁸ Epstein, *Meningomyelocele: "Pitfalls" in Early and Late Management*, 30 *Clinical Neurosurgery* 366, 366-67 (1982). See generally National Legal Center for the Medically Dependent and Disabled, *The Medical Treatment Rights of Children with Disabilities* §5.02 (J. Bopp ed. 1987).

In all but a few cases, the parents said they went along with their physician's recommendations and would have followed the same doctor's advice had his recommendation been different.

All, and I emphasize all, the doctors we spoke with confirmed this decisionmaking process.⁹

Professor Turnbull told the Commission, "[P]hysicians set the agenda. The person . . . who has the ability to set the agenda has to a large degree the ability to control the outcome."¹⁰

In an article in *Clinical Pediatrics*, Drs. Stephen Ragatz and Patricia Ellison wrote about their own case conferences with parents "during which they [the parents] were asked directly to give an indication of whether or not they concurred that support be withdrawn."¹¹ Coauthor Dr. Patricia Ellison, a pediatric neurologist in private practice in Denver who also holds an academic appointment, testified before the Commission. Asked whether her article suggested that "there was a preexisting opinion that support be withdrawn and that the parents were then asked whether they concurred or disagreed," Dr. Ellison said: "There was not a decision [in any of those cases] ever offered by the doctor that support be withdrawn. However, it should be clear that if the issue is being raised, this is a consideration

⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 50 (1986) (vol. II) (testimony of Carlton Sherwood).

¹⁰ *Id.* at 58 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas).

¹¹ Ragatz & Ellison, *Decisions to Withdraw Life Support in the Neonatal Intensive Care Unit*, 22 *Clinical Pediatrics* 729, 732 (1983). The physicians wrote:

We initially assumed that the decision to withdraw support was chiefly the [prerogative] of the physician, acting in accordance with the parents' wishes. Decisions were made after full discussion with the parents. We subsequently learned that parents considered that they had made such decisions, and we became more willing to let the parents make them, in infants who were considered eligible for such a decision by the physician. *On occasion*, quality of life issues were raised by the parents prior to discussion initiated by the physician.

Id. at 729-30 (citation omitted) (emphasis added).

¹² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 219-20 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver). Appearing before the Commission, Dr. Ellison characterized as a "misrepresentation," *id.* at 219, the view "that there was a preexisting opinion that support be withdrawn and that the parents were then asked whether they concurred or disagreed," *id.* (question by Ms. Hanrahan). *Cf.* the language in another of her articles (Walwork & Ellison, *Follow-up of Families of Neonates in Whom Life Support Was Withdrawn*, 24 *Clinical Pediatrics* 14 (1985)):

in the doctor's mind as well. You are not going to hold conferences for those babies about whom this would not be an appropriate concern."¹² When she was asked whether it is usually the parents or the health care personnel who initiate the question of continuing lifesaving support, she testified that sometimes it comes from one and sometimes from the other, but that when it comes from the parents:

[w]e try to respond to the questions and needs of the parents, but would never have held a conference where this issue of support would be set up in the sense of a decisionmaking process, unless we as physicians felt that this was an appropriate case to do that. We might meet with the parents and answer questions and say, "We understand your worries, but look, at this time, things seem to be . . . [going] this way and this is not a time for such a conference."¹³

Physicians with a bent toward denial of treatment can be quite insistent in conveying negative information, as they were with the parents of Baby Jane Doe: "During her five months in the intensive care nursery, Dan and Linda would see their baby smile and ask hopefully if she were making progress. No, the doctors would respond, she wasn't."¹⁴

Physicians had urged Dan and Linda to place Keri-Lynn [Baby Jane Doe] in a home for the severely disabled shortly after birth. Instead, the parents took her home.

[F]amilies were told, during the decision-making conference, that the decision would be made by the physician with consideration of the families' wishes and thoughts. . . .

Id. at 16.

We . . . found that the parents accepted the responsibility for the decision to withdraw support, even when the professional staff considered that the decision had been made by the professional staff, not by the parents.

Id. at 20.

In her testimony, Dr. Ellison said, "It should be also well-stated that with parents who felt that this was really something that was not in keeping with their concerns, none of the support was ever withdrawn from such a child. We would never have considered such a thing." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 220 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver.)

¹³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 239 (1986) (vol. II) (testimony of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver). *Cf. id.* at 267 (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens) ("[O]ne wonders why parents with newborns with severe disabilities are even put in a position of having to make such decisions when they are clearly operating under so much stress. Physicians often serve to exacerbate an already highly charged and tense situation by presenting the parents of an infant with severe disabilities with life and death choices that they would never, ever consider presenting to parents of a nondisabled child.")

¹⁴ 'Adorable' Baby Jane Doe Finally Is Home, Milwaukee Sentinel, May 25, 1984, pt. 1, at 8, col. 1.

"They said she'd only know pain and that she wouldn't recognize us," Linda said. "If we had placed her in a home, she would have been like they said. Now, she's out and doing things."¹⁵

Although parents may seek to do what they think is best for their children, their assessment of what is best depends on the information they have. Nondisabled parents who are suddenly confronted with the birth of a child with a disability are not likely to enter the decisionmaking process with a background of adequate and accurate information. Adrienne Asch, who teaches social psychology at the City College of New York, testified:

[B]ecause parents of disabled children, and especially disabled newborns, rarely share this minority characteristic [of being a person with a disability], . . . they are in an extremely difficult position to advocate for that infant. The parents of other children with minority characteristics can do this much better. They know what life holds in store for that infant and their child. They can advocate against those who would hurt their children for those minority characteristics, because even though they may know that life is fraught with problems, it is also going to contain various joys.

But the parents of a disabled infant, moments, days after its birth, have very little such information. In fact, they are likely to have been given information by physicians, by social workers, by any other professionals, by clergy, that reinforces whatever stereotypes they have about the limits and deficits and tragedy of so-called defective, deformed, damaged infants.¹⁶

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." One nurse has written:

Whether and to what extent such children are treated can be influenced by physicians and nurses. Suppose, for example, the staff tells the parents, "It is possible to operate on your baby and close his back, but his legs will still be paralyzed and deformed. Most likely he will never have bowel or bladder control and will probably develop

hydrocephalus, which may require many operations with possible complications. Or, we can do nothing and allow him to die." Would you be surprised if the parents opted for death?

On the other hand, a positive attitude can go a long way in persuading parents to accept their baby. This has been the stance of our nursing staff. We encourage parents to touch, hold, feed, talk to, and play with their infant. We tell them to bring in music boxes, toys, and, later, even clothes. By focusing on the normal things the baby does, we foster a positive image of the child. For example, we might say, "Look how strongly he sucks" and "See how tightly she holds your finger." We try to emphasize that their baby does things all babies do.¹⁷

One of the lead physicians involved in the selective treatment program at Children's Hospital of Oklahoma,¹⁸ Dr. Richard Gross, has said: "I think it takes a great deal of courage on the . . . [part] of parents to say, in the face of a recommendation from a physician, that they wish to go counter to that. They certainly do not have the background at the time the child is born to really know what is expected."¹⁹ Dr. Mildred Stahlman was even more direct:

I can persuade 99 percent of parents to my way of thinking if I really work at it, even if I am 100 percent wrong. If I tell them in such a way that I appear concerned and that I am knowledgeable and that I have their interest at heart and the interest of their . . . newborn baby, there is no question in my mind but that they will let me "cut off that infant's head."²⁰

From a treatment perspective opposite to that of Dr. Gross, Dr. David McLone testified concerning his experience with parents of children with spina bifida:

I have now treated about 300 newborns and had this midnight discussion with about 300 families, and I have not had one family, once fully informed of the availability and the likely outcome of treatment, who has refused to have the back repaired at the time of birth.

In my experience in the cases I am familiar with where the decision was made not to close the back, that decision, in essence, was made by the physician and by what he told

already probably stated the only requirement they have of a child was that it must be perfect. . . .").

¹⁵ Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, *Newsday*, Dec. 7, 1987, at 2, 23.

¹⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 125-26 (1986) (vol. II) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York). See also *id.* at 141 (testimony of Mary Jane Owen, Director, Disability Focus, Inc.) ("Unfortunately, handicapped infants are born into alien families, families that have

¹⁷ See chap. 1 and text accompanying notes 7-15.

¹⁸ Homer, *Selective Treatment*, 84 *Am. J. Nursing* 309, 309-10 (1984).

¹⁹ See chap. 1 and text accompanying notes 7-15.

²⁰ *Take Two: Who Lives, Who Dies?—Part II* (Cable News Network, Feb. 22, 1984), (Radio-TV Monitoring Service, Inc., Transcript at 5).

²¹ *Quoted in Patrick, Little Murders*, 10 *New Times* 32, 36 (1978).

the family, and the family went along with the decision of the physician not to close the back.²¹

The same picture emerged from testimony elicited from those associated with health care consumers. The deputy director of the National Information Center for Handicapped Children and Youth, Patricia McGill Smith, described an instance in which parents of a child with spina bifida received a medical recommendation of no treatment based on that disability and "predictable mental retardation." They initially accepted this recommendation. "Her parents were loving, good people," Smith testified, "but they were operating on the directive of the doctor who said, why sustain the life of someone who will have two kinds of disabilities. . . . Those parents were given inaccurate information. . . ." As the leader of a parent-to-parent support group, Smith was called in to assist the parents. She provided them with more accurate information about the prognosis for their child and the support systems available for them, and in time the parents changed their mind. Today, the girl is alive, without a trace of mental retardation.²²

Betsy Trombino, the parent of a child with orthopedic disabilities, has worked for 6 years in the field of parent support. She testified:

We're asked to make decisions as to whether our children live or die, and, yet, all the information is coming from people saying, he'll never do this, he'll never do that, he's not ever going to go to school or walk or talk or even roll over, so why would you want him to live?²³

Misinformation Among Medical Personnel

Special Education Professor Ruth Luckasson described the prevalence of misinformation among many health care personnel and the bioethicists who advise them:

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. . . . [O]ur review of the medical literature and the literature of the new bioethicists

revealed that typical physicians and bioethicists have little or no familiarity with life possibilities or community resources available to individuals who are born with handicaps.

Parents, who typically receive the information on the life prospects of their disabled son or daughter from their physician, cannot uniformly expect information free of false stereotypes and archaic prejudices. To the extent that parents rely on such misinformation as they make life and death decisions about their sons and daughters, their children's vulnerability to discriminatory treatment is aggravated.²⁴

Surgeon General Koop testified:

[I]t's very difficult for somebody to know, for example, as a pediatrician who sees only one or two of these in a lifetime, if that, just how other parents have done innovative and creative things, have rallied community support, have established organizations that are anatomically designed for that particular defect; and therefore, he tends to be a little less enthusiastic about what can be done than if he had all of this information at his hands.²⁵

Dr. McLone took a similar position:

The problem that I have noted and have been involved in with the decisionmaking process has been primarily ignorance on the part of the physician who is first confronted with the child, who then misinforms the family, and based on inappropriate information, the family usually makes, in my opinion, the right decision based on that information. However, the information they have been given is so inconsistent and out of line with what most major centers in the United States are experiencing at this time that the child is denied care based on misinformation.²⁶

Inaccurate stereotypes are quite pervasive; so much so, indeed, that five members of the Supreme Court have characterized the history of mistreatment of people with mental disabilities as "grotesque."²⁷

Weight of Parental Decisions

In light of this background, Professor Ellis testified that frequently the parental agreement to forego lifesaving treatment for their newborn child with a

²¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 19 (1985) (vol. I) (testimony of Dr. David McLone, Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

²² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 254-55 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

²³ *Id.* at 263-64 (testimony of Betsy Trombino).

²⁴ *Id.* at 97 (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

²⁵ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 12 (1985) (vol. I) (testimony of C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

²⁶ *Id.* at 7 (testimony of Dr. David McLone, Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

²⁷ *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 454 (1985) (Stevens, J. & Burger, C.J., concurring), and *id.* at 461 (Marshall, Brennan & Blackmun, JJ., concurring in part and dissenting in part).

disability is not legally adequate to constitute informed consent:

The law of informed consent . . . provides some guidance, . . . because legally adequate consent requires that the individual . . . have a sufficient amount of information to make a legally adequate judgment and that it be a voluntary judgment, that is, without undue influence by others.

And both on voluntariness and particularly on the point of information, to suggest that the involvement of parents, who are often ratifying a judgment which they think . . . [was] made by a professional on the basis of current knowledge that may not indeed be without prejudice, looking to the kinds of requirements in consent law may suggest to us that it is inadequate to essentially launder discriminatory decisions by saying, "Yes, well the parent acquiesced in them" when their consent may not meet those tests.²⁸

Other reservations have been expressed about taking parental denial of treatment decisions at face value. Sociology Professor Irving Zola testified that research suggests that miscommunication as well as misinformation lies behind many of them:

[W]ith the few studies that have come out, when we try to study what the doctor thinks he said and what the patient thinks he or she heard in the situation, the discrepancies are so enormous that one might go so far as to say that any doctor-patient encounter should have a mediator or somebody else there that could help both parties communicate with each other.²⁹

²⁸ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 30 (1986) (vol. II) (testimony of Prof. James W. Ellis, School of Law, University of New Mexico).
²⁹ *Id.* at 200 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University).

Carlton Sherwood's investigations substantiate concerns about the definitive nature of many parents' acquiescence in nontreatment decisions.

[W]hen death was being discussed, parents were rarely, if ever, told exactly what method was planned. Euphemisms like "let nature take its course" cover everything from starvation to deliberate efforts to infect the newborns. One can only speculate what would happen if doctors were required to put their nontreatment recommendations in writing and spell out clearly for parents what it was they intended to do in their names, along with the consequences of such actions.³⁰

Dr. Rosalyn Benjamin Darling testified:

Even if we could legislate truly informed consent, however, we could never have certain knowledge about any child's future quality of life. Some of the parents who have the most negative attitudes in the immediate postpartum situation, learn to love their children dearly months, weeks, or even days later. Some children with the poorest medical prognosis shortly after birth develop into normal, healthy children. Very few cases are predictable with any degree of certainty. Treatment in most cases, therefore, seems appropriate.³¹

Conclusion

The evidence is strong that in many instances in which lifesaving treatment is denied to children with disabilities, those decisions are often influenced by what physicians tell parents. In practice, doctors are often the prime movers in denying the treatment.

³⁰ *Id.* at 50 (testimony of Carlton Sherwood).

³¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 182 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

The Role of Quality of Life Assessments in Denial of Medical Treatment

One of the most common justifications given for denying treatment to children with disabilities is that there are circumstances in which it is in the children's best interests to spare them a life of unacceptably poor quality. In the words of Dr. Norman Fost, chairman of the Committee on Bioethics of the American Academy of Pediatrics:

Profound handicap may be a compelling reason for allowing a patient to die. For example, consider the infant with a severe intracranial hemorrhage and respirator dependency who is profoundly brain damaged but not comatose. Ever-improving technology makes it possible to keep such patients alive for longer periods. Some live in intensive care units for years, or at home at enormous expense. The treatment clearly has medical benefit—it maintains respiratory functions and prevents the complications of respiratory arrest—yet it often seems to serve no interest of the patient, who cannot appreciate any of the joys of living.¹

Impairment or Societal Attitudes?

The testimony presented to the Commission and its research suggest that, with few exceptions, people who themselves have disabilities reject this form of analysis. In a letter to the editor criticizing a columnist's support for denial of treatment to Baby Jane Doe because the child's life would be "barren of joy," Price Grisham wrote:

When will people who are perfectly intelligent, clear-headed and well-educated stop assuming that one must be healthy, handsome and preferably wealthy to be human and happy? I am not healthy (I have cerebral palsy), not

handsome and, as a GS-5 clerk, will probably never be wealthy.

My childhood and . . . [adolescence] were spent in more than a decade of operations and therapy. Yet I am quite sane and quite firm when I state that I would not exchange my handicapped body for that of the most muscular Redskins player, for through it I have learned more in the 30 years of my life than some people learn in a century.²

Typical of the views of many people with disabilities is this editorial from a leading disability rights movement newspaper, *The Disability Rag*:

The issue is that everyone agrees that life as a disabled person is most probably a fate worse than death. . . . That's the accepted fact. Many of us, in fact, don't accept it at all. . . .

. . . .

Who stops to figure out *why* being disabled is such a horrible fate? Most disabled people (we can assume we're the experts in this) will tell you that, despite what everyone thinks, the disability itself is not what makes everything difficult. What causes the difficulty are the attitudes society has about being disabled: attitudes that make a disabled person embarrassed, insecure, uncomfortable, dependent. And the physical environment.

The physical environment that keeps on being designed. . . . [w]ith no thought ever routinely given to designing things everybody can simply use. . . .

Of course disabled people rarely can talk of quality of life. But it has precious little to do with deformity, and a great deal to do with society's own defects.

¹ Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 149, 153 (1986).

² Grisham, *Baby Doe*, Washington Post, Dec. 11, 1983, at C6. See also *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens) ("Society places too much emphasis on the perception of quality of life, perceived value, intelligence and physical agility. Traditionally, persons with severe disabilities have not been consulted on those issues which have affected them most. I think my life has been worth living; I'm confident my family and those I care for feel the same way.").

This said, we can get back to talking about the newborn infant with a deformity. Now we can ask why those parents would be happier seeing it dead. Today, that child means much expense, confinement to home, special schools, special transportation, life in an institution. The public talks about that kind of a life as though it is simply inevitable for deformed infants. What they should be asking is "why is it inevitable?"

The issue is rights, but the issue is not the right to die. It is the right to live in a society that wants you. And it's easier for our society to get rid of these kinds of people right at the start than to deal with *why* life is so horrible for these people. Our society is what makes it horrible. We have the power to change that.³

When Dr. Walter Owens, the physician who delivered Bloomington's Infant Doe, appeared before the Commission, he read a letter from a couple who had written in support of the decision to let a child with Down syndrome die. The letter focused far more on the societal reaction that made life difficult than on impairments inherent in the disability itself. These parents wrote that they regretted choosing life-saving surgery for their child's esophageal atresia: "My husband and I chose life and got a hellish existence instead."⁴

That view was based almost entirely on the lack of acceptance their son encountered. After referring briefly to health problems such as "respiratory infections[,] . . . severe allergies accompanied by congestion, fatigue, irritability, sinus, and ear infections," the couple stated:

The real trouble started for Charles when he became old enough to play outside. Although there were some instances of cruelty to our Down's child, the main expression to him by neighborhood children has been to ignore him. For seven years, Charles was a bystander who was permitted to sit on the side and watch their ball games. As a result of this experience, our son became a nonperson. His self-image plummeted, and one day he began to stutter. At first barely perceptible, the stuttering increased to a very severe level.⁵

The parents went on to tell how they eventually sent Charles away to a special residential school

³ *Killing Babies: Left and Right*, The Disability Rag, May 1983, at 2, 6, © 1983 by The Advocado Press, Inc. Reprinted with permission. This view is consistent with Harlan Hahn's description of a "sociopolitical understanding which regards disability as a product of the interaction between the individual and the environment. . . . Whereas the medical approach concentrates on inabilities affecting individual performance, . . . the sociopolitical perspective emphasizes the social environment and the importance of cultural expectations." Hahn, *Public Policy and Disabled Infants: A Sociopolitical Perspective*, 3 Issues in L. & Med. 3, 3-4 (1987) (emphasis in original).

where he is "now protected from the 'kindness' of society."⁶ Looking toward the future, they asked, "Will there be a group home and some sort of semi-independent living arrangement for Charles or will our son be reduced to the subhuman institutional existence presently endured by the majority of retarded citizens?"⁷

To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission emphatically rejects the view that an acceptable answer to discrimination and prejudice is to grant the "right to die" to those against whom the discrimination and prejudice exists. It is not tolerable to choose death for children with disabilities as the societal response to unjust treatment of people with disabilities.

As Robert Williams, now deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens, who himself has a physical disability and uses communication aids, testified:

The way to secure commitments [to improve the way people with disabilities are treated and the services they receive]. . . is not. . . [to] suggest that care be withheld from newborn infants with severe disabilities until an adequate funding is provided to help them obtain their maximum developmental potential. What benefit can result from this strategy? At best it can be seen as an extreme example of circular reasoning. At worst it can lead to the most vicious of circles. Appropriate support services necessary to assist the families of newborns with severe disabilities to love and care for their child in their own home will not be available as long as we devalue the life of a child so much that it becomes acceptable to withhold the most ordinary care.⁸

Even when a negative conclusion about the quality of life of a person with a disability is not so self-consciously grounded in projections about the behavior of others, as in Dr. Owen's example, it may nevertheless be based on a view of disability colored by societal assumptions and expectations. Professor Harlan Hahn explains:

⁴ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 212 (1986) (vol. II) (testimony of Walter Owens, M.D.) (quoting anonymous letter).

⁵ *Id.*

⁶ *Id.* at 212-13.

⁷ *Id.* at 213.

⁸ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

If it is possible to characterize succinctly the prevalent popular understanding of disability, . . . the sentiment might be described by the phrase "personal misfortune." Disabled children and adults are commonly perceived as the "victims" of ill fortune or adversity which can only be "overcome" through extraordinary displays of personal courage and perseverance. The image is constantly reinforced in the mass media, not only by feature stories that depict the supposedly remarkable accomplishments of a specific disabled individual but also by telethons and other presentations that portray disabled persons as weak, pathetic, and helpless. For the nondisabled majority, there are apparently only two kinds of people with disabilities: the overachievers, who gain acceptance by performing superhuman feats, and the despondent, who are doomed to an unthinkable fate.

. . . Little thought is given to the possibility of modifying the environment or of developing policies to enhance the status of disabled persons. . . .⁹

In short, decisions purportedly—and often sincerely—made on the basis of the "best interests" of children with disabilities are all too frequently tainted by what the Supreme Court has characterized in the context of housing discrimination against people with mental disability as "irrational prejudice."¹⁰

Positive Quality of Life for Persons with Disabilities

The Commission received extensive testimony documenting the good lives that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Indeed, Professor Ruth Luckasson, who coordinates mental retardation programs at the University of New Mexico, stated:

The lives of the infants born with disabilities or who acquire disabilities after birth have more potential now than at any other time in our history. Babies who receive nondiscriminatory medically indicated treatment can expect to become participating citizens leading rich lives as members of their community.¹¹

⁹ Hahn, *supra* note 3, at 4-5.

¹⁰ *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432, 450 (1985).

¹¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 95 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

¹² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 7-8 (1985) (vol. I) (testimony of

Medical progress has been ongoing, making obsolete predictions based on past experience. Surgeon General C. Everett Koop testified: "My own lifetime has seen a complete reversal of success and failure. When I first began in the field of pediatric surgery in 1946, most of the things that now have a 95 percent survival had a 95 percent mortality, and indeed, some carried a 100 percent mortality."¹²

Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services at the Department of Education, described the striking progress seen in recent decades.

Twenty years ago, the opportunities available to a severely impaired young adult might well have been meager. . . . Today, as a result of the opportunities offered by the Education of the Handicapped Act and the Rehabilitation Act of 1973 and the technological advances that are in no small part related to these landmark pieces of legislation, the possibilities are limitless.

. . . .

For over a decade, infants with severe impairments associated with Down's syndrome and spina bifida have been placed in programs within weeks after birth. In States where services are mandated at birth, educators and therapists provide instruction within the child's home on a regular basis. In many instances, before they reach the age of 3, children are enrolled in preschool programs, often with nonhandicapped children as classmates.¹³

As Ed Roberts, president of the World Institute on Disability and former director of the California Department of Rehabilitation, put it, "At first we thought people couldn't learn, but then we recognized we didn't know how to teach. Now we've learned how to teach people."¹⁴

Approximately 4.2 million children are now in special education programs nationwide. Particularly impressive progress in maximizing the potential of children with congenital disabilities has come from the growing use of "early intervention," an approach in which preschool children are provided stimulation and education to develop their capacities. With the widespread success of these programs for children, focus is now being placed on the

C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

¹³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 84-85 (1986) (vol. II) (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

¹⁴ *Id.* at 106 (testimony of Ed Roberts, President, World Institute on Disability).

transition from education to employment, with particular attention to "supported employment," in which those with the most severe disabilities are given ongoing assistance in training and supervision while employed.¹⁵

Advances in education have been paralleled by an increase in support groups for parents of children with disabilities. The deputy director of the National Information Center for Handicapped Children and Youth testified:

There are better and more available parent-to-parent advocate support services today than there were 10 years ago. That doesn't mean that there are all the supports needed to sustain the help that families need, but as far as parent-to-parent supportive services, at the time when a child is born, there are people who are trained and who are willing to go in and help those families, and I would say I could find someone for every major medical center in this country that could do that. . . . [P]arent advocacy . . . is available and there are people who, if they have to make long distance calls or make a trip, will go and help parents when they find out they have this need. And indeed there are many systems in place to help the medical community, the legal community, the nursing staffs, to know how to get that help in.¹⁶

Also contributing to improvements in the last 20 years has been progress in rehabilitation technology, such as power wheelchairs and machines that assist people with vocal impairments to speak.¹⁷ Ed Roberts emphasized another critical aspect in the achievement of potential: motivation to attempt and to innovate.

I was told for years by the doctors I couldn't have a power chair; in fact, it was impossible, I didn't have the kind of muscles.

¹⁵ *Id.* at 87-88 (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education). Professor Luckasson testified: "In my own community, essentially all handicapped children, regardless of the severity of their disability, are educated on regular school campuses, not on isolated campuses, and are integrated to the maximum extent appropriate with nonhandicapped children." *Id.* at 95 (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico).

¹⁶ *Id.* at 256 (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

¹⁷ *Id.* at 108-09 (testimony of Ed Roberts, President, World Institute on Disability).

¹⁸ *Id.*

¹⁹ See, e.g., *supra* note 7 and accompanying text. See also *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 269-70 (1986) (vol. II) (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

Well, I fell in love. . . .and it was ridiculously inconvenient to take my attendant everywhere with me, I just couldn't be alone. Well I learned how to drive a power chair in 2 days. . . .

I think sometimes. . .we forget. . .that people can do incredible things despite the prejudices, despite the dire predictions, if we give them the help they need. In this case, all I needed was something to adapt the wheelchair for me, to turn the controller around; it didn't cost anything really, and I probably saved the State thousands of dollars in people pushing me around to my classes and to other places.¹⁸

Repeatedly, those who support denying lifesaving treatment to children with severe disabilities invoke the horrors of institutionalization.¹⁹ However, Special Education Professor Ruth Luckasson informed the Commission:

Research such as that conducted in the case of the deinstitutionalization of all of the residents of Pennhurst State School indicates that handicapped people, irrespective of the severity of their disability, can live in the community. The fact that they don't is a policy decision that has been made by this society, not a reflection of their functioning ability.²⁰

Although there is considerable experience with the effectiveness of integrated community living policies in a variety of places across the country, the availability of services to assist in finding employment and educational rehabilitative services is still spotty, varying from State to State and sometimes from community to community.²¹ This reality may partially account for the continuing view of many that the lives of people with severe disabilities remain hopeless.

²⁰ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 96 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico). See also *id.* at 98-99; and chap. 4.

²¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 100-02 (1986) (vol. II) (testimony of Prof. Ruth Luckasson, Department of Special Education, University of New Mexico). See also *id.* at 187-88 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.) (describing difficulties for families of children with disabilities in securing adequate financial support, obtaining an appropriate education, and seeking respite care and support facilities, but noting, "These are not problems that are inherent in the disability. If we had sufficient support facilities in society, if there were enough resources out there, much of the burden would be removed from parents, and the quality of life of all concerned would be significantly increased. . . .").

Quality of Life and Down Syndrome

Advocates of denial of treatment have attacked the accuracy of the positive picture of the potential quality of life with disability that appears to predominate among disability experts and people with disabilities themselves. The physician who delivered Bloomington's Infant Doe, Dr. Walter Owens, criticized those who present optimistic scenarios for children with Down syndrome: "The one who is involved in such care has to be enthusiastic about it or he can't do it, but sometimes his enthusiasm is not tempered by sufficient realization of the broader aspects of what he is doing."²²

Although Dr. Owens lacks formal training in habilitation or the diagnosis of future disability and although he performed no neurological testing on Infant Doe,²³ he did not hesitate to give the Indiana trial court this projection of the child's future:

My testimony was to the effect that I had personally had contact of one sort or another with a considerable number of Down's children over a period of years, that some of these children were mere "blobs." They were incapable of doing anything, and I used that word. That others were . . . no more than moderately retarded, that this sounded benign enough until you realize what "moderate retardation" meant. It meant that these children, as they grew up, were unable to do the normal things that normal children can, that I made the statement in regard to this, that I had never known a Down's child who was gainfully employed outside a sheltered workshop. I have had to revise that since I heard of one Down's child, a young woman, who is washing dishes in a restaurant. That's the sole one I have been able to encounter. I have never known a Down's child able to live on its [sic] own. They require constant attention the rest of their lives.²⁴

Dr. Owens also told the Commission that the "lifetime cost" of a child with Down syndrome would "almost surely be close to \$1 million," and that "The great majority of Down's syndrome children, if they survive to adulthood, develop

premature Alzheimer's disease, and the last part of their lives is spent in almost total dependency." He said such a child is "more prone to develop leukemia, which is usually fatal."²⁵

Dr. Owens' conclusions are strikingly out of touch with the contemporary evidence on the capabilities of people with Down syndrome. One author has noted:

Most early data on the development of children with Down syndrome had come from institutional populations where the lack of stimulation and even deprivation obviously lead to a decrement of cognitive development. Studies . . . generally found the child with Down syndrome who had been institutionalized soon after birth to be at a severely retarded level. Yet children who had been reared at home had a more advanced cognitive development, which lasted three years after their subsequent placement in institutions. Other studies have noted the majority of children reared at home to be functioning in at least the moderately retarded range.²⁶

One study has shown that children with Down syndrome who participated in early intervention programs performed at consistently higher levels of cognitive and adaptive functioning than comparable children raised without the benefit of such programs, and that such benefits "provide a [stable] foundation for subsequent learning and development."²⁷ Children with this foundation can develop skills that might otherwise have been lost. They can learn to walk, eat, and have the social improvement that sustains the will to learn—all freeing them from the need for "constant attention."

Both anecdotal evidence and empirical studies confirm that the availability of appropriate education and training provides a sound basis for optimism regarding the life prospects of babies born with Down syndrome. Six studies in particular demonstrate that adolescents and adults with Down syn-

should be . . . [those in the] profoundly to severely retarded range. . . ." *Id.*

²⁵ *Id.* at 234-35.

²⁶ Schnell, *Psychomotor Development, The Young Child With Down Syndrome* 207, 209 (S. Pueschel ed. 1984) (footnotes omitted).

²⁷ Connolly, Morgan, & Russell, *Evaluation of Children with Down Syndrome Who Participated in an Early Intervention Program: Second Follow-up Study*, 64 *Physical Therapy* 1515 (1984). See also Dmitriev, *Cognition and the Acceleration and Maintenance of Developmental Gains Among Children With Down Syndrome: Longitudinal Data*, 11 *Down's Syndrome* 6 (1988); Hanson, *Early Intervention for Children With Down Syndrome*, in *New Perspectives on Down Syndrome* (S. Pueschel et al. eds. 1987).

²² *Id.* at 210 (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

²³ *Id.* at 224.

²⁴ *Id.* at 224-25. Owens defined "normal" as having an IQ above 80, although he said some might place it at 70 or above. "[I]n any case, a child [is normal] who has intelligence that would enable him to function as an independent individual in our society, and whose physical handicaps are not so great that he cannot at least have some function. . . ." *Id.* at 225. Pediatric neurologist Dr. Patricia Ellison would set a lower level for the point below which consideration of denial of treatment is appropriate. Those with an IQ of 50 to 70, she testified, "by and large live independently, they hold jobs, they do not attain levels of education of many people present in this room, but they function in society." *Id.* at 226. In her view, in "decisionmaking processes, your first concern

drome can acquire skills that advance their development of independence.

In 1974 Menolascino studied the attainment of such adaptive and independent living skills as ambulation, feeding, dressing, toilet etiquette, and grooming among a population of 72 adults with Down syndrome with a mean age of 33.4 years. Even though these individuals learned their skills in a residential facility with little stimulation, 75 percent were able to "walk freely and unassisted," and 79 percent could feed themselves "completely and neatly without help. . . ." Sixty-four percent were able to undress well and dress partially, i.e., "needing only occasional or minor help." Finally, significant levels of grooming ability were demonstrated: 69 percent could wash and dry their faces; 56 percent could brush their teeth; 24 percent could comb, brush, and/or part their hair; and 39 percent could shower and dry themselves completely and adequately. Menolascino concluded that "[o]verall, the levels of functioning are inconsistent with the prevailing belief that Down's syndrome prevents one from performing self-care tasks."²⁸

In another area, in 1973 Sidman and Cresson reported on an attempt to devise a method that would allow two men with Down syndrome, who were labeled severely retarded, to learn to read. Beginning with the assumption that most people learn to read by first learning to match spoken words with pictures, and then to match printed words with pictures, Sidman and Cresson postulated that, through faulty teaching, most children with mental retardation never learn the final, purely visual step in the reading comprehension process, even though they have the capability of doing so. They devised a method to address this problem. The two subjects in the study were initially unable to read the 20 words that Sidman and Cresson had chosen as their focus. Ten months later, however, after experimentation with the new method, the two men were able to read between 50 percent and 75 percent of the words with comprehension. The researchers concluded that "teaching procedures, rather than subjects' deficiencies, may have set the

limiting conditions, even at this level of retardation."²⁹

In 1979 Hobson and Duncan reported on a study in which a small group of adults with Down syndrome was taught to use sign language. All had lived in institutions for most of their lives, their mean IQ was 20.2, and they were labeled profoundly retarded. At the beginning of the study, four of the subjects were "nonverbal with little ability to gesture," three had "very limited vocal skills and gesturing abilities," and two could be understood, on occasion, only with great difficulty. After 66 weeks of focused instruction, they had learned the signs.³⁰

A study reported by Buddenhagen in 1971 described an effort to promote vocalization in "institutionalized children with Down syndrome who were severely retarded and exhibited very maladaptive behaviors." Institution records indicated that Larea, an 18-year-old woman who participated in the study, could not talk and frequently kicked, bit, and struck other residents and institution aides, although she did have some self-help skills and could respond appropriately to some verbal stimuli. After 21 hours of training that used a combination of incentives and direct instruction, Larea had acquired a fairly sizable verbal repertoire. Furthermore, Larea's social behavior improved so dramatically that reports that had previously characterized her as stubborn and mercurial began to call her cooperative and polite.³¹

These investigations all show 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. They provide "positive impetus for further exploration of specific techniques"³² that may be used, at ever earlier ages, to prepare people with Down syndrome for independent living.

Despite Dr. Owens' statement to the court that he had "never known a Down's child who was gainfully employed outside a sheltered workshop,"³³ even persons with severe disabilities can be "productive employees. . . [W]ith appropriate support and ongoing supervision, individuals who typically would be targeted for sheltered employment or day habilita-

²⁸ Putnam & Rynders, *Advancing the Development of Independence in Adults with Down Syndrome*, in *Down Syndrome: Advances in Biomedicine and the Behavioral Sciences* 468-69 (S. Pueschel & J. Rynders ed. 1982).

²⁹ *Id.* at 469-70.

³⁰ *Id.* at 471-72.

³¹ *Id.* at 472-73.

³² *Id.* at 473.

³³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 225 (1986) (vol. II) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.). Dr. Owens told the Commission that subsequent to his court testimony, "I have had to revise that since I heard of one Down's child, a young woman, who is washing dishes in a restaurant. That's the sole one I have been able to encounter." *Id.*

tion programs can become productive, earning employees in industry settings.”³⁴ One long term study has shown that the employability of adults with mental retardation in competitive environments is much more a function of factors other than the mere fact that an individual has mental retardation. The two factors with the greatest effect on the length and quality of the employment of the person with mental retardation were the extent to which they were accurately matched to jobs maximizing their particular abilities, and the degree to which relevant, high-quality, onsite supervision was available. In situations in which both of these maximized, the mean length of employment was 19 months.³⁵ By contrast, the mean length of employment for nondisabled people performing similar jobs was 5 months.³⁶ The 167 individuals in the study earned \$1,069,309 over a 6-year period and paid \$245,941 in taxes.³⁷

Other studies show the ability of people with mental retardation to learn employable vocational skills. One example is the work of Gold, reported in 1973. Gold taught a group of 64 moderately and severely retarded individuals (about 40 percent of whom had Down syndrome) how to assemble bicycle braking mechanisms. After their training, 63 of the 64 were able to assemble the braking mechanisms correctly in six of eight consecutive trials. A year later, 53 of the 64 put together a 24-piece training brake, exhibiting a high degree of skill retention. The individuals with Down syndrome performed comparably with the others.³⁸

Anecdotes corroborate what empirical studies postulate about the actual employability of persons with mental retardation. JoAnne Putnam and John Rynders relate several such success stories in their essay, “Advancing the Development of Independence in Adults with Down Syndrome.” In this work, they describe individuals with Down syndrome who all lead prosperous vocational lives. Kathy Hagarty, 19 years old in 1978, was the librarian at the St. Collette School for Mentally Retarded Children. Jacques Dumont, in his early twenties in 1977, ran the addressograph and mimeo-

graph machines in his office, ran errands to the bank and post office, made the morning coffee, and was considered a trustworthy employee. At age 23, David Kaul was earning \$2.90 an hour for maintenance work for the contact lens manufacturer Precision Cosmet, and also mowed lawns with a \$2,400 tractor that he had bought with his own savings. On weekends, Kaul cleaned the local fire station on a volunteer basis. At 31 years old, Dave Stevenson in 1979 was a grounds maintenance worker with the Maryland National Park and Planning Commission, earning \$3.04 per hour. Stevenson received training through the vocational training program at the Melwood Horticulture Center, Inc. When he enrolled there in 1967, he was considered the lowest functioning person in the program because he had scored below 35 on the Wechsler Adult Intelligence Scale, and he was lacking even in self-care skills. These factors make his later success as a paid employee all the more impressive.³⁹

Informed of Dr. Owens’ estimate that the lifetime cost of a child with Down syndrome would be close to a million dollars, Diane Crutcher, executive director of the National Down Syndrome Congress, wrote that “the lifetime cost of a person with Down syndrome will drop dramatically because they are now being raised in the community to live in the community as tax-payers and not tax-burdens.”⁴⁰ Dr. Owens’ estimate of the cost associated with a person with Down Syndrome is a function of his assumptions about the inability of such an individual to take care of or support himself or herself. Yet, early intervention programs now foster such ability.

It is important to recognize that Down syndrome, with the lessened mental capacity associated with it, does not mean “an inability to learn, but rather as a slowed rate of learning.”⁴¹ Early intervention provides the framework for developing additional skills. By themselves, these skills avoid the cost of continual assistance. But they also create the basis for participation in employment, through which many people with Down syndrome can support themselves.

³⁴ Kiernan, *Opportunities and Options for Employment*, in *The Young Person With Down Syndrome*[:] Transition From Adolescence to Adulthood 155, 161-62 (S. Pueschel ed. 1988) (footnote omitted). Cf. Wehman et al., *Competitive Employment for Persons with Mental Retardation: A Follow-up Six Years Later*, 23 *Mental Retardation* 274 (1985) [hereinafter Wehman].

³⁵ Wehman, *supra* note 34, at 276-79.

³⁶ *Id.* at 279.

³⁷ *Id.*

³⁸ Putnam & Rynders, *supra* note 28, at 475.

³⁹ *Id.* at 474-75.

⁴⁰ Letter from Diane M. Crutcher, Executive Director, National Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

⁴¹ Edwards, *Living Options for Persons with Down Syndrome*, in *New Perspectives on Down Syndrome* 337, 340 (1987).

These studies and anecdotes demonstrate the positive and powerful effects that focused and appropriate training and education can have on the lives of people with Down syndrome. As such, they suggest that a proper response to the diagnosis of Down syndrome at birth is not fatalistic resignation, but the "exploration of specific techniques" capable of advancing the development of independence.⁴²

The final ground advanced by Dr. Owens to defend denying lifesaving treatment to children with Down syndrome is his assertion that they are prone to leukemia and Alzheimer's disease. Although it is true that those with Down syndrome have a somewhat greater statistical likelihood of developing leukemia, that incidence is still only 1 in 60,000.⁴³ That lifetime risk is less than the annual risk each of us faces of death from accidental drowning or as a result of a fire.⁴⁴ Dr. Owens may have been influenced by early studies that gave what proved to be highly inflated estimates for the incidence of leukemia in children with Down syndrome.⁴⁵

Dr. Owens' statement that a majority of persons with Down syndrome develop premature Alzheimer's disease is flawed as well. In the words of the executive director of the National Down Syndrome Congress: "[A]lthough there is early evidence of Alzheimer-like. . . [symptomatology] in the brains of many persons with Down syndrome around the age of 35 (via autopsy), the majority do not show clinical signs of the disease until their 50's to 60's (if at all). . . ."; i.e., at about the same age as people without Down syndrome begin to exhibit clinical symptoms of the affliction.⁴⁶

⁴² Putnam & Rynders, *supra* note 28, at 473.

⁴³ Letter from Diane M. Crutcher, Executive Director, Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

⁴⁴ In 1982, 2.3 people drowned and 2.2 died as a result of accidents caused by fires and flames for every 100,000 people in the United States. U.S. Bureau of the Census, *Statistical Abstract of the United States 1986*, p. 77 (106th ed.) (table 120). The risk that a person with Down syndrome has of developing leukemia in an entire lifetime is equivalent to 1.7 in 100,000.

⁴⁵ "One factor that confused early researchers. . . was the large number of [infants] with Down syndrome who developed what was thought to be acute myelocytic leukemia and then underwent spontaneous remission." Later researchers "showed that [infants] with Down syndrome are more likely to develop a leukemoid reaction clinically and histologically resembling acute leukemia. This leukemoid reaction, however, undergoes spontaneous remission and therefore cannot be classified as leukemia. Furthermore, [infants] with this leukemoid reaction who die of other causes have no histologic signs of leukemia outside of the blood or bone marrow, which is in contrast to true neonatal leukemia. . . ." Sassaman, *Oncology*, in *Down Syndrome*[:] *Advances in Biomedicine and the Behavior Sciences* 237, 237 (S. Pueschel & J. Rynders eds. 1982).

Studies have indeed shown that the autopsies of brains of most persons with Down syndrome over the age of 35 evidence "laboratory traits" of Alzheimer's.⁴⁷ Therefore, "many neuropathologists have simply stated that all persons with Down syndrome develop Alzheimer disease with age."⁴⁸ Oliver and Holland state, "From the neuropathological literature the assumption arises that all elderly people with Down's Syndrome. . . would therefore be expected to have the clinical signs of dementia."⁴⁹

But this is not the case. There is a lack of correspondence between the laboratory results and clinical observations of senility.⁵⁰

Some older persons with Down syndrome are considered "as normal as their juniors and hardly ever exhibit the personality changes or psychological problems observed in Alzheimer disease."⁵¹ In a study of individuals with Down syndrome over age 36 whose autopsies showed the neuropathology of Alzheimer disease, only about one-fourth were characterized as exhibiting dementia.⁵²

Inaccurate Prognoses

A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proved wrong.⁵³ Too many examples have been adduced to be dismissed as isolated instances.

One of the most highly publicized cases, that of Baby Jane Doe in New York, is a striking example. The case contained many elements typical of such sagas: the denial of surgery following her birth; the

⁴⁶ Letter from Diane M. Crutcher, Executive Director, National Down Syndrome Congress, to U.S. Commission on Civil Rights (May 9, 1988).

⁴⁷ Oliver & Holland, *Down's Syndrome and Alzheimer's Disease: A Review*, 16 *Psychological Medicine* 307, 307 (1980).

⁴⁸ Schweber, *Interrelation of Alzheimer Disease and Down Syndrome*, *New Perspectives on Down Syndrome* 135, 135 (1987).

⁴⁹ Oliver & Holland, *supra* note 47, at 318.

⁵⁰ Schweber, *supra* note 48, at 138. "[P]rimary care providers have long been aware that the majority of adults with Down syndrome live out their lives with no apparent changes in personality or behavior." *Id.* at 135.

⁵¹ Pueschel, *Health Concerns in Persons With Down Syndrome*, *New Perspectives on Down Syndrome* 113, 127 (1987).

⁵² Schweber, *supra* note 48, at 138.

⁵³ See *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 180 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.) ("[Q]uality of life is not highly predictable even with the best information about a child's current situation. Often, quality of life is better than what early prognoses would suggest.").

unsuccessful efforts of a private attorney—prompted by a whistle blower—to obtain a court order for surgery; and the unsuccessful efforts of the Department of Health and Human Services to gain access to her medical records.⁵⁴ Finally, throughout the controversy, the accounts of the future predicted for her—should she survive—were unremittingly bleak.

The director of the American Academy of Pediatrics, Dr. Harry Jennison, said, “Baby Jane Doe’ . . . not only has spina bifida but fluid on the brain and an abnormally small brain. The baby is so severely deformed that there is nothing that can be done.”⁵⁵ A *Los Angeles Times* editorial noted, “Doctors say that without surgery the girl may live up to two years; with it she could live until she is 20, but she would be severely retarded, epileptic and paralyzed from the waist down, as well as in constant pain.”⁵⁶

The *Washington Post* quoted the court testimony of pediatric neurologist Dr. George Newman: “[O]n the basis of the combination of malformations that are present in this child, she is not likely to ever achieve any meaningful interaction with her environment, nor ever achieve any interpersonal relationships. . . .”⁵⁷ Newman also testified, “It’s unlikely that she is going to develop any cognitive skills” and would experience “nothing whatsoever” that he considered positive on the cognitive scale.⁵⁸

The baby’s parents described in an interview what they were told about the child’s future by medical personnel—the information on the basis of which they decided against surgery:

“We were told. . . that the part of the brain that controls much of our awareness was either missing or not entirely formed.

We are not talking about a spina bifida child, . . . one who could perhaps walk someday with braces. . . . She will be an epileptic. Her condition for future life is to be bedridden, and she would not have use of her hands.

⁵⁴ See chap. 5, text accompanying notes 25–32; and chap. 6, text accompanying notes 89–107.

⁵⁵ *Pro and Con[.]: Should Uncle Sam Protect Handicapped Babies?* U.S. News & World Report, Jan. 16, 1984, at 63, 64.

⁵⁶ *Indecent Zealotry*, *Los Angeles Times*, Nov. 16, 1983, pt. II, at 6.

⁵⁷ Barringer, *Meese Approved Intervention in Baby Case*, *Washington Post*, Nov. 16, 1983, at A16.

⁵⁸ Transcript at 47, 95–96, *People ex rel. Washburn v. Stony Brook Hosp.*, No. 83–19910 (N.Y. Sup. Ct. Oct. 19, 1983).

⁵⁹ Quoted in J. Lyon, *Playing God in the Nursery* 51–52 (1985).

⁶⁰ Caplan, *Is It a Life?* *The Nation*, Jan. 21, 1984, at 37, 37.

We also know that as she grew older, she would always be an infant. She would never know love. And while she might feel sorrow and joy, her overall condition would be pain.”⁵⁹

Asking “Is it a Life?” bioethicist Arthur Caplan (then on the staff of the prestigious Hastings Center) wrote of Baby Jane Doe, “No one should be forced by the government, [or] civil libertarians. . . to live such a life, even briefly.”⁶⁰

Notwithstanding the legal efforts opposed to providing medical treatment for Baby Jane Doe, she is alive today.⁶¹ Although the courts had upheld her parents’ decision to withhold operations to install a shunt and to close her back, the parents had time to change their minds. A shunt was installed, her back healed, and she was taken home.⁶² As she left the hospital, Dr. George Newman had not changed his prognosis: “She will still be severely retarded and, I still think, bedridden all the days of her life.”⁶³

When they took her home, her father commented to a reporter, “We’re happy because she appears to be happy.”⁶⁴ About a month later, a reporter described her as “smiling and cooing as her mother feeds her. . . . [S]he grasps a visitor’s finger in a tiny fist. . . .”⁶⁵ Already she was using her “unusable” hands. In June 1986, when she was 2 years and 8 months old:

Her. . . father said [she] likes to throw a ball to the family’s golden retriever, cruise around in a walker and try to sing “Row, Row, Row Your Boat.” He said he and his wife decided initially against surgery because it appeared she could die at any moment and they did not want to add to the baby’s pain.

“All of a sudden it turned around,” he said. “From that moment on, we really saw her sense of fighting and sense to live and we were full steam ahead with what had to be done for her.”⁶⁶

In December 1987, when she was 4, a reporter wrote of her, “Keri-Lynn talks and laughs; she

⁶¹ Baer, *The Half-told Story of Baby Jane Doe*, *Col. Journalism Rev.*, Nov.-Dec. 1984, at 35, 38.

⁶² Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment of the Handicapped Newborn*, 52 *Linacre Q.* 45, 54 (1985). Healing of the spinal lesion is rare without surgery but not without precedent.

⁶³ Quoted in Lyon, *supra* note 59 at 55.

⁶⁴ *Baby Jane Doe Goes Home*, *Milwaukee J.*, Apr. 6, 1984, pt. 2, at 3, col. 1.

⁶⁵ ‘Adorable’ *Baby Jane Doe Finally Is Home*, *Milwaukee Sentinel*, May 25, 1984, pt. 1, at 8, col. 1.

⁶⁶ Associated Press, “*Baby Doe*” *Parents Applaud Supreme Court Ruling*, *Domestic News PM Cycle*, June 10, 1986.

smiles and hugs and screams and plants kisses firmly on a stranger's cheek."⁶⁷ She was using a wheelchair and attending school.⁶⁸ "I'm thrilled as can be," her father said. "The fact that she's able to relate to us and her environment is amazing. Her mental awareness is fabulous now."⁶⁹ She was "learning to mix with her peers."⁷⁰ Of course, she still has spina bifida. She does not walk, and requires frequent catheterization; she has had to have surgery for a dislocated hip.⁷¹ But, in the following description of Baby Jane Doe at 4, it is hard to recognize the pain-wracked, unaware, bedridden creature of her doctors' confident predictions:

She has recently begun to demand more than her share and often resorts to throwing toys or M&Ms when the focus shifts away from her. Then she whispers, "I'm bad," aware that her mother is displeased with her behavior.

. . . Later, she whispered, "Dance, Daddy, dance," as her father swept her into his arms to sway to the music of Stevie Wonder.⁷²

A woman who works in parent support in Phoenix, Arizona, told the Commission about a similar story:

We also have our own little Baby Doe in Arizona and her name is Jessie. . . Jessie was supposed to die the first night that she was born. She also had spina bifida, hydrocephalus, lots of severe brain damage, and all of those things that were not compatible with life, so no treatment was done for Baby Jessie. Days and days and days went on and Baby Jessie fooled everybody and did not die.

Finally about the 21st day, right at the time the signs were hanging up in the nurseries, somebody got real nervous and said, maybe she's not going to die, maybe we better do surgery. So by this time, unfortunately it was really too late to do much repair on her back, but they did put a shunt in and that little girl now talks in sentences and goes to regular preschool.

Her family really believed what the doctors said: She will die. So they just waited for her to die. And so for me

⁶⁷ Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2.

⁶⁸ Kerr, *Baby Doe's Success*[:] *Legal, Medical Legacy of Case*, Newsday, Dec. 7, 1987, at 2, 23.

⁶⁹ Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2, 23.

⁷⁰ Kerr, *Baby Doe's Success*[:] *Legal, Medical Legacy of Case*, Newsday, Dec. 7, 1987, at 2, 23.

⁷¹ Kerr, *Baby Doe's Success*[:] *Progress Defying Prognosis*, Newsday, Dec. 7, 1987, at 2, 23.

⁷² *Id.*

⁷³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 264-65 (1986) (vol. II) (testimony of Betsy Trombino).*

as a parent I have a real difficult time with someone making that kind of a prognosis for a child and not doing any treatment. Because I have seen too many kids who defy all the prognoses made for them.⁷³

One family in the Chicago area can give two examples of negative predictions disproved. They are the adoptive parents of a child with spina bifida left to die in Robinson, Illinois, until the Justice Department intervened.⁷⁴ When he was a year old, the *Chicago Tribune* reported that his adoptive parents "believe that his alertness proves there has been no brain damage and that his paralysis from the knees down won't keep him from walking."⁷⁵ Their other example is their child born a few years earlier:

"When she was 4 months old, the doctor told us she had some kind of neurological impairment—they still don't know exactly what. They advised us to put her in an institution and forget about her," said the mother.

The child is now an alert, active 5-year-old who moves normally around the house, and speaks many words, with only slight hesitation.⁷⁶

Patricia McGill Smith, deputy director of the National Information Center for Handicapped Children and Youth, told the Commission about a case in Omaha, Nebraska. A child was born with spina bifida, and there was "a recommendation of no treatment based on the fact that the child had spina bifida and predictable mental retardation." After 4 months of debate, the parents changed their initial decision to accept that recommendation, and the child received treatment and lived. Ms. Smith testified, "I have tracked the progress of that child and that family ever since. The young lady had no mental retardation whatsoever."⁷⁷

Such positive results for children born with spina bifida are not anomalous. Dr. David McLone, who heads a major neurosurgical department and formerly chaired the Professional Advisory Council of the Spina Bifida Association of America, testified:

⁷⁴ Telephone interview with Robert D'Agostino, Former Deputy Assistant Attorney General, Civil Rights Division, Department of Justice (Dec. 1, 1988).

⁷⁵ Nelson, *2d miracle baby gives family joy*, *Chicago Tribune*, Apr. 24, 1983, Sec. 3, at 1, col. 1.

⁷⁶ *Id.*

⁷⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 254-55 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).*

[S]ince I have been at Children's Memorial Hospital, [we have]. . .operated on all children and have not used any form of selection.

. . .85 percent of them survived and 15 percent of the children have died from complications. . . .Of the 85 survivors, 73 of them have normal intelligence. Approximately 85 percent of them have a shunt for their hydrocephalus.

Eighty-nine percent of the survivors are community ambulators. . . .someone who can walk from the school bus to the classrooms, between classrooms, and can walk in their neighborhood. A significant number of those children who are community ambulators, however, are walking with braces and crutches. We have a very small number of children who are in wheelchairs. Ninety-five percent of them have no bladder and bowel control, but are rendered socially continent of bladder and bowel by training in the use of intermittent catheterization. We would, therefore, estimate, based on these numbers, that something like three-quarters of the children who survive will be competitive and independent as adults.

There will be another 10 percent. . . .who will require some kind of sheltered care, and about 10 percent of the survivors will be impaired to the point that they will require some kind of nursing care throughout their life.⁷⁸

Despite these results, Dr. McLone observed:

One of the problems. . . .with spina bifida is that a pediatrician in practice may see one or two of these in an entire lifetime. . . . [T]here still are occasions in which physicians are confronted with spina bifida who are not aware of the outcome or the changes that have occurred over the last 20 or 30 years and give information based on what the outcome was 30 or 40 years ago. It's just not appropriate.⁷⁹

Ed Roberts, president of the World Institute on Disability, testified before the Commission:

I began to be a principal in physical disability. . . .at 14 years of age. I got polio in 1953. Within 2 or 3 days, I went from a child who was achieving his independence to patient and to the label of a helpless cripple, and within 2 days I was in an iron lung. My mother went to a doctor and she asked whether I would live or would I die, and the doctor looked at her and very patronizingly said, "Maybe you should hope he dies, because if he lives he'll be nothing more than a vegetable for the rest of his life."

. . . .

⁷⁸ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 6-7* (1985) (vol. I) (testimony of David McLone, M.D., Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

⁷⁹ *Id.* at 10.

⁸⁰ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 102-03, 104* (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

One of the real ironies is when I was about 18 years old, I went to the California Department of Rehabilitation and I asked to be a client, and I was immediately rejected as too severe to ever go to work. Well, I became director of that department 10 years later.⁸⁰

John Kemp, a lawyer, testified: "I was born without arms or legs, . . .and my parents were told. . . .by the doctor that delivered me. . . .that the best I could hope for would be a life of, hopefully of comfort, but certainly not of any kind of achievement."⁸¹

Robert Williams is deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens, with monitoring responsibility for implementation of a court decree requiring transfer of many people with disabilities from institutions to community living arrangements. He has cerebral palsy with a speech impairment. He testified:

My parents were told from the start just how severe my disability was. In fact, they were advised on numerous occasions to put me away in . . .an institution. . . .

. . . I come from solid blue-collar stock. My Dad and two brothers own and operate a small construction company. . . .It was clear from the start that I would not be cut out for such a life. My parents decided if I was to make it, I would have to do it by a different way and they provided me with ample support on my journey. As it turned out, I'm the first in my family to graduate from college, the first to have taken an active interest in politics, the arts, and literature.⁸²

Another person with a disability who testified was Irving Kenneth Zola, who now teaches sociology at Brandeis University. After he had polio, he used canes with leg and back supports for walking; his rehabilitation agency advised him to go to a vocational school, and people at the agency "were upset when I was accepted at Harvard University."⁸³ Mary Jane Owen was once told that her daughter was mentally retarded; she later graduated cum laude from Harvard.⁸⁴

Margaret Burley told the Commission about her 24-year-old son who "was diagnosed at various times in his life as having an IQ of somewhere

ty).

⁸¹ *Id.* at 123 (testimony of John Kemp, Director of Human Resources, National Easter Seal Society).

⁸² *Id.* at 269-70 (testimony of Robert R. Williams, Project Analyst, D.C. Association for Retarded Citizens).

⁸³ *Id.* at 178 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University).

⁸⁴ *Id.* at 137 (testimony of Mary Jane Owen, Director, Disability Focus, Inc.).

between 5 and 42. . . .He is totally blind, somewhat hearing impaired. . . .It has been said he is emotionally disturbed. He has had every label you would want to put on him. . . ." When he was young, medical personnel told her that he would adversely affect her other three children and urged her to "put him away." She testified, however, that he now works 5 days a week and enjoys going to rock and roll concerts and nightclubs with friends. "[H]e can enjoy life. . . .He is just like anybody else, and I will tell you my other children have turned out to be better citizens, and I think our whole family has been improved [by his presence]."⁸⁵

Special Education Professor H. Rutherford Turnbull, himself the parent of a child with mental retardation, has analyzed letters written to the Department of Health and Human Services as part of the public comment on the "Baby Doe" regulations under section 504. Letters written by people with disabilities or their family members described a number of instances in which pessimistic predictions made by physicians were later proved inaccurate. Thirty percent of the correspondents indicated a lack of confidence in health care providers.⁸⁶

The Limitations of Medical Experience

Why do so many negative predictions about the future quality of life of children with disabilities turn out to be wrong? 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.

In the words of Surgeon General Koop, "[N]o pediatrician can be expected to know what all of the community supports are that might be available to a child with a given diagnosis. He might understand hemophilia perfectly well in the community, but not cystic fibrosis."⁸⁷ Dr. Koop continued, "Therefore, it has been my lifelong endeavor to prevent snap

diagnoses, prognostications made without sufficient knowledge. . . ."⁸⁸

Dr. David McLone testified:

[W]hen you look at the criteria that have been used, such as a child who has a T-12 level shouldn't be operated on—Dr. John [Lorber], a pediatrician from England, is the one who first advanced that criterion—when you look at the results that he published in 1981, in which he treated something like 30 percent of the entire population—if you look at those 30 percent survivors and compare them to our study in which we treated essentially all children, they are not significantly different. So the selection criteria that have been used to select these children that is supposed to be predictive of quality of life or outcome have been shown in almost every center in the United States to be invalid and not predictive and do not produce a population of children with spina bifida who are superior to the group where everyone is treated.⁸⁹

Wolraich, Siperstein, and O'Keefe surveyed random samples of pediatricians on their assumptions about persons with varying degrees of mental retardation. They asked pediatricians to describe specific skills that each group could be expected to develop and compared their answers with those of physician members of the American Association on Mental Deficiency (now the American Association on Mental Retardation, or AAMR). They then compared the answers of each of the two groups with those of special educators and social workers who were also members of the association. "Pediatricians were strikingly restrictive in their expectations of the capabilities of severely mentally retarded individuals. Their categorizations placed these individuals as devoid of most human capabilities, including the ability to sustain friendships; pediatricians believed they were unlikely to work in any setting or reside outside an institutional setting."⁹⁰ The pediatricians had significantly more pessimistic expectations than the physician members of the AAMR, who in turn had significantly lower expectations than the special educator and social worker members.⁹¹

Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

⁸⁵ *Id.*

⁸⁵ *Id.* at 257-58 (testimony of Margaret Burley, Director, Ohio Coalition for the Education of Handicapped Children).

⁸⁶ *Id.* at 42-43 (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas). Professor Turnbull's written statement excerpts a number of these letters. See app. B. It also cites a number of publications and research studies that document "the positive quality of life that people with severe to mild physical or mental disabilities can have and do have." *Id.*

⁸⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 8 (1985) (vol. I) (testimony of C.

⁸⁸ *Id.*

⁸⁹ *Id.* at 12 (testimony of David McLone, M.D., Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Ill.).

⁹⁰ Wolraich, Siperstein & O'Keefe, *Pediatricians' Perceptions of Mentally Retarded Individuals*, 80 *Pediatrics* 643, 647 (1987).

⁹¹ *Id.* at 648. See also *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 49 (1986) (vol. II) (testimony of Carlton Sherwood) (As a result of

Another survey by Siperstein, Wolraich, Reed, and O'Keefe queried a random sample of Fellows of the American Academy of Pediatrics on their views of the future for a child born with spina bifida without hydrocephalus and with hydrocephalus of varying severity.⁹² The differences in projection based on degree of hydrocephalus were great. For example, 47.9 percent thought the child without hydrocephalus would live in an unsupervised apartment; only 2.1 percent believed such a child would require institutionalization. On the other hand, the child with severe hydrocephalus was expected by only 2.9 percent to live in an unsupervised apartment and by 54.3 percent to live in an institution. Similarly, 53.8 percent thought the child without hydrocephalus would have skilled competitive employment, with 5.0 percent predicting that such a child would be incapable of any employment. Fully 66 percent stated that the child with severe hydrocephalus would be incapable of any employment, and only 2.3 percent predicted that the child could enter skilled competitive employment. Only 4.6 percent believed the child with severe hydrocephalus would be capable of any type of unsupervised employment.⁹³

Evidently most of the pediatricians thought that as the degree of hydrocephalus increases, so does the degree of mental retardation, and also believed that as the degree of mental retardation increases, the capacity for independent and productive living decreases.⁹⁴ However, as the authors of the study pointed out, the pediatricians were wrong:

Yet the findings concerning the effect of hydrocephalus on the intellectual abilities of children born with meningo-myelocele indicate a discrepancy between what the pediatricians perceived as the impact of hydrocephalus and current information about the actual impact.

In contrast to the pediatricians' prognoses for mental retardation, actual follow-up studies of children with meningo-myelocele accompanied by hydrocephalus have

his investigations, Sherwood concluded, "[D]octors frequently exaggerate the degree of the handicapped newborn's illness in an effort to justify their decisions and their prejudices." A possible explanation is that physicians are most likely to see persons with disabilities only when they are sick. See *infra* notes 96-97 and accompanying text.

⁹² Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants with Meningomyelocele*, 113 *The Journal of Pediatrics* 835 (1988).

⁹³ *Id.* at 838, table 2. The results in this table are reprinted in chap. 4 of this report.

⁹⁴ Chap. 4 includes a detailed analysis and empirical refutation of the latter assumption.

found that the intellectual capabilities of these children are difficult to predict. Although there is an increased chance that there will be some intellectual impairment, other factors, such as shunt infection, are more important. In fact, five studies found no clear relationship between intelligence and the degree of hydrocephalus. Even if there is a relationship between hydrocephalus and mental retardation, as one study did find in correlating the palladium thickness to subsequent intelligence, it does not appear that the degree of mental retardation is as low as pediatricians perceive it to be. When the degree of mental retardation was determined by calculating the mean intelligence quotient scores for children with meningo-myelocele and varying degrees of hydrocephalus, most children with severe hydrocephalus had mild to moderate retardation (mean IQ 57.6). In contrast, the pediatricians in this study predicted that those children were likely to function at a much lower level. "Thus it appears that pediatricians have an unduly pessimistic perception about the eventual intellectual abilities of children born with meningo-myelocele who have severe hydrocephalus."⁹⁵

Physicians may have such a propensity for negative prognosis at least in part because they tend to see children with disabilities at the time that the children are fighting medical problems, when they are in the hospital—when their condition is at its worst.⁹⁶ Those 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. According to Dr. Darling: "[T]he few pediatricians who are wholeheartedly in support of treatment for the disabilities that I have known have all, interestingly enough, had a sibling or other close family member who did have a disability."⁹⁷ In the sample Dr. Darling studied, however, only 7 percent of the pediatricians had a close family member who had a disability.⁹⁸

Unfortunately, despite the many instances in which pessimistic quality of life projections have been proved dramatically wrong, all too frequently

⁹⁵ Siperstein, Wolraich, Reed and O'Keefe, *supra* note 90, at 839 (footnotes omitted).

⁹⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 115 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

⁹⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 186 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention

Services, City Council Clinic in Johnstown, Inc.). Dr. Darling commented, "I think that the experience of getting to know a person with a disability is a significant experience in changing the way a person views that situation. . . ." *Id.*

⁹⁸ *Id.* at 183.

the prophecies themselves help to bring about what they predict. As Ed Roberts testified: "People who are fundamentally seen as less than they are often accept that. It becomes very self-fulfilling when you're put away or put in a nursing home; you begin to accept it."⁹⁹

Dr. Rosalyn Benjamin Darling, who has conducted studies of the physicians and families of children with disabilities, testified that these negative attitudes are often based on the nature of the individual's background.¹⁰⁰ Surgeon General Koop expressed a similar view:

The snap judgment by the physician. . . can be based upon ignorance. It can also be based upon prejudice. And that prejudice might be of two kinds. One, having seen a similar patient in the past that he didn't think had the quality of life that he liked, he might advise that family that nothing should be done. Or his prejudice may be along the lines, which I think is more common, and that is a stranger looking at a defective newborn baby says, "Gee, if that were mine, I couldn't hack it." But it isn't his, and the parents feel quite differently about their child than a strange physician.¹⁰¹

Families, Society, and Persons with Disabilities

The quality of life argument extends beyond the life of the person with a disability. It is frequently argued that the continued existence of a person with disabilities will damage the quality of life of the person's family, or of society as a whole.¹⁰² In other words, the burden the person creates for others outweighs the benefits they experience because she or he exists. Dr. Ellison testified:

I do think that factors, such as if you have to take home a child who requires 24-hour nursing care,. . . and society provides no other person but the mother and the father, but mostly the mother to do that, that is to say, there's no respite care, there's no homemaker service, there's no one else who is going to care for that child, and in addition to that, the family has to pay for a good many of the medical

expenses for that, I think the family ought to be permitted to participate in that discussion and in that decision.¹⁰³

A letter submitted for the record by Dr. Walter Owens (who delivered Bloomington's Infant Doe) exemplifies a willingness to make denial of treatment decisions based on the utility of the life to others. The anonymous woman followed Dr. Owen's 1971 advice to deny treatment to her child born with spina bifida, hydrocephalus, and unspecified "other anomalies."

I don't think I would be able to have the happy, complete quality of life I have now if I had not made the proper decision about that baby, based on your wise and compassionate counsel. My decision might seem self-serving to some, but in my heart, I truly feel that I made that choice based on that baby's lack of potential for a meaningful life, and yes, for my own need for a full life too.¹⁰⁴

Similarly, in the Bloomington Infant Doe case itself, the trial court's opinion reveals that the father "testified that. . . he and his wife have determined that it is in the best interest of the Infant Doe and the two children who are at home and their family entity as a whole" that the child should not be provided lifesaving surgery.¹⁰⁵

Children with disabilities, thus, are alleged to have a negative effect on their parents' qualities of life. Dr. Darling's research indicates that the sort of parental attitude exemplified by Dr. Owen's correspondent and the father of Bloomington's Baby Doe tends to change over time and with increased interaction with the child:

Parents. . . start out with the same kind of. . . stigmatizing attitude physicians have. . . .

. . . Even though the initial experience tends to be negative, usually within a short period of time, attitudes turn around.

Parents realize that this child is just as lovable as anybody else's child, and they begin to see positive aspects

⁹⁹ *Id.* at 105 (testimony of Ed Roberts, President, World Institute on Disability).

¹⁰⁰ *Id.* at 188-89 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

¹⁰¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 11-12 (1985) (vol. I) (testimony of C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

¹⁰² See chap. 4 for a discussion of the economic effect on society as a whole.

¹⁰³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 223 (1986) (vol. II) (testimony

of Dr. Patricia Ellison, Research Professor, Department of Psychology, University of Denver).

¹⁰⁴ Letter from anonymous person to Dr. Walter Owens (Aug. 20, 1983) (available in Commission files).

¹⁰⁵ *In re Treatment and Care of Infant Doe*, No. GU 8204-004A, slip op. at 2 (Monroe Co. Cir. Ct. Apr. 12, 1982), reprinted in *Declaratory Judgment in the Infant Doe Case*, 2 Issues in L. & Med. 77, 79 (1986), petition for writ of mandamus and prohibition denied sub nom. State of Indiana ex rel. Infant Doe v. Monroe Circuit Court, No. 482 S 140 (Ind. Apr. 14, 1982), appeal dismissed sub nom. *In re Guardianship of Infant Doe*, No. 1-782A 157 (Ind. Ct. App. Feb. 3, 1983), petition for transfer denied, No. 1-782 A 157 (Ind. June 15, 1983), cert. denied, 464 U.S. 961 (1983).

of life with a child who is disabled. Many parents have said that it has become a maturing kind of process with them. Living with a problem that can't be solved is a very maturing kind of thing. Many become exposed to a whole world of people and activities that they never knew existed before. Once it happens, they learn to make the best of it, and even learn to find some positive aspects of it and those aspects are the very things parents don't hear right at the beginning in that decisionmaking situation. . . .¹⁰⁶

In both the Baby Jane Doe case of 1983-84¹⁰⁷ and the Milwaukee Baby Doe case of 1987¹⁰⁸ the parents ultimately decided to provide the lifesaving surgery courts had ruled they could legally deny.

The deputy director of the National Information Center for Handicapped Children and Youth, referring to comments concerning burdens imposed on parents by the continued life of children with disabilities, testified:

I have supported hundreds of parents over the 12 years that I have worked, and when parents are supported in the help to their children, and when the medical support is given, even for severely handicapped children, I have not met a parent yet that does not want to do it if they can. And I think it is our job to make sure that they have those supportive services.¹⁰⁹

Propriety of Quality of Life Judgments

The deficiencies in quality of life assessments are demonstrated above. The more fundamental question is: to what extent should quality of life judgments be viewed as acceptable grounds for life and death decisions?

There is an important difference between technical medical judgments about whether a given course of treatment is likely or not to preserve life or ameliorate an impairment, and judgments about whether a person's life should or should not be preserved by giving lifesaving treatment. 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. This no more becomes a "medical" judgment by virtue of its implementation through the denial or provision of medical treatment than the decision whether to impose capital punishment becomes a "medical" judgment if execution is to be by lethal injection.¹¹⁰

Disability rights advocates argue that to take into consideration the burden that children with disabilities might impose on their families or society in deciding whether they should live or die constitutes discrimination on the basis of disability. Adrienne Asch testified:

[D]isabled people. . . have separate interests and civil rights apart from any family, societal, economic, social, or emotional burden that they might cause. Other people cause burdens, too, but we don't consider whether they should be alive, if it is all right with someone else. . . . We talk about the burden that disabled people will cause to their families, to their siblings, as though it means that the only way that disabled children should be allowed to live is if it is all right with someone else.¹¹¹

Recent decades have seen significant although mixed progress in understanding the burdens that society places on people with disabilities and in recognition of their rights and full humanity. At the Federal level, section 504 of the Rehabilitation Act of 1973¹¹² applies a general principle of nondiscrimination based on handicap to all programs or activities receiving Federal financial assistance; the Education for All Handicapped Children Act of 1975¹¹³ promises to all children with disabilities a "free appropriate public education which emphasizes special education and related services designed to meet their unique needs"; the Developmental Disabilities Assistance and Bill of Rights Act¹¹⁴ gives the Nation's assurance "that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such

¹⁰⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 184-85 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

¹⁰⁷ See *supra* text accompanying notes 54-72.

¹⁰⁸ *In re T.A.P.*, No. 03231186 (Milwaukee County, Wisc. Cir. Ct. July 31, 1987), *rehearing* (Aug. 12-13, 1987).

¹⁰⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 256 (1986) (vol. II) (testimony of Patricia McGill Smith, Deputy Director, National Information Center for Handicapped Children and Youth).

¹¹⁰ See *id.* at 116-17 (testimony of Prof. Ruth Luckasson,

Department of Special Education, University of New Mexico); *id.* at 202 (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

¹¹¹ *Id.* at 126 (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

¹¹² 29 U.S.C.A. § 794 (West Supp. 1988).

¹¹³ 20 U.S.C.A. § 1401 note (West 1978 & Supp. 1988).

¹¹⁴ 42 U.S.C.A. §§ 6000-6083 (West 1983 & Supp. 1988).

persons to achieve their maximum potential through increased independence, productivity, and integration into the community"; and the Architectural Barriers Act of 1968¹¹⁵ is intended to make public buildings physically accessible to people with disabilities.¹¹⁶

It is the interpretation of the Department of Health and Human Services, the Federal agency charged with implementing the Child Abuse Amendments of 1984, that "the law [does] not permit life and death treatment decisions to be made on the basis of subjective opinions regarding the future 'quality of life' of a retarded or disabled person."¹¹⁷ Before passage of the Child Abuse Amendments, nine major disability and medical associations adopted a set of "Principles of Treatment" that also rejected the use of quality of life criteria: "Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care."¹¹⁸

¹¹⁵ 42 U.S.C.A. §§4151 to 4157 (West 1977 & Supp. 1988).

¹¹⁶ See generally U.S. Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 46-62 (1983).

¹¹⁷ Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14879 (1985). See also *id.* at 14880; 45 C.F.R. pt. 1340 App. Interpretative Guideline 9 (1987); chap. 7.

¹¹⁸ *Joint Policy Statement: Principles of Treatment of Disabled Infants*, 73 Pediatrics 559, 559 (1984). The cosigning organizations were the Association for Retarded Citizens, the National Down's Syndrome Congress, the American Coalition of Citizens with Disabilities, Inc., the Association for Persons with Severe Handicaps, the American Association on Mental Deficiency, the American Association of University Affiliated Programs for

Conclusion

The bases typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability—that the quality of life of a person with a disability will be unacceptably poor, or that such a person's continued existence will impose an unacceptable burden on his family or on the Nation as a whole—are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities. A country committed to the civil rights of all should address the very real problems people with disabilities and their families face through fostering supportive services and social acceptance, and through defending their rights to accessible and integrated transportation, housing, education, health care, and employment—not by eliminating those with disabilities.

Persons with Developmental Disabilities, the Spina Bifida Association of America, the National Association of Children's Hospitals and Related Institutions, Inc., and the American Academy of Pediatrics. However, the American Academy of Pediatrics has since argued, with regard to the Child Abuse Amendments, that Congress did not "clearly intend[] to exclude consideration of the infant's quality of life." Comment of the American Academy of Pediatrics on Proposed Rules Regarding Child Abuse Neglect Prevention and Treatment Program 30 (Feb. 8, 1985), quoted in 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, 227 (1986).

The Role of Economic Considerations in Denials of Medical Treatment

An argument frequently heard in favor of denial of treatment is the claim that the costs associated with children born with disabilities create a burden too great to be borne by family or society.

For example, Dr. Walter Owens, the physician in attendance during the death of Bloomington's Infant Doe, told the Civil Rights Commission:

In an ideal society, one might say we should consider only the welfare of the child, but this is not an ideal world and we do not have unlimited resources. . . .

Money which is spent—and we're talking of many times \$100,000 or even \$500,000 or even \$1 million spent on such children—that is money not available for the education of normal children.¹

A similar perspective was articulated by Dr. George Crile, former head of the Department of General Surgery of the Cleveland Clinic, who argued in 1984, shortly after passage of the Child Abuse Amendments:

Despite the law, the debate. . . continues. . . [The question] must be viewed. . . in the light of. . . society's right for its members to have productive and pleasant lives, not to be lived mainly to support the growing numbers of hopelessly disabled, often unconscious people whose

costly existence is consuming so much of the gross national product. . . .²

If a child is born with Down syndrome, Crile wrote:

parents can be told that their child has no chance of growing up to be able to take care of itself. If the parents still want to rear their child, that should be their decision, but there should be no support from the community or the state.

I wish to emphasize that I do not believe that existence is necessarily unhappy for the child with Down's nor that such a child cannot be a joy to its parents. That is why the parents should make the final decision. It remains that a child with Down's syndrome. . . will not grow up to be self-sustaining or able to contribute to the economy. Neither the community nor taxpayers should be obliged to support the child.³

Similar thinking is found in an article on cost-benefit analysis published in July 1984 in the journal of the American Academy of Pediatrics.⁴ The article was written by doctors and researchers affiliated with the Women and Infants Hospital of Rhode Island and Brown University.

This cost-benefit analysis was based on the records of 247 infants who weighed between 500 and

¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 205-06 (1986) (vol. II) (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.)*.

² Crile, *The Right to Life*, Med. Tribune, Dec. 19, 1984, at 27. Commenting on a draft of relevant portions of this report, Dr. Crile charged that this quotation gives a "false impression" of his position because he has "never stood against rehabilitation of any one with a brain that was functional or a body that was salvageable. . . . I am referring to people who are hopelessly disabled, and that means disabled to the extent that rehabilitation could not help them to improve or recover." Letter from George

Crile, Jr., M.D., to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Sept. 15, 1988) (emphasis in original), reprinted in app. D. As his article (which is reprinted in full in app. D) makes clear, however, Dr. Crile's notion of a hopelessly nonfunctional brain is broad enough to include "totally incurable and accurately diagnosable brain defects such as Down's syndrome." Crile, *supra*, at 27.

³ *Id.* For a consideration of the validity of such claims about those with Down syndrome, see chap. 3.

⁴ Walker, Feldman, Vohr & Oh, *Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less Than 1,000 Grams at Birth*, 74 Pediatrics 20 (1984).

999 grams at birth and who were born between January 1977 and December 1981. Eighty-seven percent of the survivors were evaluated for from 1 to 5 years. Most (74 percent) were unimpaired or minimally impaired. Ten percent were "moderately impaired" and 16 percent were labeled "severely handicapped." Their projected lifetime costs (estimated in 1982 dollars) ranged from \$362,992 for the lowest birthweight group—600 to 699 grams—to \$40,647 per survivor for those in the highest birthweight group—900 to 999 grams. Lifetime earnings were estimated at zero for those in the 500 to 699 gram birthweight group and \$77,084 for those in the highest birthweight group of 900 to 999 grams.⁵

The authors concluded that "neonatal intensive care may not be justifiable for infants weighing less than 900 grams at birth."⁶ They reached this conclusion even though 63 percent of the 700 to 799 gram and 57 percent of the 800 to 899 gram birthweight groups had no or minimal disabilities.⁷ They did so by straightforwardly comparing their estimates of the cost of lifetime care to their estimates of lifetime earnings.⁸

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.⁹ The Commission emphatically rejects the view that lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society. The Commission considers it important, however, to give critical examination to the factual premises of an argument for denial of treatment that is made as frequently as is the economic one.

Underlying most cost-benefit projections are two superficially plausible assumptions: (1) the more serious the level of disability, the poorer the prognosis for residential placement and productive employment; and (2) the poorer the prognosis, the higher the net cost of lifetime care.¹⁰

This approach is based on what may be called a "mythology" of disability, a mythology grounded in the basic assumption that the circumstances of

disability (i.e., the living arrangements and work and social opportunities for those who have disabilities) emanate from the disability itself, and hence the costs associated with these arrangements are the direct result of the disability. However, as shown below, this assumption has been refuted during the past 10 years by the performance of people with disabilities.

The importance of the assumptions that underlie this mythology in the practice of denial of treatment should not be underestimated. To understand and critically appraise estimates of long term care or public costs associated with severe disability as they appear in the medical literature, it is important to recognize how dependent these estimates are on assessing the potential of the individual with the disability.

A recent medical journal article reported the results of a random survey of 604 Fellows of the American Academy of Pediatrics. Of the 604 pediatricians contacted, 373 or 62 percent returned the questionnaires; 56 of these were discarded due to incomplete information.¹¹

One series of questions inquired what each doctor thought the future would be like, in terms of their residential placement and potential for work, for children with spina bifida. Approximately half the doctors were asked to make predictions about children born with spina bifida but no hydrocephalus and those with spina bifida and moderate hydrocephalus; the other half were asked to make predictions about those with no hydrocephalus and those with severe hydrocephalus. That is, the questionnaire ascertained where the doctors thought each of these examples of disability would place a child on the spectrum from relative independence in living and working all the way to total dependence with no hope of securing employment.

The results of this survey, undertaken to determine how pediatricians would influence treatment decisions based on the presence of varying degrees of hydrocephalus in children born with spina bifida, suggested that most pediatricians assume that moderate hydrocephalus leads inexorably to a lessened

⁵ *Id.* at 20.

⁶ *Id.*

⁷ *Id.* at 22 (table 3).

⁸ *Id.* at 20.

⁹ For example, we do not routinely compare the costs juvenile delinquents are likely to cause society with their probable economic benefits and then choose death for those with regard to whom the costs are calculated to exceed the benefits.

¹⁰ As later portions of this chapter demonstrate, such assumptions are inaccurate in light of the progress made in the last decade that has enabled even those labeled most severely disabled to live in community settings and to become productive members of society.

¹¹ Siperstein, Wolraich, Reed, & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants With Meningomyelocele*, 113 *J. of Pediatrics* 835 (1988).

TABLE 4.1
Pediatricians' Responses to the
Prognostic Belief Scale

	Infant without hydrocephalus n = 317	Infant with moderate hydrocephalus n = 139	Infant with severe hydrocephalus n = 178
Prognostication for Adult Capabilities			
Mean Score	21.7	15.8	6.4
Standard Deviation	6.1	8.0	7.1
Prognostications for Residential Placement			
Unsupervised apartment	47.9%	18.5%	2.9%
Supervised apartment	35.7%	31.1%	12.0%
Group home	14.2%	31.1%	30.8%
Institution	2.1%	14.5%	54.3%
Prognostications for Vocational Placement			
Skilled competitive employment	53.8%	19.7%	2.3%
Unskilled competitive employment	5.6%	6.6%	2.3%
Supervised full-time employment	20.9%	25.4%	7.6%
Supervised part-time employment	14.7%	31.1%	21.5%
Incapable of any employment	5.0%	17.22%	66.3%

Source: Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications for Infants with Meningomyelocele*, 113 *Journal of Pediatrics* 838 (1988). Reprinted with permission.

ability to live independently (say only in a supervised apartment or group home) and that severe hydrocephalus leads just as inexorably to life in an institution. (See table 4.1.) They make similar assumptions concerning the child's ability to work—that moderate hydrocephalus makes only supervised employment possible, while severe hydrocephalus means no employment at all.¹²

It is not surprising that these predictions result in a tendency by pediatricians to incline away from encouraging lifesaving surgery toward discouraging it as hydrocephalus becomes more severe. Although 34.2 percent of the pediatricians would either not know what to do or would provide only supportive care if the child were their own and had spina bifida without hydrocephalus, 75.7 percent would not know what to do or would provide only supportive care if their child had spina bifida with severe hydrocephalus.¹³

Costs of Residential Placement

A recent study of the costs of residential placements for over 1,000 persons with severe disabilities in three States calls into question the assumption that the more severe the disability, the greater the cost of residential placement.

The objective of [the project] was to identify differences in costs associated with providing services to persons in different types of residential arrangements and with varying levels of disability. Accordingly, in selecting service systems for study, the aim was to identify systems embracing a variety of residential service options.

Two of the three regional systems have been recognized by the University of Syracuse Center on Human Policy as "model" residential programs. The third, in New Hampshire has been widely recognized for its commitment to serve persons with all levels of disability in small community-based living arrangements and integrated work settings.¹⁴

Each system relies on a broad range of integrated community homes, including group homes, apartments, and family-type homes. Using data from 1984–85 and 1985–86, the study examined costs for 1,287 individuals living in 169 group homes, 151 family homes, and 43 apartments.¹⁵ Cost data were also examined for approximately 250 persons from these three regions living in institutions.¹⁶ Each individual was identified on a scale of 1 to 100 to determine similar and differing levels of disability.¹⁷

The study concluded: "The average annual cost of residential services per client varied more, far more, by the type of residential option employed than by the level of need of the client."¹⁸ Group homes, apartments, and family-type homes were significantly less costly than institutions for individuals at all levels of disability, including the most severe levels.¹⁹ Persons labeled and considered most disabled, severely and profoundly handicapped by every definition, were found in significant numbers in all four residential options (institutions, group homes, apartments, and surrogate family homes).²⁰ More persons in the most severe range of disabilities were found in community settings than in institutional ones.²¹

The definition of severe disability used in this study was limited to those individuals who usually had more than one very significant disability. Profound mental retardation alone was not considered enough for a classification of severe disability by any of the regions. For such a classification, a person had to experience severe retardation together with blindness or deafness or complex medical or behavioral needs.²²

Despite widely divergent cost of living differences and salary differences in the three regions, for all:

¹² *Id.* at 838, table 2. The article points out that these assumptions are erroneous.

¹³ *Id.* at 837, table 1. See chap. 3 (text accompanying notes 92–95) and chap. 9 (text accompanying notes 13–18) for a further discussion of this survey.)

¹⁴ Ashbaugh & 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* 2 (1988).

¹⁵ *Id.* at 2. Costs for Michigan and Nebraska, July 1, 1984, to June 30, 1985; for New Hampshire, July 1, 1985, to June 30, 1986.

¹⁶ Interview with Thomas Nerney, coauthor and project coordinator for the above-referenced study (Nov. 29, 1988) [hereinafter Nerney interview].

¹⁷ Ashbaugh & Nerney, *supra* note 15 at 6.

¹⁸ *Id.* at 14.

¹⁹ Nerney interview, *supra* note 17.

²⁰ More than 33 percent of the sample met the definition of those considered most severely disabled. *Id.*

²¹ *Id.* In Michigan's Macomb-Oakland region, there were five times the number of those considered most severely disabled living in community homes than in institutions.

²² *Id.*

- The differences in average cost per person per year for those with identical disabilities ranged from over 2 times to as much as 6 times as much from one option to another.²³
- The average institutional cost was higher than any of the average community costs no matter which community option was chosen and no matter what the level of disability.²⁴
- Administrators (public officials) agreed that the most costly option, the institution, was in every case the least desirable programmatically: the person with a disability benefited the least from the institution and in most cases was harmed by it.
- Administrators agreed that family or family-scale placements were always preferable to institutional placements for children.²⁵
- The smaller the unit of community residential placement, the lower the average cost incurred, no matter the severity of the disability.²⁶
- Family-type placements with appropriate backup supports were the least costly and, for children, the most desirable.²⁷

The cost differentials for the same level of disability by nature of residential placement in Michigan's Macomb-Oakland system, Nebraska's Region V system, and Region V in New Hampshire are shown in figure 4.1.

Family Placement

The trend in providing care for those with the most severe disabilities appears to be moving away from the use of high-cost institutional settings to a variety of community-based ones with significant programmatic and fiscal differences. A clear trend in

the direction of use of family-type placements, the least costly alternative, is developing, especially for children.²⁸ It seems probable, therefore, that in real terms the average cost of residential placement for people with disabilities is headed downward, not upward.

Despite the clear cost (and desirability) advantage of family placement, most contemporary Federal and State policies do not encourage it. There are important, often unrecognized, historical reasons for this.

In the early part of this century, the eugenics movement gave rise to the institutional program for persons with disabilities,²⁹ with most public institutions being established to remove persons with disabilities from their communities and families because they were, mistakenly, thought to be dangerous and responsible for society's ills.³⁰ The ingrained pattern established by this practice goes a long way toward explaining why it is still so difficult automatically to think of and foster the natural (or adoptive) family as the most humane and logical choice for initial support when a child with a disability is born.³¹

As discussed above in chapter 1, government reports from the early part of this century labeled persons with mental retardation and persons with disabilities generally as "a parasitic, predatory class," "a danger to the race," and "a blight and a misfortune both to themselves and to the public."³² State laws required persons with disabilities to be removed from the community and parents to surrender their children or allow State officials to take them.³³ In the State of Washington it even became a

²³ *Id.* See also Ashbaugh & Nerney, *supra* note 15, at fig. 16 and fig. 35.

²⁴ Nerney interview, *supra* note 17. For example, in Michigan's Macomb-Oakland system, community placement could result in saving over \$47,000 per person per year compared to institutional placement.

²⁵ *Id.* See also *Medicaid Home and Community Quality Services Act of 1987: Hearing on S. 1673 Before the Subcomm. on Health of the Senate Comm. on Finance, 100th Cong., 2d Sess. 5 (1988)* (hereinafter *Medicaid Hearing*) (statement of K. Charlie Lakin, Director of Research, Minnesota University Affiliated Program on Developmental Disabilities/Center for Residential and Community Services, Minneapolis, Minn.) (regarding the inferiority of institutions to community-based settings).

²⁶ *Id.* See also fig. 4.1, with regard to those considered "most severely disabled"; Ashbaugh & Nerney, *supra* note 15, at fig. 16 and fig. 35.

²⁷ Nerney interview, *supra* note 17.

²⁸ *Id.*

²⁹ Motion and Brief Amici Curiae of Association for Retarded Citizens/USA, Association for Retarded Citizens/Texas, National Down Syndrome Congress, People First International, and People First Organizations of Iowa, Louisiana, Michigan, Nebraska, Oregon and Washington, United Together, S.T.A.N.D. Together, Speaking for Ourselves, Consumer Advocacy Board of the Massachusetts Association for Retarded Citizens, Texas Advocates, Wisconsin Advocates, Capitol People First, and Self-Advocates of Central New York at 5-6, *Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985) (No. 84-468).

³⁰ D. Rothman & S. Rothman, *The Willowbrook Wars* 47 (1984).

³¹ See chap. 1 and text accompanying notes 36-59.

³² See chap. 1 and text accompanying notes 55-57.

³³ Brief Amici Curiae of the American Coalition of Citizens with Disabilities, People First Organizations of California, Iowa, Louisiana, Michigan, Nebraska, Oregon and Washington, People First International, United Together Organizations of Arkansas, California, Florida, Idaho, Kansas, Massachusetts, Minnesota, and Montana, Speaking for Ourselves of Pennsylvania, Consumer Advisory Board of Massachusetts, Self-Advocates of Central

criminal offense, punishable by a fine, to keep a child with mental retardation at home.³⁴

More enlightened attitudes in recent decades led to some reform. In the early 1970s, Congress allowed the States to begin using Federal medicaid funds to improve the terrible conditions found in institutions.³⁵ The Federal medicaid route to reform resulted in an enormous investment of Federal and State dollars in the institutions.³⁶

Soon, however, members of the disability rights parent and advocacy movement came to the conclusion that these institutions could not be reformed. Instead, they demanded that the individuals residing there return to their communities.³⁷

The use of what were originally called "alternatives" to the institutions, i.e., group homes and family homes, became commonplace. A number of States, including Maine, Rhode Island,³⁸ Michigan, Nebraska, and New Hampshire, established community-based systems.³⁹ The results were impressive:

Numerous studies have compared social participation of institution and community residents. They consistently and clearly find community residents to be better integrated. They go to more restaurants, more stores, more movies, more sporting events. They go on more walks off the facility grounds. They visit more often with friends who live elsewhere. They are more likely to have friendships with non-handicapped peers. They have more contact with their own families. In short, they are better integrated in every conceivable way.⁴⁰

These policies, however, did not address the needs of families who kept their children at home.⁴¹ The fiscal incentives to States remained with the institutions first, the community homes a bad second,⁴²

New York, Texas Advocates, Wisconsin Advocates, Disabled in Action of Pennsylvania, Disabled in Action of New York, and the National Association of Protection and Advocacy Systems at 13-14, *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986) [hereinafter ACCD Amicus].

³⁴ Cleburne amicus, *supra* note 33, at 13.

³⁵ See generally S.B. Sarason & J. Doris, *Educational Handicap, Public Policy and Social History* (1979).

³⁶ *Medicaid Hearing*, *supra* note 26, at 2 (opening statement of Sen. George Mitchell).

³⁷ See, e.g., *Pennhurst State School and Hosp. v. Halderman*, 451 U.S. 1, 6 & n.1 (1981); Rothman & Rothman, *supra* note 31, at 49-50.

³⁸ *Medicaid Hearing*, *supra* note 26, at 2 (opening statement of Sen. George Mitchell).

³⁹ Nerney, Nisbet & Conley, *Economic Analysis of Three Regional Community Developmental Service Regions* (1989) (in press).

⁴⁰ *Id.* at 5-6 (statement of K. Charlie Lakin, Director of Research, Minnesota University Affiliated Program on Develop-

and the natural family last.⁴³ Only recently has an attempt been made to change the Federal medicaid legislation to give priority in funding to families and community homes. Legislation to accomplish this, such as the Medicaid Home and Community Quality Services Act of 1987, has yet to be enacted.⁴⁴ Because providing support for the family is the most cost-efficient way to provide residential services, changing the economic incentives from the institution to the family would cause the cost associated with disability to drop significantly.

Productivity of Persons with Severe and Profound Disabilities

State vocational rehabilitation agencies, together with advocacy and service agencies, have begun to offer new and experimental job training programs for those with the most profound disabilities.⁴⁵ These programs are the result of a relatively new concept in employment training variously referred to as "supported employment" or, for school-age adolescents, "transitional employment."⁴⁶ The evidence of earning capacity among people commonly viewed as inherently unproductive after less than approximately 5 years of Federal- and State-funded employment programs is dramatic.

One example is a program run by a nonprofit agency, New England Business Associates. Under the program, a job coach accompanies a person with a severe or profound disability to the place of employment, provides onsite assistance as needed, and helps train the individual while she or he is working at a regular job paid for by an ordinary employer. This job coach fades back as the individu-

mental Disabilities/Center for Residential and Community Services, Minneapolis, Minn.).

⁴¹ *Id.* at 8-9 (statement of Valerie J. Bradley, President, Human Services Research Institute, Cambridge, Mass.).

⁴² D. Braddock, R. Hemp & G. Fujiura, *Public Expenditures for Mental Retardation and Developmental Disabilities in the United States* 50-52 (2d ed. 1986).

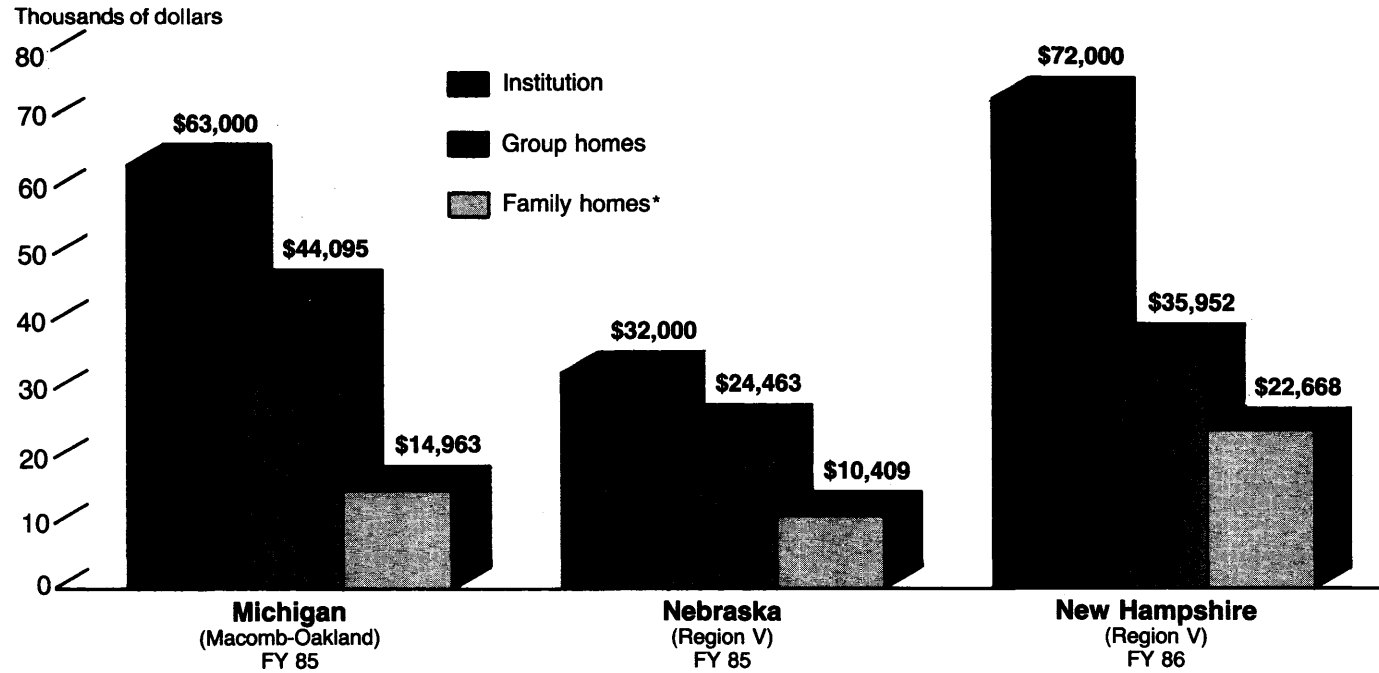
⁴³ National Study Group on State Medicaid Strategies, *The Center for the Study of Social Policy* (Tom Doe, Director), *Restructuring Medicaid: An Agenda for Change* 11 (1983).

⁴⁴ See *Medicaid Hearing*, *supra* note 26, at 1 (opening statement of Sen. George Mitchell) and 3 (opening statement of Sen. John Chafee).

⁴⁵ See generally Congress Passes Voc Rehab Bill: Supported Work for CMIs E National Association of State Mental Health Program Directors Report: The U.S. Congress, Oct. 7, 1986, at 3-5.

⁴⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 88 (1986) (vol. II) (testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education).

FIGURE 4.1
Comparative Costs of Institutions, Group Homes and Family Homes in Three States
 Average annual per person costs for those considered "most severely disabled"



*Family home refers to individuals and families, not the natural parents, who take a person(s) with severe disabilities into their own home or apartment.

al gains skills and income but remains always available both to the individual with a disability and to the employer.⁴⁷

Kathy Moore, executive director of New England Business Associates, provided the Commission with these examples of people active in the program:

J. C. profoundly deaf, legally blind, severely retarded 1987-88 earnings \$7,860.00

M. D. profoundly deaf, legally blind, brain tumor, mentally retarded, institutionalized at birth 1987-88 earnings \$6,220.85

M. Gl. profoundly deaf, totally blind, profoundly retarded, institutionalized at birth 1987-88 earnings \$7,221.60

M. K. profoundly deaf, totally blind, severely mentally retarded 1987-88 earnings \$2,163.00

E. R. profoundly deaf, totally blind, severely retarded, progressive sensory neural loss 1987-88 earnings \$10,400.00

L. T. profoundly deaf, totally blind, severely retarded, institutionalized at birth 1987-88 earnings \$332.13⁴⁸

A similar program for adults with autism and severe behavioral difficulties has been operating in Montgomery County, Maryland, for almost 8 years. This program, run by Community Services for Autistic Adults and Children, included over 46 persons ruled "unemployable" by every agency they had ever contacted. After living most of their lives in institutions, now all live in small homes in Rockville, Maryland, and all earn at least the minimum wage in a program using supported employment.⁴⁹

An 8-year longitudinal study of the costs and benefits of supported employment for 117 persons with moderate to severe mental retardation found that, in comparison to the \$1,361,951 that would have been required in SSI payments and alternative service programs had these persons not been employed, the supported employment program cost \$1,212,117. Those participating in the program

⁴⁷ Interviews with Kathy Moore, Executive Director, New England Business Associates (Sept. 19-20, 1988).

⁴⁸ *Id.*

⁴⁹ Interview with Susan Goodman, Executive Director, Community Services for Autistic Children and Adults (Sept. 17, 1988).

earned wages totaling \$1,503,779.⁵⁰ In other words, in place of a net average cost of \$11,640.61 for each person with moderate or severe mental retardation, with supported employment there was a net average benefit of \$2,492.84 for each such person. The authors of the study pointed out that with ongoing job retention, the net benefit will significantly increase over time, since the costs of supportive employment are substantially frontloaded while the average income is constant or increasing.⁵¹ Furthermore, they noted:

Our university-based demonstration is very small; in fact, the . . . consumers served over 8 years are unfortunately dwarfed when compared with large day programs in which the sole purpose is to provide vocational or day care services. Consider the dramatic savings in programs, over time, if substantial reorganization of the operations at the centers were converted to community- or industry-based programs. It is in this area where the truly large dollar savings can be made over a multi-year time period.⁵²

Conclusion

Disability does entail cost. But the real economic costs now associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled. The assumption has been that the level of severity of disability is the major determinant of lifetime costs and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency and the more expensive it will be to meet that person's basic needs. 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.

⁵⁰ Hill, Wehman, Kregel, Banks & Metzler, *Employment Outcomes for People with Moderate and Severe Disabilities: An Eight-Year Longitudinal Analysis of Supported Competitive Employment*, 12 J. Ass'n for Persons with Severe Handicaps 182, 185-86 (1987).

⁵¹ *Id.* at 187-88.

⁵² *Id.* at 188 (emphasis in original).

State Law

What is the law governing denial of lifesaving medical treatment to children with disabilities? Every State now provides a statutory basis for the civil authorities to act to protect a child whose life or well-being is threatened by abuse or neglect.¹ In 46 of those States, those that receive Federal funding for child abuse and neglect programs, this law must be applied to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions in order to comply with the Child Abuse Amendments of 1984.²

The Child Abuse Amendments were enacted largely because Congress perceived preexisting State law to be inadequate to provide needed protection.³ To understand this perception, it is helpful to contrast the near unanimity in recent State

cases, which have ensured the provision of lifesaving medical care to nondisabled children, with the mixed record of State cases dealing with the withholding of such care from children with disabilities.

Increasing Societal Interest in Protecting Children

Over the past century, the States have significantly expanded their jurisdiction in protecting children. In 1874 a dying woman in New York City pleaded with the parish visitor, Mrs. Etta Wheeler, to go to the authorities about the incessant screams and cries for help of a child in an adjacent apartment. When Mrs. Wheeler finally agreed to do so, the police, district attorney, charitable agencies, and clergy all turned her away. So great was the universal respect for absolute parental autonomy in decisions concern-

¹ See Ala. Code §26-14-1(2) (1986); Alaska Stat. §47.17.070(5) (1984); Ariz. Rev. Stat. Ann. §36-2281 (1986); Ark. Stat. Ann. §9-30-103(5)(A) (Supp. 1987); Cal. Pen. Code §11165(C) (West 1982); Colo. Rev. Stat. §19-1-103(20)(d) (1986); Conn. Gen. Stat. Ann. §46(b)-120(b) (West Supp. 1988); Del. Code Ann. tit. 31, §301(3) (1975); D.C. Code Ann. §16-2301(9)(B) (1981); Fla. Stat. Ann. §39.01(37) (West Supp. 1988); Ga. Code Ann. §15-11-2(8)(A) (Supp. 1988); Hawaii Rev. Stat. §350(1)1 (Supp. 1984); Idaho Code §16-1602n-1 (Supp. 1988); Ill. Ann. Stat. ch. 37, §802-3(1) (West Supp. 1988); Ind. Code Ann. §31-6-4-3(a)(1) (Burns 1987); Iowa Code Ann. §232.2(6)(e) (West 1985); Kan. Stat. Ann. §38-802(g)(1) (1981); Ky. Rev. Stat. Ann. §199.011(b) (Michie 1982); La. Rev. Stat. Ann. §40:1299.36.1 (West Supp. 1988); Me. Rev. Stat. Ann. tit. 22, §4002(1) (Supp. 1988); Md. Fam. Law Code Ann. §5-701(n)(2) (Supp. 1988); Mass. Gen. Laws Ann. ch. 119, §51A (West Supp. 1988); Mich. Comp. Laws Ann. §722.622(d) (West Supp. 1988); Minn. Stat. Ann. §626.556-2(C) (West Supp. 1988); Miss. Code Ann. §43-21-105(1)(i) (Supp. 1987); Mo. Ann. Stat. §210.110(5) (West Supp. 1988); Mont. Code Ann. §41-3-102(3)(C) (1987); Neb. Rev. Stat. §28-710(3)(C) (1985); Nev. Rev. Stat. Ann. §200.508(3)(a) (Michie 1986); N.H. Rev. Stat. Ann. §169-C:3 XIX(b) (Supp. 1987); N.J. Stat. Ann. §9:6-8.21(c)(4)(a) (West Supp. 1988); N.M. Stat. Ann. §30-6-1(A)(2) (1978); N.Y. Soc. Serv. Law

§371.4-a(i)(A) (McKinney 1983); N.C. Gen. Stat. §7A-517(21) (Supp. 1988); N.D. Cent. Code §27-20-02-5(a) (Supp. 1987); Ohio Rev. Code Ann. §2151.03(C) (Anderson 1976); Okla. Stat. Ann. tit. 21, §845(B)(1) (West Supp. 1988); Or. Rev. Stat. §418.740(1)(e) (1987); Pa. Stat. Ann. tit. 11, §2203 (West Supp. 1988); R.I. Gen. Laws §40-11-3 (Supp. 1987); S.C. Code Ann. §20-7-490(c)(3) (Law Co-op. 1985); S.D. Codified Laws Ann. §26-8-6(4) (1984); Tenn. Code Ann. §37-1-102(10)(D) (Supp. 1987); Tex. Fam. Code Ann. §34.01 (West 1988); Utah Code Ann. §78-3a-2(17)(C) (1987); Vt. Stat. Ann. tit. 33, §682(3)(C) (Supp. 1987); Va. Code Ann. §16.1-228(2) (1988); Wash. Rev. Code Ann. §26.44.020(12) (West Supp. 1988); W. Va. Code §49-1-3(g)(1)(A) (1986); Wis. Stat. Ann. §48.981(1)(d) (West 1987); Wyo. Stat. §14-6-201(a)(xvi)(A) (1986).

The same is true of other jurisdictions: Am. Samoa Code Ann. §45.2001(a)(1)(C) (1986); Guam Gov't Code §9120.20(c)(3) (Supp. 1970); P.R. Laws Ann. tit. 8, §404(b) (Supp. 1987); and V.I. Code Ann. tit. 5, §2502(20) (Supp. 1987).

² See chap. 7 for a comprehensive discussion of the Child Abuse Amendments of 1984.

³ Such a perception was also a motive for efforts by the executive branch of the Federal Government to attempt special measures under §504 of the Rehabilitation Act of 1973. See chap. 6.

ing their children that the only person she could get to help was the counsel for the American Society for the Prevention of Cruelty to Animals, Elbridge Gerry.⁴

Gerry persuaded a judge to take a novel course: to issue an order requiring that the child be brought before a court. In the court proceeding, 8-year-old Mary Ellen testified that she was beaten with a whip almost daily, was given no bed or shoes, was never permitted outside except in the yard at night, and was never allowed to play with other children. She was never kissed or caressed. Based on that testimony, the judge ordered her removed from the home and allowed Mrs. Wheeler to assume her guardianship.⁵ This incident led Gerry to found the New York Society for the Prevention of Cruelty to Children (NYSPCC) in 1875.

The first child neglect statutes were relatively simple and tended to cover merely the failure of parents to provide for their children's upkeep. The coverage of the laws was gradually enlarged. By the end of the 1880s, for example, the New York statute was broad enough to protect children from neglect in the provision of food, clothing, sanitation, and medicine.⁶

In 1922 New York was among the first States to adopt a statute empowering courts to order that medical or surgical care be furnished to a child.⁷ Applying that statute two decades later, a court observed:

It is doubtful that under the common law, the courts had the powers now conferred on them, to order treatment for

⁴ Landau, *An Overview of Child Protection and the Abused and Neglected Child*, in *The Abused and Neglected Child* 7, 9 (1982). See also Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations*, 1 *Issues in L. & Med.* 91, 92 (1985).

⁵ Landau, *supra* note 4, at 10.

⁶ 1876 N.Y. Laws, ch. 122, §4; see also *Cowley v. People*, 83 N.Y. 464 (1881) (benevolent institution subject to statute declaring it a misdemeanor to permit a child to be endangered or injured in life or health).

⁷ 1922 N.Y. Laws ch. 547, §§2 and 23.

⁸ *In re Rotkowitz*, 175 Misc. 948, 25 N.Y.S. 624, 625 (1941). Under the common law, it was recognized that parents owed duties toward their children, as well as having rights over them. Blackstone, the preeminent legal commentator of his day, described the parent-child relationship and the responsibilities of the parent in this way:

The duty of parents to provide for the *maintenance* of their children, is a principle of natural law; an obligation, . . . laid on them not only by nature herself, but by their own proper act, in bringing them into the world. . . . By begetting them, therefore, they have entered into a voluntary obligation, to endeavor, as far as in them lies, that the life which they have

children to the extent even of a surgical operation or to require of parents to do that which is promotive of the interests and is protective of the rights of a child. We have emerged from that period in . . . history. . . , and left behind its prejudices, biases and limitations. . . .⁸

In current law, State intervention to ensure medical care for nondisabled children, even over parental objection, is commonplace. Although recognition and great deference is given to parental authority,⁹ parents do not have unbridled control over their children. Their rights, whether rooted in the Constitution or in a basic public policy, may be limited or terminated, particularly when they affect their children's life and death.¹⁰ "[T]he family itself is not beyond regulation in the public interest."¹¹ Civil government may act to "guard the general interest in youth's well being, the state as *parens patriae* may restrict the parent's control. . . ."¹²

Parens patriae is the legal doctrine which provides that the state has the authority, in proper circumstances, to intervene in the normal parent-child relationship for the protection of the child. The doctrine is largely composed of common law, distinguishing it from the provisions found in the child protection statutes. The conception of the doctrine of *parens patriae*, like that of other legal doctrines, has developed over the past few centuries as the common understanding of the role of law in society, as well as the cultural, economic, and social conditions, have changed.¹³

Under the modern understanding of that doctrine, the state can intervene to limit parental authority:¹⁴

bestowed shall be supported and preserved. And thus the children will have a perfect *right* of receiving maintenance from the parents.

1 W. Blackstone Commentaries* 435.

⁹ The Supreme Court observed in *Wisconsin v. Yoder* that:

The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. The primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition.

406 U.S. 205, 232 (1971). See also *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925) ("The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.").

¹⁰ See *Custody of A Minor*, 375 Mass. 733, 379 N.E.2d 1053 (1978).

¹¹ *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

¹² *Id.*

¹³ See generally Custer, *The Origins of the Doctrine of Parens Patriae*, 27 *Emory L. J.* 195 (1978).

¹⁴ *In re N.H.*, 373 A.2d 851 (Vt. 1977).

Like all authority. . . parental authority may be abused. Family privacy may become a cover for exploiting the inherent inequality between adult and child. Thus children who, by definition, are both physically and psychologically at risk may sometimes be placed at further risk by the adult "caretakers" who are presumed to be essential to their well-being.¹⁵

Although primary authority is vested in the parent, that authority is restricted, or even abrogated in full, whenever that authority is abused. In the words of the highest court of Massachusetts, "Parental rights. . . do not clothe parents with life and death authority over their children."¹⁶

The most frequently encountered situations involving life-threatening conditions for nondisabled children have been cases in which parents have refused to authorize medical care because of their religious beliefs. Jehovah's Witnesses have provided a recurring example. The traditional view of Jehovah's Witnesses has been that blood transfusions are morally prohibited.¹⁷ In the usual situation, the parents refuse to consent to a transfusion that is necessary for a child in need of an operation. The parents are brought to court, normally by the hospital, to compel a transfusion through the appointment of a guardian *ad litem* to consent to the necessary medical care. Court after court has found that the State has the authority to intervene and direct a blood transfusion when a child's life is in imminent danger, invoking the State's child neglect

or abuse statute or the expanded doctrine of *parens patriae*.¹⁸

As stated by the Supreme Court:

Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.¹⁹

Different Treatment of Children with Disabilities

The government's disposition changes when the child denied treatment is one who has a disability. Commentator Joseph Goldstein, who wrote in 1977 of the danger of abuse of parental authority that may "cover for exploiting the inherent inequality between adult and child,"²⁰ also wrote: [I]t must be left to the parents to decide, for example, whether their congenitally malformed newborn with an ascertainable neurologic deficiency and highly predictable mental retardation, should be provided with treatment which may avoid death, but which offers no chance of cure—no opportunity, in terms of societal consensus, for a life worth living or a life of relatively normal healthy growth.²¹

In 1984 the Minnesota Supreme Court explicitly based its support for denial of treatment on the degree of disability:

[T]he few patients who have recovered consciousness after a prolonged period of unconsciousness were severely

of cases of abuse and neglect. In the 1960s, this need led to the adoption of laws requiring specified individuals to report suspected cases to the appropriate State agency. Enactment of such laws was proposed by the Children's Bureau in 1963. U.S. Children's Bureau, *The Abused Child: Principles and Suggested Language for Legislation on Reporting of the Physically Abused Child* (1963) as cited in Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 *Hastings L. J.* 765, 794 (1986). These principles were adopted swiftly: all States enacted mandatory reporting laws within 4 years. Fraser, *A Glimpse at the Past, A Gaze at the Present, A Glimpse at the Future: A Critical Analysis of the Development of Child Abuse Reporting Statutes*, 54 *Chi.[-]Kent L. Rev.* 641 (1978). Although the wording of such statutes varies, it normally requires that physicians, other health care providers, school personnel, social workers, and others report to the proper agencies if they suspect any neglect. Some States provide that everyone is obligated to report any suspected neglect. See, e.g., N.J. Stat. Ann. §9:6-8.10 (West Supp. 1988). Reporting is frequently obligatory even if the individual receives information in a confidential capacity. The penalty for failure to report varies from a small fine to incarceration. Smith & Meyer, *Child Abuse Reporting Laws and Psychotherapy: A Time for Reconsideration*, 7 *International J. L. & Psychiatry* 351 (1984).

²⁰ Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 *Yale L.J.* 645, 647 (1977).

²¹ *Id.* at 655-56.

¹⁵ Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 *Yale L.J.* 645, 647 (1977).

¹⁶ *Custody of a Minor*, 379 *N.E.2d* at 1063.

¹⁷ Jehovah's Witnesses' objections are based upon their understanding of biblical passages directly prohibiting eating blood, which they regard as equivalent to a transfusion. See, e.g., *Gen.* 9:3-6; *Lev.* 7:26-27; 17:10-14; *Det.* 12:23-25.

¹⁸ *In re Clark*, 21 *Ohio Op.* 2d 86, 185 *N.E.2d* 128, 129 (1962) ("When a child's right to live and his parent's religious belief collide, the former is paramount and the religious doctrine must give way."). See also *In re Pogue*, No. M-18-74 (Super. Ct. D.C., Nov. 11, 1974); *People ex rel. Wallace v. Labrenz*, 411 *Ill.* 618, 104 *N.E.2d* 769 (1952), *cert. denied*, 344 *U.S.* 824 (1952); *Morrison v. State*, 252 *S.W.2d* 97 (Mo. App. 1952); *State v. Perricone*, 37 *N.J.* 463, 181 *A.2d* 751, *cert. denied*, 371 *U.S.* 890 (1962); *Muhlenberg Hosp. v. Patterson*, 128 *N.J. Super.* 498, 320 *A.2d* 518 (1974); *Hoener v. Bertinato*, 67 *N.J. Super.* 517, 171 *A.2d* 140 (1961); *Sampson v. Taylor*, 29 *N.Y.2d* 900, 278 *N.E.2d* 918 (1972); *Santos v. Goldstein*, 16 *App. Div.* 2d 755, 227 *N.Y.S.2d* 450, *appeal dismissed*, 12 *N.Y.S.2d* 672, 185 *N.E.2d* 904 (1962); *Application of Brooklyn Hosp.*, 45 *Misc.2d* 914, 258 *N.Y.S.2d* 621 (1965); *In re Green*, 448 *Pa.* 338, 292 *A.2d* 387 (1972), *later appeal*, 452 *Pa.* 373, 307 *A.2d* 279 (1973); *Jehovah's Witnesses v. King County Hosp.*, 278 *F. Supp.* 488 (W.D. Wash. 1967), *aff'd*, 390 *U.S.* 598 (1968).

¹⁹ *Prince v. Massachusetts*, 321 *U.S.* 158, 170 (1940). For a child protection system to be effective, the system must become aware

disabled. The degree of permanent damage varied but commonly included inability to speak or see, permanent distortion of the limbs, and paralysis. Being returned to such a state would be regarded as of very limited benefit by most patients; it may even be considered harmful if a particular patient would have refused treatments expected to produce this outcome. Thus, even the extremely small likelihood of "recovery" cannot be equated with returning to a normal or relatively well functioned state.²²

The trial court judge who decided the Bloomington, Indiana, Infant Doe case²³ later made explicit that it was the child's disability, Down syndrome, that was the ground for his ruling that the parental denial of lifesaving treatment should not be disturbed. In his reply to a correspondent who questioned him about the case, he wrote:

[E]ven at common law the right of the parents to autonomy over their children was not absolute and the State could intervene by way of the Court, acting as *parens patriae*, to protect minors and incompetents whose guardians were acting to the clear detriment of the ward. Today, parental autonomy is still favored, but of paramount concern, in case law and by statute, is the best interest of the child. A child is no longer merely a property right. Now the parent-child relationship is more in the nature of a trust, subject to the well-being of the child as perceived by the Court. . . .

The State's role in protecting the welfare of the child becomes more complicated in a situation as that of the "Infant Doe" case. To say that parents are neglectful implies that the State or society knows what is best for the child. In the "Infant Doe" case, it could not be said that the parents were not acting in the best interests of the child, even though other parents might have acted differently. It is a harsh view that no life is preferable to life, but the great weight of the medical testimony at the hearing I conducted was that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was nonexistent.²⁴

In the Baby Jane Doe case, the New York State courts upheld denial of treatment to a child born

with spina bifida and other disabilities.²⁵ After her birth in Port Jefferson, New York, on October 11, 1983, her pediatric neurosurgeon arranged for her transfer to the University Hospital of the State University of New York at Stony Brook so she could receive lifesaving surgery.²⁶ Advice her parents received there, however, led them to opt against authorizing the surgery.²⁷ Based on information from a source within the hospital, an attorney who objected to the denial of treatment applied to a State court of general jurisdiction for the appointment of a guardian *ad litem* to argue that the court should order treatment, a request the court granted.²⁸

The court conducted 2 days of hearings, taking testimony from physicians and the father of the child.²⁹ At their conclusion, the trial court judge ruled that surgery should be performed:

The testimony of the witnesses before the Court indicated that the neurosurgeons' initial advice that surgery be performed was changed by Dr. Newman.

. . . .

. . . A parent, however, may not deprive a child of lifesaving treatment, however well intentioned. Even when the parents' decision to decline necessary treatment is based on Constitutional grounds such as religious beliefs, it must yield to the State's interests as [parens] patriae in protecting the health and welfare of the child. . . . There was instead an affirmative answer to the question, is there imminent danger of infection, and there was testimony indicating that the presence of infection would lead to death, and that in the Court's view the testimony further provided that by correcting the myelomeningocele condition, that this would significantly reduce the risk of infection.

. . . It is clear. . . that the infant is in imminent danger, and that the infant has an independent right to survive; that right must be protected by the State acting the [parens] patriae, where a life is in jeopardy and the parents have elected to provide no surgical care. . . .³⁰

²² *In re Conservatorship of Torres*, 357 N.W.2d 332, 338 (Minn. 1984). Although the case related to denial of treatment to an older person who was unconscious, it revealed an attitude toward disability relevant to a judicial perspective on denial of treatment to children with disabilities. The court also considered as relevant the cost associated with disability: "[L]ong-term treatment commonly imposes severe financial and emotional burdens on a patient's family, people whose welfare most patients before they lost consciousness, placed a high value on." *Id.* at 339.

²³ See chap. 1 and text accompanying notes 16-27.

²⁴ Baker, *June 8, 1982 Letter of Judge John Baker to Anonymous Person*, 2 Issues in L. & Med. 81, 82 (1986).

²⁵ See chap. 3, text accompanying notes 54-72, and chap. 6, text accompanying notes 89-107.

²⁶ *United States v. Univ. Hosp., State Univ. of New York at Stony Brook*, 729 F.2d 144, 146 (2d Cir. 1984).

²⁷ Horan & Balch, *Infant Doe and Baby Jane Doe: Medical Treatment of the Handicapped Newborn*, 52 *Linacre Q.* 45, 53 (1985).

²⁸ *Id.*

²⁹ Transcript, *People ex rel. Washburn v. Stony Brook Hosp.*, No. 83-19910 (N.Y. Sup. Ct. Oct. 19, 1983) (available in files of the U.S. Commission on Civil Rights).

³⁰ *Id.* at 229, 236-38.

This decision, however, was promptly overturned by an intermediate appellate court,³¹ and when that ruling was appealed to the state's highest court, the New York Court of Appeals, it held that the trial court had been without authority to entertain the case at all and affirmed the appellate division's dismissal. The court said:

There are overtones to this proceeding which we find distressing. Confronted with the anguish of the birth of a child with severe physical disorders, these parents, in consequence of judicial procedures for which there is no precedent or authority, have been subjected in the last two weeks to litigation through all three levels of our State's court system. We find no justification for resort to or entertainment of these proceedings.³²

There have been other cases in which State courts have upheld denial of lifesaving treatment to children on the basis of disability,³³ as well as cases in which State courts have prevented the withholding of such treatment from children with disabilities.³⁴ The key point is that while State courts in the

³¹ *Weber, Guardian ad litem for Baby Jane Doe v. Stony Brook Hosp.*, No. 3467E (N.Y. App. Div. Oct. 21, 1983).

³² *In re Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 469 N.Y.S.2d 63, 456 N.E.2d 1186, 1188 (1983).

contemporary era have invariably overridden parental decisions to deny treatment clearly necessary to preserve the lives of their nondisabled children, prior to the adoption of the Child Abuse Amendments of 1984, they had at best a mixed record in doing so when the children had disabilities.

Conclusion

In popular debate, the question whether children with disabilities should be denied lifesaving treatment has frequently been couched as though the issue were whether the government should intrude into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental autonomy is given serious sympathetic consideration.

³³ See *In re Barry*, 445 So.2d 365 (Fla. App. 1984), *cert. denied*, 464 U.S. 1026 (1985); *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); and *In re P.V.W.*, 424 So.2d 1015 (La. 1982).

³⁴ See *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct., Feb. 14, 1974); and *In re Cicero*, 101 Misc.2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979).

The Rehabilitation Act of 1973

The history of efforts by the Federal Government to prevent medical discrimination against people with disabilities, particularly children, is closely interwoven with section 504 of the Rehabilitation Act of 1973.¹ Soon after the April 1982 Bloomington Infant Doe case brought public attention to the issue of denying treatment to children with disabilities, the Department of Health and Human Services (HHS) relied on section 504 as the basis for a written warning to hospitals throughout the country that discriminatory denial of treatment on the basis of handicap was illegal. In March 1983, HHS issued an "Interim Final Rule" requiring hospitals to post notices giving the telephone number of a 24-hour hotline for reporting suspected 504 violations. This poster rule evoked heated reaction.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and the American Academy of Pediatrics, joined by other medical organizations, condemned the regulation. They argued that the use of hospital-based ethics committees was preferable to Federal involvement in treatment decisionmaking. The American Academy of Pediatrics sued HHS and convinced a Federal district court to strike down the regulation on the ground that the procedures used to issue it had not complied with those mandated by administrative law.

HHS then published a substantially similar rule as a proposed regulation in July 1983, inviting public comment. While HHS was analyzing that comment and meeting with medical and disability groups seeking a compromise, the New York Baby Jane Doe case arose in October 1983. Under the authority

of section 504, HHS sought Baby Jane Doe's medical records and, when the hospital refused to provide them, took it to court. But HHS lost in both the district court and the Second Circuit Court of Appeals, with the latter ruling in February 1984 that section 504 had no application to medical treatment decisions regarding newborn children with disabilities.

Meanwhile, in January 1984, HHS had reissued a modified form of its poster regulation as a Final Rule. The American Medical Association and other medical organizations promptly challenged it in court as unjustified by section 504. Relying on the holding in the Baby Jane Doe case, both a district court and the Second Circuit Court of Appeals struck down the mandatory sections of the Final Rule. In June 1986, the Supreme Court affirmed in a 5-3 vote. However, an opinion explaining the affirmation was joined only by a plurality of the Court, and it addressed much narrower grounds than had the Second Circuit, leaving important issues concerning the application of section 504 to denial of treatment on the basis of handicap unresolved.

This chapter details these events and analyzes the legal issues at stake in the controversy over the applicability of section 504 to the discriminatory denial of medical treatment to children with disabilities.

Enactment of Section 504 of the Rehabilitation Act

Section 504 provides:

¹ 29 U.S.C.A. § 794 (West Supp. 1988).

No otherwise qualified handicapped individual in the United States. . . shall, solely by reason of his handicap, 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. . . .²

Robert Scotch, who has written a history of the provision's crafting and enactment, notes: "Section 504. . . has been hailed as the first major civil rights legislation for disabled people. In contrast to earlier legislation that provides or extends benefits to disabled persons, it establishes full social participation as a civil right and represents a transformation of federal disability policy."³ Modeled on legislation prohibiting race and sex discrimination by recipients of Federal financial assistance, section 504 may be enforced not only by cutting off such assistance but also through suits for injunctive relief by the Attorney General⁴ and by aggrieved private individuals.⁵

Section 504 was derived from companion bills introduced by Senator Hubert Humphrey and Representative Charles Vanik.⁶ "[T]he treatment and regard for the rights of handicapped citizens in our country is one of America's shameful oversights," Representative Vanik said in the speech with which he introduced the bill.⁷ He referred to the "100,000 babies [who] are born with defects" each year.

² 29 U.S.C.A. § 794 (West Supp. 1988). For purposes of § 794 handicapped individual is defined as:

any individual who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.

³ 29 U.S.C.A. § 706(8)(B) (West Supp. 1988).

⁴ R. Scotch, *From Good Will to Civil Rights 3* (1984). The material that follows in this section relies heavily on National Legal Center for the Medically Dependent & Disabled, *The Medical Treatment Rights of Children with Disabilities* § 2.03 at 2:9-2:10 (J. Bopp ed. 1987).

⁵ Section 504 may be enforced by "any other means authorized by law, which includes suits by the Attorney General." 42 U.S.C. § 2000d-1 (1982); see *United States v. Marion County School Dist.*, 625 F.2d 607, 611-12 (5th Cir. 1980), *cert. denied*, 451 U.S. 910 (1981).

⁶ *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984).

⁷ The Supreme Court has emphasized the importance of this history: "[T]he intent with which Congressman Vanik and Senator Humphrey crafted the predecessor to § 504 is a primary signpost on the road toward interpreting the legislative history of § 504." *Alexander v. Choate*, 469 U.S. 287, 296 n.13 (1985).

⁸ 117 Cong. Rec. 45,974 (1971) (statement of Representative Vanik).

⁹ *Id.*

¹⁰ 118 Cong. Rec. 525 (1972).

¹¹ 118 Cong. Rec. 9,499, 9,500 (1972).

¹² *Id.*

¹³ S. Rep. No. 1297, 93rd Cong., 2d Sess. 38 (1974). In 1977 the Department of Health, Education, and Welfare (the predecessor

Referring to older citizens with disabilities, he condemned "confinement without treatment" and "unexplained deaths."⁸ In a speech introducing his bill, Senator Hubert Humphrey said it would afford people with disabilities the "right to health."⁹

Later, to demonstrate a need for the legislation, Humphrey placed in the *Congressional Record* articles criticizing medical professionals for devaluing children with disabilities. One article referred to parents who "spoke angrily about pediatricians and purported experts in the field of retardation—the professionals who know pathetically little about the unused potential of retarded children and who continually discourage and delude parents."¹⁰ One parent said, "There was so much willingness to eliminate the child, because they did not consider him a productive member of society. . . ." The article concluded that many parents of children with disabilities have a "deep anger" at a "system which regularly has written off certain categories of handicapped children, their children, as hopeless."¹¹

It was in response to concerns such as these that the Senate committee report on the Rehabilitation Act of 1973 specifically stated that section 504's coverage was to include discrimination in "health services."¹²

to the Department of Health and Human Services) took the position that section 504 prohibits discrimination in the provision of medical treatment, although it does not create new entitlements for what was not previously provided to anyone:

[A] burn treatment center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

45 C.F.R. Part 84, App. A para. 36 (1987). The Department thus took the position that section 504 did not mean that psychiatric patients have a right to receive treatment for the psychiatric problem for which they have been involuntarily committed or else be released. 41 Fed. Reg. 29548, 29559 (1976). Although this position was later cited for the proposition that the Department's view had been that section 504 does not authorize regulations dealing with rights to receive treatment, *United States v. Univ. Hosp.*, 729 F.2d 144, 152 (2d Cir. 1984), Martin Gerry, former Director of the Office for Civil Rights of HHS during the development of the initial implementing regulations to section 504, explained that civil rights laws, including section 504, have been routinely applied to health care providers who receive Federal financial assistance:

The direct application of federal civil rights laws to the operation of hospitals and other health care providers which receive Federal financial assistance was first established in 1964. The Final Regulation implementing Title VI of the Civil Rights Act of 1964, issued by the Department of Health, Education and Welfare in December 11 of the same year. . . prohibits discrimination on the basis of race, color or national origin in the operation of health care facilities

In May 1977, under the compulsion of a court order,¹³ the Department of Health, Education, and Welfare (the predecessor of HHS) issued a regulation generally implementing section 504, much of which is still in effect. The Supplementary Information published with the 1977 regulation noted that "there is overwhelming evidence that in the past handicapped persons have been excluded from programs entirely or denied equal treatment, simply because they are handicapped."¹⁴

The regulation defines a "qualified handicapped person," for contexts other than employment or education, as "a handicapped person who meets the essential eligibility requirements for the receipt of such services."¹⁵ It prohibited the providing of different services or benefits to qualified handicapped persons unless necessary to ensure that the services or benefits were as effective as those provided to nonhandicapped persons.¹⁶ Indeed, a recipient of Federal funds must afford a qualified person with a disability a benefit or service that is as effective as that provided to nonhandicapped persons.¹⁷ The regulation also proscribed the use of criteria or methods of administration having the purpose or effect of substantially impairing the accomplishment of program objectives for qualified individuals with a disability.¹⁸

Resort to Section 504 in the Aftermath of the Bloomington Infant Doe Case

The highly publicized Bloomington Infant Doe case in April of 1982 led to considerable public and press criticism of the denial of treatment that resulted in the child's death.¹⁹ Reacting to the case and the widespread negative response to it, President Reagan on April 30, 1982, sent a memorandum to the Attorney General and Secretary of HHS

receiving funds under a wide variety of federal health care programs. . . . Civil rights obligations imposed upon hospitals and other health service providers by federal civil rights laws are neither new nor secret.

M. Gerry, *The Right of Handicapped Infants to Receive Beneficial Medical Treatment: The Responsibilities of Health Care Providers Under Section 504 of the Rehabilitation Act of 1973*, Statement Submitted to the 1985 Hearings of the United States Commission on Civil Rights on the Protection of Handicapped Newborns 27-28 (July 12, 1985) (available in the files of the U.S. Commission on Civil Rights).

¹³ *Cherry v. Mathews*, 419 F. Supp. 922 (D.D.C. 1976).

¹⁴ *Part 84—Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting From Federal Financial Assistance*, 42 Fed. Reg. 22,676, 22,676 (1977).

¹⁵ 45 C.F.R. § 84.3(k)(4) (1987).

¹⁶ *Id.* § 84.4(b)(1)(iv) (1987).

concerning the enforcement of Federal laws prohibiting discrimination against individuals with a disability.²⁰ The memorandum required HHS to issue an explanation to health care providers of section 504's applicability to the denial of treatment to newborn children with a disability. HHS was also to enforce section 504 and other appropriate Federal laws to prevent the withholding of potentially lifesaving treatment from children with a disability that would normally be provided to children without a disability. The Attorney General was directed to report on "the possible application of Federal constitutional and statutory remedies in appropriate circumstances to prevent the withholding from the handicapped of potentially lifesaving treatment that would be given as a matter of course to those who are not handicapped."²¹

Accordingly, on May 18, 1982, the Office for Civil Rights of the Department of Health and Human Services sent hospitals receiving Federal financial assistance a Notice to Health Care Providers which indicated that it was unlawful to deny nutrition or medical or surgical treatment to an infant with a disability if the denial was based upon the existence of a handicap and the handicap did not render treatment or nutritional sustenance medically contraindicated.²² Reflecting a concern that hospitals or their staff might attempt to do indirectly what could not lawfully be done directly, the notice stated that hospital "[c]ounseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under Section 504."²³

In December 1982, internal guidelines for investigating complaints of discriminatory denial of treatment were sent to the regional divisions of the HHS Office for Civil Rights.²⁴ Between the death of

¹⁷ *Id.* § 84.4(b)(1)(ii) (1987).

¹⁸ *Id.* § 84.4(b)(4) (1987).

¹⁹ See chap. 1 and text accompanying notes 16-27 for a description of the case.

²⁰ R. Reagan, President's Memorandum to the Attorney General and the Secretary of Health and Human Services, *Enforcement of Federal Laws Prohibiting Discrimination Against the Handicapped* (Apr. 30, 1982), noted in S. Rep. No. 246, 98th Cong., 2d Sess. 6, portions reprinted in 1984 U.S. Code Cong. & Admin. News 2918.

²¹ *Id.*

²² *Discriminating Against the Handicapped by Withholding Treatment or Nourishment; Notice of Health Care Providers*, 47 Fed. Reg. 26,027 (1982).

²³ *Id.*

²⁴ Memorandum from Nathan D. Dick, Deputy Director, Office of Program Operations, HHS, to Regional Directors, Office for

Bloomington's Infant Doe in April 1982 and March 7, 1983, HHS received 11 complaints of discriminatory denial of lifesaving medical treatment to newborn children with disabilities.²⁵ HHS conducted investigations in 9 of the 11 instances, including 5 onsite investigations.²⁶

The "Interim Final Rule" of March 1983

On March 7, 1983, HHS issued a new regulation that was to provoke a storm of controversy.²⁷ It was the first of three versions of regulations or proposed regulations under authority of section 504 that explicitly and specifically addressed the withholding of medical treatment from children with disabilities.²⁸

The Supplementary Information published with the Interim Final Rule gave as its purpose to "acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to *save the life of the infant*."²⁹ Expressing concern that individuals with knowledge of actions violating section 504 did not have adequate opportunity to give immediate notice to governmental authorities, HHS designed the Interim Final Rule to increase public knowledge of the law and the manner of bringing suspected violations to the attention of HHS, and to increase the ability of HHS to investigate alleged violations promptly.

HHS wrote that the rule had become necessary because events "of the past several years suggest that handicapped infants have died from denial of food in federally assisted programs."³⁰ The Department said that although the extent of discriminatory

denial of treatment was unknown, "for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable."³¹

The May 1982 Notice to Health Care Providers, the Supplementary Information stated, "explained what is already clear from the language of Section 504 and [its existing] regulations. . . : The discriminatory failure of a federally assisted health care provider to feed a handicapped infant, or to provide medical treatment essential to correct a life-threatening condition, can constitute a violation of Section 504."³² Therefore, HHS wrote, the Interim Final Rule was not intended to create any variance in the substantive obligations of health care providers "previously set forth in the statutory language of Section 504, in the implementing regulations, and in the Notice to Health Care Providers."³³ Instead:

The interim final rule sets forth procedural specifications designed: (1) To specify a notice and complaint procedure, within the context of the existing regulations, and (2) to modify existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care.³⁴

The Interim Final Rule required infant health service facilities to display posters in conspicuous places in nurseries and in delivery, maternity, and pediatric wards. The notices were to state that discriminatory failure to feed and care for handicapped infants in the facility is prohibited by Federal law, that anyone having knowledge of an infant being denied food or customary medical care should contact the HHS hotline or the State child protec-

Civil Rights, HHS Directive OPO-83-1-8 (Dec. 14, 1982) (available in files of U.S. Commission on Civil Rights).

²⁵ *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1,622, 1,646-47 (1984) [hereinafter Final Rule (504)].

²⁶ *Id.* In one of the two remaining cases in which no investigations were undertaken, HHS "postponed" investigation at the request of local prosecutors. In the other case, HHS reported having conducted an "inquiry," though not an investigation. On the basis of the "inquiry," HHS closed the case, finding no violation. For further discussion of investigations conducted by the HHS Office for Civil Rights, see chap. 12, text accompanying notes 3-11.

²⁷ *Nondiscrimination on the Basis of Handicap, Interim Final Rule*, 46 Fed. Reg. 9630 (1983).

²⁸ The number and variety of Federal regulations related to "Baby Doe" that have been proposed or issued at various times can be confusing. The regulations promulgated under section 504, discussed in this chapter, must be distinguished from the regulations promulgated under the Child Abuse Amendments of 1984, discussed in the next chapter. For convenience, a chronology of the relevant laws, regulations, and court decisions challenging them may be helpful:

1973: Passage of Rehabilitation Act, including section 504

1977: Basic section 504 regulations issued

Mar. 7, 1983: Interim Final Rules (504) issued

Apr. 14, 1983: Judge Gesell strikes down Interim Final Rules

July 5, 1983: Proposed Rules (504) issued for comment

Jan. 12, 1984: Final Rules (504) promulgated

Feb. 23, 1984: In Baby Jane Doe case, Second Circuit holds 504 inapplicable to medical treatment decisions

June 11, 1984: Final Rules (504) enjoined by Federal district court

Oct. 9, 1984: Child Abuse Amendments of 1984 (CAA) signed into law

Dec. 10, 1984: Proposed Rules (CAA) issued for comment

Apr. 15, 1985: Final Rules (CAA) promulgated

Oct. 9, 1985: CAA and Final Rules (CAA) go into effect

June 9, 1986: U.S. Supreme Court holds mandatory portions of Final Rules (504) unjustified by administrative record

²⁹ *Nondiscrimination on the Basis of Handicap, Interim Final Rule*, 48 Fed. Reg. 9,630, 9,630 (1983) (emphasis in original).

³⁰ *Id.* at 9,631.

³¹ *Id.*

³² *Id.* at 9,630.

³³ *Id.*

³⁴ *Id.*

tive agency, and that the failure to feed and care for infants might violate State law.³⁵

Normally, HHS is required to wait 10 days from the time that the Secretary notifies the suspected violator of a failure to comply with section 504 before legal action is initiated. The Interim Final Rule provided for a waiver of this waiting period whenever, in the judgment of HHS, immediate access was necessary to preserve the life or health of an infant with a disability.³⁶ It also allowed HHS immediate access to business records outside normal business hours when necessary to protect the infant's life or health.³⁷

Although it set up a 24-hour hotline to receive reports of suspected denial of treatment, HHS indicated that it intended to rely heavily on the voluntary cooperation of State and local agencies closest to the scene, which could provide "speedy investigation of life-threatening abuse and neglect."³⁸ State child protective agencies would be informed of cases of which HHS became aware. When the State "expeditiously and effectively investigated" the cases, additional Federal involvement would be unnecessary although HHS would hold itself open for whatever assistance was desired.³⁹

President's Commission Report

In March 1983—the same month the Interim Final Rule was promulgated—the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report entitled *Deciding to Forego Life-Sustaining*

Treatment.⁴⁰ Although HHS would later cite with favor some of the statements in the report,⁴¹ not only did the President's Commission Report specifically criticize the HHS regulation,⁴² but its general perspective significantly differed from that of HHS. The President's Commission believed that "seriously erroneous decisions about the treatment of newborns. . . appear to be very rare."⁴³ Nevertheless, it acknowledged three shortcomings in decisionmaking about infants with a disability: "[first,] appropriate information may not be communicated to all those involved in the decision; [second,] professionals as well as parents do not at times understand the bases of a decision to treat or not to treat; and [third,] actions can be taken without the informed approval of parents or other surrogates."⁴⁴

The President's Commission divided circumstances in which a child with a disability has life-threatening conditions into three categories: "(1) a treatment is available that would clearly benefit the infant, (2) all treatment is expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain."⁴⁵ The actions it recommended are shown in table 6.1.

Under the proposal of the President's Commission, both when the physician's assessment is "unclear" and when the joint decision of parents and physician is to forego treatment, the assessment would be reviewed by "intra-institutional mechanisms and possibly thereafter by the court."⁴⁶ By "intra-institutional mechanisms" the President's

³⁵ The poster was to read:

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

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D.C. 20201
Phone 800— (Available 24 hours a day)
In the City of Washington, D.C.—863-00 (TTY capability)
or

Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

HHS provided the sign, and the only permissible alteration was the addition of the agency's name and its address and telephone number. *Id.* at 9,631-32.

³⁶ *Id.* at 9,630.

³⁷ *Id.*

³⁸ *Id.* at 9,631.

³⁹ *Id.*

⁴⁰ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (1983) [hereinafter *President's Commission Report*].

⁴¹ See, e.g., *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants, Final Rules*, 49 Fed. Reg. 1,622, 1,622 (1984).

⁴² *President's Commission Report*, *supra* note 40, 225-26 & n.95.

⁴³ *Id.* at 208-09.

⁴⁴ *Id.* at 209.

⁴⁵ *Id.* at 217.

⁴⁶ *Id.*

TABLE 6.1

Physician's assessment of treatment options*	Parents prefer to accept treatment**	Parents prefer to forego treatment**
Clearly beneficial	Provide treatment	Provide treatment during review process
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do so	Forego treatment

*The assessment of the value to the infant of the treatments available will initially be by the attending physician. Both when this assessment is unclear and when the joint decision between parents and physician is to forego treatment, this assessment would be reviewed by intra-institutional mechanisms and possibly thereafter by court.

**The choice made by the infant's parents or other duly authorized surrogate who has adequate decisionmaking capacity and has been adequately informed, based on their assessment of the infant's best interests.

Source: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life Sustaining Treatment (1983), 218, table 1 (certain footnotes omitted).

Commission primarily meant hospital ethics committees.⁴⁷

When treatment is “clearly beneficial,” the President’s Commission wrote, “[p]arents should be able to choose among alternative treatments with similarly beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved.”⁴⁸ The President’s Commission emphasized that this is a “very strict standard” because:

[I]t excludes consideration of the negative effects of an impaired child’s life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants. The Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.⁴⁹

The President’s Commission specifically pointed to infants with Down syndrome, indicating that this disability, in itself, does “not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.”⁵⁰ The President’s Commission thus implicitly criticized the result in the *Bloomington Infant Doe* case.

On the other end of the treatment spectrum, the “clearly futile” category, the President’s Commission took the position that it is unnecessary to provide treatment that would only maintain life for a short period of time:

When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably futile endeavors is ethically and legally justifiable. Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period. The moment of death. . . might be delayed for a short time—perhaps as long as a few weeks—by vigorous therapy.⁵¹

In such circumstances, however, the President’s Commission said that the children are still owed “whatever relief from suffering and enhancement of

life can be provided, including feeding, medication for pain, and sedation, as appropriate.”⁵²

The third category delineated by the President’s Commission consisted of “ambiguous cases.”

Although for most seriously ill infants there will be either a clearly beneficial option or no beneficial therapeutic options at all, hard questions are raised by the smaller number for whom it is very difficult to assess whether the treatments available offer prospects of benefit—for example, a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator-dependent premature infant whose long-term prognosis becomes bleaker with each passing day.⁵³

While the section 504 approach adopted by HHS put emphasis on the substantive standards establishing what treatment must be provided, the approach adopted by the President’s Commission emphasized the procedural standards establishing who should decide what treatment should be given. Rejecting both regular resort to the courts and the section 504 regulatory approach adopted by HHS, the President’s Commission recommended instead a reliance on intra-institutional review. It suggested that hospitals should:

have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants. . . . Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. . . . Some cases may require only a medical consultation to confirm a diagnosis of an inevitably fatal condition. . . . In other cases, when the benefits of therapy are less clear, an “ethics committee” or similar body might be designated to review the decisionmaking process. This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases.⁵⁴

Section 504 is directed against discrimination based on handicap. Thus, the measure of what treatment is required is what treatment would be provided to a similarly situated nonhandicapped individual. Since, for example, futile treatment that would merely prolong dying is not normally given to nonhandicapped terminally ill patients, section 504 would not require that it be provided to similarly situated individuals with handicaps.⁵⁵

interpretations of section 504 and the Child Abuse Amendments of 1984.

⁴⁷ *Id.* at 227.

⁴⁸ *Id.* at 217–18.

⁴⁹ *Id.* at 219.

⁵⁰ *Id.* at 218–21.

⁵¹ *Id.* at 219. The President’s Commission’s conclusion that treatment that merely prolongs dying should not be mandated by law has found few dissenters and is congruent with both HHS

⁵² *Id.* at 220.

⁵³ *Id.*

⁵⁴ *Id.* at 227.

⁵⁵ See 45 C.F.R. Part 84 App. C(a)(2) (1987).

Essentially, HHS interpreted the substantive rule under section 504 to be that unless the handicap itself medically contraindicates the treatment (and thus renders the individual not "otherwise qualified" for the treatment), the handicap must be deemed irrelevant in treatment decisionmaking.⁵⁶

The President's Commission approach could be said to have established substantive standards, since it divided cases into three categories. However, the descriptions of the categories were too generalized to provide much guidance for specific instances, with the meager exception of the Commission's condemnation of withholding of treatment solely on the basis of Down syndrome. The effect of the generalizations is that the formulae can be widely interpreted, leaving, at best, wide discretion in applying the principles. Although the basic notion of futility is defined with some clarity, the breadth and vagueness of the "clearly beneficial" and the "ambiguous" categories leave much room for differing judgments.

This lack of specificity reflected a deliberate choice by the President's Commission. It quoted with approval bioethicist Robert Veatch:

The decision [to treat or not] must . . . include evaluation of the meaning of existence with varying impairments. Great variation exists about these essentially evaluative elements among parents, physicians, and policy makers.⁵⁷

The report then stated:

The Commission agrees that such criteria necessarily include value considerations. Supposedly objective criteria such as birth weight limits or checklists for severity of spina bifida have not been shown to improve the quality of decisionmaking in ambiguous and complex cases. Instead, their use seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers.⁵⁸

The central themes embodied in the President's Commission report were to become the most widely reiterated grounds on which medical groups and others opposed the advocacy by disability groups of

⁵⁶ See *infra* note 100 for a discussion of the situation in which the handicap is itself the source of the life-threatening condition to be treated.

⁵⁷ *President's Commission Report*, *supra* note 40, at 222, quoting R. Veatch, *The Technical Criteria Fallacy*, 7 *Hastings Ctr. Rep.* 15 (1977).

⁵⁸ *President's Commission Report*, *supra* note 40, at 223.

⁵⁹ *Am. Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983).

government action to protect the treatment rights of children with disabilities. These key points were repeatedly echoed in criticisms of the section 504 regulation and—later—the Child Abuse Amendments of 1984:

- Inappropriate treatment decisions, although they occur, do so rarely.
- Situations in which treatment decisions must be made are best broken into the three categories of clearly beneficial, ambiguous, and futile.
- Apart from saying treatment for children with Down syndrome is clearly beneficial, little definition can be given to distinguish the clearly beneficial from the ambiguous.
- Within these broad categories, discretion must be given to well-informed parents and physicians to make decisions in the best interests of children.
- Intra-institutional review, usually in the form of ethics committees, is the best check on possible abuses.
- Government agencies or courts should normally become involved only when an ethics committee considers that clearly beneficial treatment is being refused by adamant parents.

American Academy of Pediatrics v. Heckler

The HHS regulation was soon subject to more than rhetorical attack. The American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and the Children's Hospital National Medical Center filed suit in the Federal District Court for the District of Columbia to invalidate it, contending that the Interim Final Rule was arbitrary and capricious, that HHS lacked the statutory authority to promulgate the rule, and that the rule impermissibly intruded into confidential relationships protected by the Constitution.⁵⁹ On April 14, 1983, Judge Gerhard Gesell invalidated the Interim Final Rule on procedural grounds, holding that the Interim Final Rule should have been published for public comment.⁶⁰

⁶⁰ The Administrative Procedure Act requires that a general notice of proposed rulemaking be published in the Federal Register at least 30 days prior to the effective date. An agency must then give interested individuals the ability to participate in the rulemaking through submission of written data, views, or arguments. An agency need not adhere to these restrictions if either (i) the rules are interpretative (that is, non-binding), general statements of policy, or rules of organization, procedure or practice or (ii) the agency, for good cause, finds the notice and public procedure are impracticable, unnecessary or contrary to the public interest. 5 U.S.C.A. §553 (1977).

He also ruled that Secretary of Health and Human Services Margaret Heckler had insufficient material before her to consider relevant factors and assure rational consideration of the effect of the contemplated regulatory action.⁶¹ Gesell also expressed considerable skepticism that section 504 was intended to apply to medical treatment decisions involving children with disabilities and suggested that, if it were, it might in at least some applications be an unconstitutional infringement on the right of privacy.⁶²

Proposed 504 Rule, July 1983

HHS quickly moved to overcome the procedural objections that caused Judge Gesell to invalidate the Interim Final Rule. On July 5, 1983, HHS published a revised version of the earlier rule for public comment in the form of a "proposed rule."⁶³

The Supplementary Information for the proposed rule addressed Gesell's criticisms of the Interim Final Rule. Finding nothing in the plain language of section 504 or its legislative history to indicate an intent that infants not be given the protection the statute affords those who are not infants, the preamble concluded that an infant with a disability is both an "individual" within the protection of section 504, and a "person" within the protection of its implementing regulation. A "qualified handicapped infant" was defined as one who could benefit medically from the treatment:

Judge Gesell rejected the government's argument that the Interim Final Rule was either procedural or interpretive, viewing the action as substantive because it provided for an "intrusive on-premises enforcement mechanism." *American Academy of Pediatrics*, 561 F. Supp. at 401. The good cause exception of § 553 of the Administrative Procedure Act, the court noted, is narrowly construed and only reluctantly countenanced. *Id.* The government argued that the lives of the infants were at risk, and this required the expedited implementation of the regulations. Judge Gesell saw this as a slippery slope:

Such an argument could as easily be used to justify immediate implementation of any sort of health or safety regulation, no matter how small the risk for the population at large or how long-standing the problem. There is no indication in this case of any dramatic change in circumstances that would constitute an emergency justifying shunting off public participation in the rulemaking.

Id.

⁶¹ Among the factors Judge Gesell believed HHS should have considered were (i) the disruptive effects of the hotline; (ii) "the sudden descent of 'Baby Doe' squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment"; (iii) the interests of a child forcibly removed from a hospital if the parents refuse to consent to surgery; (iv) termination of Federal assistance to the hospital as a whole if a violation occurred; (v) weighing of other factors

Section 504 would hold that where an infant would not benefit medically from a particular treatment, the infant would not be "qualified" to receive the treatment; thus, its denial would not violate Section 504.⁶⁴

HHS responded to Judge Gesell's concern that there was insufficient evidence of widespread denial of treatment to justify the rule by reviewing a number of cases and citing surveys indicating that denial of treatment was accepted by the majority of pediatricians.⁶⁵

The proposed rule was substantially similar to the Interim Final Rule. In response to charges that the Interim Final Rule would lead to a plethora of unsubstantiated reports by janitors, visitors, and other members of the general public incompetent to make judgments about the adequacy of medical treatment, the proposed rule allowed the required poster to be placed only in nurses' stations, rather than in wards open to the public. It added a new provision relating to child protective services agencies receiving Federal financial assistance. They were required to develop procedures to ensure prompt processing of denial of treatment reports, with provisions for onsite investigations and the seeking of court orders to secure treatment. They were to notify the HHS Office for Civil Rights of reports received and the steps taken to investigate them.⁶⁶

against the malpractice and disciplinary risks that would be imposed upon doctors and hospitals; (v) whether the termination of painful procedures would be preferable when the prognosis is certain death; (vi) the means of funding the extensive care that would be required by the children whom the regulation saved and the allocation of scarce medical resources between defective newborns and other patients; and (vii) alternative means of protecting infants with a disability. *Id.* at 399-400.

⁶² 561 F. Supp. at 403.

⁶³ *Nondiscrimination on the Basis of Handicap*, 48 Fed. Reg. 30,846 (proposed July 5, 1983).

⁶⁴ *Id.* In response to Judge Gesell's expressed concern that HHS had given inadequate consideration to whether the termination of painful procedures would be desirable for a child whose prognosis is certain death, the preamble stated:

Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. . . which merely temporarily prolong the process of dying of an infant born terminally [ill]. . . . Such medical decisions, by medical personnel and parents, concerning whether to treat, and if so, what form the treatment should take, are outside the scope of Section 504.

Id. at 30,846-47.

⁶⁵ *Id.* at 30,847-48.

⁶⁶ *Id.* at 30,851.

Final 504 Rule

HHS received nearly 17,000 comments on the proposed rule, of which 97.5 percent were favorable.⁶⁷ It also conducted intensive negotiations with medical organizations and disability rights advocacy groups.⁶⁸ Of particular importance in these discussions was the position of the American Academy of Pediatrics (AAP). In congruence with the President's Commission report, the AAP proposed:

as an alternative to the proposed rule, that all hospitals, as a condition of participation in the Medicare program (not as a requirement of section 504) establish a review committee. Under this proposal. . . the committee would have three functions: (1) to develop hospital policies and guidelines for management of specific types of diagnoses; (2) to monitor adherence through retrospective record review; and (3) to review, on an emergency basis, specific cases when the withholding of life-sustaining treatment is being considered. When the committee disagreed with a parental or physician decision to withhold treatment, the case would be referred to the appropriate court or child protective agency, and treatment would be continued pending a decision.⁶⁹

As a result of the negotiations, the HHS Final Rule, issued on January 12, 1984, was a compromise that incorporated features of the AAP proposal and made other modifications in the proposed rule; in return, the AAP agreed not to challenge the Final Rule.⁷⁰ HHS wrote: "These modifications are designed to establish a framework under which the substantial controversy that has attended the Department's efforts to strengthen enforcement of section 504 in this area can be replaced by a more cooperative effort involving the Federal Government, the medical community, private advocacy groups and state governments."⁷¹

Key components of the Final Rule were (1) its integration of a voluntary, modified form of ethics committees, to be called "Infant Care Review Committees"; (2) its modified poster requirement; (3) its requirements for State agencies; and (4) its

provisions for expedited investigation and enforcement action.

The Final Rule encouraged, but did not require, hospitals to establish infant care review committees (ICRCs),⁷² and it described the purpose, procedures, and composition of a model committee.⁷³ The differences between the AAP model and that in the Final Rule were intended to "underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."⁷⁴

The Department does not seek to take over medical decisionmaking regarding health care for handicapped infants. HHS agrees that the best decisionmakers are generally the parents and the physicians directly involved. However, there is, and must be, a framework within which the decisionmakers, the parents and physicians, operate.

That framework is established by laws. . . includ[ing] section 504. . . .

The fundamental issue involved in deciding whether review boards should be a substitute for enforcement of section 504 is whether the legal framework within which the decisionmaking parents and physicians are supposed to function (and generally do function) will be utilized. Under the proposal that review boards act in lieu of government, whether physicians or hospital review boards adhere to the principles of section 504 would be determined by those physicians and boards alone. . . . Whether they ever utilize the implementation schemes established by law to ensure that those principles are adhered to would also be decided by those parents, physicians, and review boards. . . . This alternative proposal simply does not provide sufficient safeguards that the requirements of section 504 will be met. . . . [I]t would not be justifiable for the Department to refrain from exercising a regulatory role to enforce the statute.

. . . [A]lthough unacceptable as a substitute, review boards can be very valuable. . . . [A] committee that includes individuals with medical expertise and people with non-medical perspectives and that is guided by proper standards and protocols can be very helpful in bringing about informed, enlightened and fair decision-making. . . .⁷⁵

7,000 hospitals in the country would be difficult, and that because the American Medical Association and other medical groups opposed any mandatory requirement, "there would likely be protracted legal proceedings challenging the regulation." *Id.* at 1,624.

⁶⁷ 45 C.F.R. § 84.55(a) & (f) (1987). Infant care review committees, and the difference between their role as conceived by the President's Commission Report and AAP, on the one hand, and HHS, on the other hand, are discussed in chap. 11.

⁶⁸ Final Rule (504), *supra* note 25, at 1,625.

⁶⁹ *Id.* at 1624.

⁶⁷ Final Rule (504), *supra* note 25, at 1,623.

⁶⁸ Barringer, *Koop Acted as Midwife for New "Baby Doe" Rule*, Washington Post, Jan. 10, 1984, at A15, col. 3.

⁶⁹ Final Rule (504), *supra* note 25, at 1,623.

⁷⁰ Barringer, *supra* note 68, at A15, cols. 3-4. This agreement did not keep the AAP's fellow medical organizations, the American Medical Association and the American Hospital Association, from suing (successfully) to enjoin them. See *infra* note 109 and accompanying text.

⁷¹ Final Rule (504), *supra* note 25, at 1,622.

⁷² *Id.* at 1651. HHS noted that review boards were still untried, that enforcement of a requirement for such committees in the

HHS agreed that when it investigated reports of discriminatory denial of treatment at a hospital, it would generally first consult with the hospital ICRC and delay investigating for 24 hours to receive information from the ICRC unless "other action is necessary to protect the life or health of a handicapped infant."⁷⁶ It encouraged State child protective services agencies to adopt similar guidelines for consulting with ICRCs.⁷⁷

The Final Rule not only redrafted the original notice required to be posted in hospitals, but also gave hospitals the option of posting either of two alternative notices. A hospital with an internally adopted policy congruent with section 504 and with an internal review mechanism, including the opportunity to make an anonymous report free of retaliation, could post a notice with language designed to avoid suggesting that the hospital was an object of suspicion.⁷⁸ The notice could be posted in any location where medical professionals such as nurses could see it; it need not be posted where patients, visitors, or others could see it; and its size was reduced to 5 by 7 inches.⁷⁹

The Final Rule established basic duties for State child protective services agencies receiving Federal financial assistance in dealing with reports to them of medical neglect of children with disabilities. Each such agency was obligated to establish and maintain procedures to ensure that the agency use its "full authority. . . to prevent instances of medical neglect of handicapped infants."⁸⁰ The procedures included requirements that health care providers report in-

stances of known or suspected medical neglect on a "timely basis";⁸¹ that a method be established by which the agency receives these reports;⁸² that there be immediate review, and, where appropriate, onsite investigation, of such reports,⁸³ and provision for the protection of "medically neglected handicapped infants," including, if necessary, court orders to compel necessary nourishment and medical treatment.⁸⁴ Further, each State agency was to provide timely notification to HHS of every report of "suspected unlawful medical neglect of handicapped infants."⁸⁵

As had its predecessors, the Final Rule authorized expedited access to hospital records when, in the judgment of HHS, immediate access was necessary to protect the life or health of an individual with a disability.⁸⁶ The Final Rule also eliminated the normal 10-day notice requirement when, in the judgment of the responsible HHS official, immediate action to effect compliance was necessary to protect the life or health of an individual with a disability.⁸⁷

The expedited compliance provisions were designed to permit HHS to obtain a temporary restraining order to sustain the life of an infant in imminent danger of death.⁸⁸

Effect of *University Hospital*

The underlying premise of the Final Rule was called into question by the Second Circuit's ruling in the *Baby Jane Doe* case on February 23, 1984.⁸⁹ *Baby Jane Doe* was born on October 11, 1983.⁹⁰ The final New York court ruling against requiring

⁷⁶ 45 C.F.R. Part 84 App. C(b)(2) (1987).

⁷⁷ 45 C.F.R. § 84.55(c)(2) (1987).

⁷⁸ The notice read:

PRINCIPLES OF TREATMENT OF DISABLED INFANTS

It is the policy of this hospital, consistent with Federal law, that nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgements) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments.

This Federal law, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of handicap in programs or activities receiving Federal financial assistance. For further information, or to report suspected noncompliance, call:

[Identify designated hospital contact point and telephone number] or

[Identify appropriate child protective services agency and telephone number] or

U.S. Department of Health and Human Services (HHS): 800-368-1019 (Toll-free: available 24 hours a day; TDD capability).

The identity of callers will be held confidential. Retaliation by this hospital against any person for providing information about possible noncompliance is prohibited by this hospital and Federal regulations.

Id. § 84.55(b)(3). The notice to be used in hospitals without such policies was essentially the same, but began "Federal law prohibits discrimination on the basis of handicap" and eliminated references to hospital policy. *Id.* § 84.55(b)(4).

⁷⁹ Final Rule (504), *supra* note 25, at 1,626.

⁸⁰ *Id.* § 84.55(c)(1).

⁸¹ *Id.* § 84.55(c)(1)(i).

⁸² *Id.* § 84.55(c)(1)(ii).

⁸³ *Id.* § 84.55(c)(1)(iii).

⁸⁴ *Id.* § 84.55(c)(1)(iv).

⁸⁵ *Id.* § 84.55(c)(1)(v). The Supplementary Information made clear that this applied to decisions of parents. Final Rule (504), *supra* note 25, at 1,622.

⁸⁶ 45 C.F.R. § 84.55(d).

⁸⁷ 45 C.F.R. § 88.45(e).

⁸⁸ Final Rule (504), *supra* note 25, at 1,628.

⁸⁹ The case is also discussed in chap. 2 (text accompanying notes 14-15); chap. 3 (text accompanying notes 54-72); and chap. 5 (text accompanying notes 25-32).

⁹⁰ *United States v. Univ. Hosp.*, 729 F.2d 144 (2d Cir. 1984).

lifesaving operations to close her back lesion and install a shunt for her hydrocephalus came on October 28, 1983. On October 19, HHS had received a complaint under section 504 relating to the case.⁹¹ After studying the evidence entered in the State court proceedings, which included the child's medical records from birth through October 19, the Surgeon General considered it necessary to obtain more recent medical records to determine if any violation of section 504 had occurred. The Surgeon General stated: "An appropriate determination concerning whether the current care of Infant Jane Doe is within the bounds of legitimate medical judgment, rather than based solely on a handicapping condition which is not a medical contraindication to surgical treatment, cannot be made without immediate access to . . . current medical records. . . ." ⁹² When repeated requests for the records by HHS were rebuffed, the Department of Justice filed suit in Federal district court for an injunction requiring the hospital to make them available.⁹³

Although acknowledging that University Hospital was a recipient of Federal financial assistance and subject to section 504, the district court entered summary judgment against the government, holding that the records already available established that the hospital had not engaged in discrimination prohibited by 504. The court found that "the papers submitted demonstrate conclusively that the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available. . . ." ⁹⁴

The government appealed to the Second Circuit Court of Appeals. It maintained that the district court's ruling had the absurd effect of requiring HHS to make an advance evidentiary showing concerning the ultimate issue of unlawful conduct as a prior condition to securing the materials necessary

to reach the determination whether unlawful conduct had occurred. The Second Circuit noted that "[a]n administrative agency is entitled to access to information 'not plainly incompetent or irrelevant to any lawful purpose of the [agency] in the discharge of [its] duties.'" ⁹⁵ However, the Second Circuit concluded that the proper question was whether "the subject matter of the investigation is within the agency's statutory jurisdiction." ⁹⁶

The Second Circuit concluded it was not. After dismissing the regulatory history as "inconclusive," ⁹⁷ and holding that Baby Jane Doe was indeed a "handicapped individual" for purposes of section 504, ⁹⁸ the court essentially argued that the language of the provision was not naturally adapted to the evaluation of medical treatment decisions. First, the court focused on the statute's requirement that such an individual be "otherwise qualified" for the benefits in question:

[T]he phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents.⁹⁹

Second, the court wrote that medical decision-making is too complex to be analyzed in terms of "discrimination":

Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". . . . Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment," however that phrase might be defined.¹⁰⁰

⁹¹ *Id.* at 146.

⁹² *Quoted in id.*

⁹³ HHS relied upon 45 C.F.R. § 80.6(c):

Each recipient [of Federal funds] shall permit access by the responsible Department official or his designee during normal business hours to such of its books, records, accounts and other sources of information, and its facilities as may be pertinent to ascertain compliance. . . . Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance. . . .

⁹⁴ *United States v. Univ. Hosp.*, 575 F. Supp. 607, 614-15 (E.D.N.Y. 1983), *aff'd* 729 F.2d 144 (2d Cir. 1984).

⁹⁵ *University Hospital*, 729 F.2d at 149, quoting *Endicott Johnson Corp. v. Perkins*, 317 U.S. 501, 509 (1943).

⁹⁶ *Id.* at 150.

⁹⁷ *Id.* at 154.

⁹⁸ *Id.* at 155.

⁹⁹ *Id.* at 156.

¹⁰⁰ *Id.* at 157. In fact, HHS had already described the distinction between the condition requiring treatment and the "handicap" which is illegitimate as a ground for discrimination under section 504. It did so in the supplemental information published with the Final Rule on Jan. 12, 1984:

[W]here the handicapping condition and the condition to be treated are the same. . . the "handicap" is the physical or mental impairment the infant has or will have (or "is

Next, the Second Circuit reviewed the legislative history of section 504 and concluded that “Congress never contemplated that section 504 would apply to treatment decisions of this nature.”¹⁰¹ It quoted with approval Judge Gesell’s *dicta* in his opinion striking down the Interim Final Rule: “[N]o congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking. . . .”¹⁰²

Finally, the court took the position that requiring a hospital to go to court or to child protective services agencies to override parental refusals of consent to their children’s lifesaving treatment “would impose a particularly onerous affirmative action burden on the hospital.”¹⁰³ Although it conceded that the precedent was “not directly on point,” the Second Circuit quoted the 1979 Supreme Court decision in *Southeastern Community College v. Davis*¹⁰⁴ distinguishing between the “evenhanded treatment of qualified handicapped persons” required by 504 and “affirmative efforts to overcome the disabilities caused by handicaps” not required by 504.¹⁰⁵ Therefore, the Second Circuit held that

regarded as having”) after completion of the treatment under consideration. . . . [I]f the surgery would. . . be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding. . . fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is because of the handicap and in spite of the infant’s being qualified to receive the surgery.

Final Rule (504), *supra* note 25, at 1637 (emphasis in the original).

¹⁰¹ 729 F.2d at 157. The legislative history of section 504 described at the beginning of this chapter paints a different picture. See *supra* notes 6–12 and accompanying text.

¹⁰² *Id.* at 159, quoting *Am. Academy of Pediatrics v. Heckler*, 561 F. Supp. at 401.

¹⁰³ *Id.* at 160.

¹⁰⁴ 442 U.S. 397 (1979).

¹⁰⁵ *University Hospital*, 729 F.2d at 160, quoting *Davis*, 442 U.S. at 410. HHS took the position that hospitals generally do go to court or to child protection agencies to override parental refusals of consent to lifesaving treatment for nondisabled children (when, for example, parents refuse to consent to blood transfusions for their children for religious reasons), so that requiring them to do so on behalf of children with disabilities merely mandates evenhanded treatment, not affirmative action. Final Rule (504), *supra* note 25, at 1,631.

section 504 did not authorize the type of investigation that had precipitated this lawsuit.¹⁰⁶

The government did not ask the Supreme Court to review *University Hospital*. Baby Jane Doe’s parents changed their minds, directing that their daughter be given life-preserving surgery;¹⁰⁷ with the risk to her life removed, the government no longer saw a need to pursue the case.

Bowen v. American Hospital Association

Following the Second Circuit’s decision in *University Hospital*, the American Hospital Association amended its complaint in an existing suit, and the American Medical Association filed a separate suit, to challenge the four mandatory components of the Final Rule.¹⁰⁸ The plaintiffs in both suits asserted that the Final Rule was beyond the authority of HHS under section 504. The two suits were consolidated.¹⁰⁹

The district court, regarding the legal issues as having been settled by the holdings in *University Hospital*, concluded that the mandatory provisions of the Final Rule were “invalid, unlawful and must be set aside pursuant to the Administrative Procedure Act, because [these provisions were] promulgated without statutory authority.”¹¹⁰ The district court issued an extremely broad injunction prohibiting HHS from:

¹⁰⁶ *University Hospital*, 729 F.2d at 161. Circuit Judge Ralph Winter dissented. He wrote:

[In adopting section 504,] Congress was persuaded that a handicapped condition is analogous to race and that, so far as the administration of federal financial assistance is concerned, discrimination on the basis of a handicap should be on statutory par with discrimination on the basis of race.

. . . A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down’s Syndrome is not a *bona fide* medical judgment.

Id. at 162.

¹⁰⁷ Kerr, *Baby Doe’s Success[er] Legal, Medical Legacy of Case*, *Newsday*, Dec. 7, 1987, at 2, col. 2, 23, col. 1.

¹⁰⁸ Additional plaintiffs included the Hospital Association of New York State, the American College of Obstetricians and Gynecologists, the Association of American Medical Colleges, the American Academy of Family Physicians, and individual physicians. *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 613, n.2 (1986).

¹⁰⁹ *Bowen*, 476 U.S. at 620.

¹¹⁰ *Am. Hosp. Ass’n v. Heckler*, 585 F. Supp. 541, 542 (S.D.N.Y.), *aff’d without opinion* 794 F.2d 676 (2d Cir. 1984), *aff’d sub nom.* *Am. Hosp. Ass’n v. Bowen*, 476 U.S. 610 (1986) (citation omitted).

any further implementation of the Final [Rule. . .and from] any other actions. . .to regulate treatment involving impaired newborn infants taken under authority of Section 504, including currently pending investigation and other enforcement actions.¹¹¹

The Second Circuit summarily affirmed the district court in an unpublished opinion.¹¹²

By a vote of five to three, the Supreme Court also affirmed. However, only four Justices joined in the opinion, making it a nonbinding plurality, rather than a majority, opinion.¹¹³ Justice Stevens wrote the plurality opinion, in which Justices Powell, Marshall, and Blackmun joined. Former Chief Justice Burger concurred in the judgment without an opinion and without explaining his refusal to join Stevens' decision. Justices White, O'Connor, and Brennan dissented, and Justice Rehnquist took no part in the decision.

The plurality acknowledged that section 504 protects a child with a disability from discrimination solely by reason of the person's disability: "[H]andicapped infants are entitled to 'meaningful access' to medical services provided by hospitals, and. . .a hospital rule or state policy denying or limiting such access would be subject to challenge under Section 504."¹¹⁴ However, noting that the suit arose out of a facial challenge to the Final Rule and was not an enforcement action in a particular case, the plurality opinion declined to express a view on whether section 504 "ever applies to individual medical treatment decisions involving handicapped infants," thus refusing to reach the central issue decided by the Second Circuit.¹¹⁵

Instead, Justice Stevens focused on what the plurality regarded as a lack of evidence in the administrative record sufficient to support the regulation: "It is an axiom of administrative law that an agency's explanation of the basis for its decision must include 'a "rational connection between the facts found and the choice made."'"¹¹⁶ Substantial evidence had been assembled by HHS demonstrating widespread denial of treatment to children with disabilities, but Stevens pointed out that in the cases

documented, the children's parents had agreed not to give consent for treatment: "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 decision-maker the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"¹¹⁷

This, perhaps the central point in the plurality opinion, stimulated the U.S. Commission on Civil Rights to invite extensive testimony and undertake substantial research focusing on the interrelationship of parents and physicians in the making of treatment decisions. The evidence thus gathered has been analyzed in chapter 2 of this report. In the view of the Commission, it provides convincing proof that, in the words of Professor James Ellis:

[The Stevens plurality opinion] misperceives the nature of the process by which parents, in conjunction with their doctors, make decisions about handicapped newborns.

. . . .

. . . All of the literature suggests and all of the accounts by parents, including those who testified before [the Commission], suggest that. . .it's one in which parents look to their physician for information, seek guidance from their physician and, although they ultimately have the formal and ultimate decision, often that's shaped by what they're told. And discrimination can take place in what they're told.¹¹⁸

In dissent in *Bowen*, Justices White and Brennan raised this very point:

[T]he parental consent decision does not occur in a vacuum. In fact, the doctors (directly) and the hospital (indirectly) in most cases participate in the formulation of the final parental decision and in many cases substantially influence that decision. Consequently, discrimination against a handicapped infant may assume guises other than the outright refusal to treat once parental consent has been given. Discrimination may occur when a doctor encourages or fails to discourage a parental decision to refuse consent to treatment for a handicapped child when the doctor would discourage or actually oppose a parental decision to refuse consent to the same treatment for a

¹¹¹ 476 U.S. at 625 n. 11.

¹¹² *Id.* at 620.

¹¹³ *Cf.* *United States v. Pink*, 315 U.S. 203 (1942): "[T]he lack of an agreement by a majority of the Court on the principles of law prevents [an opinion] from being an authoritative determination for other cases." *Id.* at 216 (citation omitted).

¹¹⁴ *Bowen*, 476 U.S. at 624.

¹¹⁵ *Id.*

¹¹⁶ *Id.* at 626, quoting *Motor Vehicle Mfrs. Ass'n v. State Farm Mut.*, 463 U.S. 29, 43 (1983) and *Burlington Truck Lines v. United States*, 371 U.S. 156, 168 (1962).

¹¹⁷ *Bowen*, 476 U.S. at 630. Since section 504 applies only to recipients of Federal financial assistance and parents are not such recipients, section 504 does not reach decisions by parents themselves to withhold consent for treatment solely on the basis of handicap.

¹¹⁸ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 18 (1986) (vol. II) (testimony of James W. Ellis, School of Law, University of New Mexico).

nonhandicapped child. Or discrimination may occur when a doctor makes a discriminatory treatment recommendation that the parents simply follow. Alternatively, discrimination may result from a hospital's explicit laissez-faire attitude about this type of discrimination on the part of doctors.¹¹⁹

However, the plurality could not find such reasoning or evidence for it in the administrative record: "The Secretary. . .has not even adumbrated a theory of 'discrimination' remotely resembling the one invented by the dissent, and therefore has not made the essential connection between the evidence of physician attitudes and the regulatory choice made here."¹²⁰

Because the plurality believed that the administrative record then before it supplied no basis for this approach to a justification of the HHS investigations and regulatory action, Justice Stevens' plurality opinion did not reach the question of what effect the existence of such an administrative record might have had on the ruling in *Bowen*. It did, however, briefly raise two potential objections to such an approach.

"[T]he dissent's theory," Justice Stevens wrote, "rests on the unstated premise that the statute may prevent the giving of advice to do something which Section 504 does not itself prohibit. It is hardly obvious that the Rehabilitation Act of 1973 forbids physicians from 'aiding and abetting' a parental decision which parents admittedly have a right to make."¹²¹

But most civil rights laws, when they do not reach purely private discrimination, nevertheless prohibit cooperation with it by the State or by those who may be held accountable for their use of public money. "That the Constitution may compel toleration of private discrimination in some circumstances does not mean that it requires state support for such discrimination."¹²² Section 504 exists to ensure that tax funds are not used to participate in or foster discrimination based on handicap. A regulation dating to 1977 includes in the list of discriminatory actions prohibited by section 504 an attempt to

"[a]id or perpetuate discrimination against a qualified handicapped person by providing significant assistance to. . .[a] person that discriminates on the basis of handicap in providing any aid, benefit, or service to beneficiaries of the [recipient's] program."¹²³

Justice Stevens' second objection was based on the first amendment. "[O]ne might expect an explanation from the Secretary," he wrote, "as to how the hotlines and emergency on-site inspections contemplated by the Final [Rule] square with the constitutional doctrines on regulation, direct or indirect, of speech in general and of decisionmaking by health care professionals in particular."¹²⁴

This objection misconceives the protections the Constitution affords to freedom of speech. A physician is protected by the first amendment in making the general claim that children with disabilities ought to be denied lifesaving medical treatment, just as she or he would be in advocating in general terms the violent overthrow of the government. But a physician is no more protected in using words to bring about denial of treatment to a particular child in violation of section 504 than she or he would be in using words to conspire in a specific and particular attempt to assassinate the President. "[T]he constitutional guarantees of free speech and free press do not permit a State to forbid or proscribe advocacy of. . .law violation *except where such advocacy is directed to inciting or producing imminent lawless action and is likely to incite or produce such action.*"¹²⁵ The exception is tailormade for circumstances in which health care personnel urge the parents to opt for denial of lifesaving medical treatment to a particular otherwise qualified child solely on the basis of the child's handicap.¹²⁶

As the plurality recognized, HHS independently sought to justify the Final Rule on the ground that "a hospital's failure to report parents' refusals to consent to treatment violates Section 504, and that past breaches of this kind justify federal oversight."¹²⁷ Justice Stevens recognized that "a hospital's selective refusal to report medical neglect of

rights of children with disabilities to be free of discriminatory denial of medical treatment is laid to rest by *Whalen v. Roe*, 429 U.S. 589 (1977). There, the Court held that a physician's right to administer medical care is no greater than the patient's right to receive it—that, in effect, any constitutional rights physicians possess specifically in their role as physicians is only a derivative one. *Id.* at 604, n.33.

¹²⁷ *Bowen*, 476 U.S. at 637.

¹¹⁹ 476 U.S. at 658–59 (White & Brennan, JJ., dissenting).

¹²⁰ *Id.* at 637 n.22 (plurality opinion).

¹²¹ *Id.* at 636–37 n.22.

¹²² *Norwood v. Harrison*, 413 U.S. 455, 463 (1973).

¹²³ 45 C.F.R. § 84.4(b)(v) (1987).

¹²⁴ 476 U.S. at 637 n.22.

¹²⁵ *Brandenburg v. Ohio*, 395 U.S. 444, 447 (1969) (emphasis added).

¹²⁶ The argument that there may be some constitutional right of physicians that precludes governmental action to protect the

handicapped infants might violate Section 504. . .if the hospital failed to report medical neglect of a handicapped infant when it would report such neglect of a similar nonhandicapped infant.”¹²⁸ Nevertheless, the plurality considered that “the Secretary has failed to point to any specific evidence that this has occurred,”¹²⁹ and therefore concluded the regulation was not adequately supported by the administrative record.¹³⁰

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,¹³¹ only that HHS had provided insufficient evidence of the prevalence of discriminatory nonreporting to provide an administrative justification for the Final Rule. Yet, Justice Stevens wrote, “the injunction forbids continuation or initiation of regulatory and investigative activity directed at instances in which parents have refused consent to treatment. . . .”¹³² Taken literally, that might appear to forbid investigations of discriminatory nonreporting by a Federal financial assistance recipi-

ent, nonreporting that, of course, could only become an issue when parents have at least nominally refused consent.¹³³

Because there was no binding majority opinion, and because the plurality opinion is ambiguous, it might be appropriate for the Department of Health and Human Services to act to enforce section 504 in a well-documented instance of discriminatory failure to report as a way of ultimately obtaining clarification or adjustment from the Court.

Enforcement of section 504 is contingent, of course, on receipt of Federal financial assistance by the source of alleged discrimination. In the plurality opinion, Justice Stevens wrote: “We do not address the question whether reporting, either as a hospital practice or as a requirement of state law, constitutes a ‘program or activity receiving Federal financial assistance’ under Section 504.”¹³⁴ The Commission concludes that passage of the Civil Rights Restoration Act eliminates this concern, since it defines “program or activity” under section 504 as including “all of the operations of . . .an entire corporation, partnership, or other private organization. . .which is principally engaged in the business of providing . . .health care. . . .”¹³⁵ If a hospital engages in

¹²⁸ *Id.* at 637 n.23. Justice Stevens wrote:

Because respondents have challenged the Secretary’s regulations on their face, we have no occasion to address the question whether infants with birth defects are similarly situated with infants in need of blood transfusions (the paradigm case in which hospitals have reported or have sought to override parental decisions. . .) or whether a hospital could legitimately distinguish between the two situations on the basis of the different risks and benefits inhering in certain operations to correct birth defects, on the one hand, and blood transfusions, on the other hand.

Id. at 637–38 n.23. Naturally, if consent for treatment is withheld, not because there is a preference that the child die, but because the risks to the child’s life from the treatment appear to outweigh the chance that the treatment would be successful in preserving the child’s life, there is no violation of section 504.

¹²⁹ *Bowen*, 476 U.S. at 637–38.

¹³⁰ The plurality also regarded as unjustified HHS directives to State child protective services agencies that receive Federal financial assistance concerning the manner in which they should process reports of medical neglect of children with disabilities and the priority they should give to them:

The Final Rule also order[s] state agencies to “immediate[ly]” review reports from hospitals, § 84.55(c)(1)(iii), to conduct “on-site investigation[s],” *id.*, and to take legal action “to compel the provision of necessary nourishment and medical treatment,” § 84.55(c)(1)(iv)—all without regard to the procedures followed by state agencies in handling complaints filed on behalf of nonhandicapped infants. . . .

The complaint-handling process the Secretary would impose on unwilling state agencies is totally foreign to the

authority to prevent discrimination conferred on him by Section 504. . . .

. . . .

. . . .Even if a state agency was scrupulously impartial as between the protection it offered handicapped and nonhandicapped infants, it could still be denied federal funding for failing to carry out the Secretary’s mission with sufficient zeal.

Id. at 639–41.

¹³¹ But see text accompanying note 134, *infra*.

¹³² *Bowen*, 476 U.S. at 625, n.11.

¹³³ The dissent took note of this point:

The plurality apparently would enjoin all enforcement actions by the Secretary in situations in which parents have refused to consent to treatment. . . .Yet it is not clear to me that the plurality’s basis for invalidating these regulations would extend to all such situations. I do not see, for example, why the plurality’s finding that the Secretary did not adequately support his conclusion that failures to report refusals to treat likely result from discrimination means that such a conclusion will *never* be justified. The Secretary might be able to prove that a particular hospital generally fails to report nontreatment of handicapped babies for a specific treatment where it reports nontreatment of nonhandicapped babies for the same treatment. . . .The fact that the Secretary has not adequately justified generalized action under the regulations should not mean that individualized action in appropriate circumstances is precluded.

Id. at 2132 (White & Brennan, JJ., dissenting).

¹³⁴ *Id.* at 2119 n.25.

¹³⁵ Pub. L. No. 100–259, § 4, 102 Stat. 29 (1988), codified at 29 U.S.C. § 793(b)(3)(A)(ii) (Supp. 2, July 1988).

reporting cases of medical neglect to the State child protective services agency, that is part of the operations of a corporation that principally provides health care; if any part of the hospital receives medicaid or medicare, discrimination based on handicap in the reporting operation, therefore, violates section 504.

Importance of Section 504 Enforcement

Although there is another basis for Federal enforcement of the right to treatment of children born with disabilities—the Child Abuse Amendments of 1984,¹³⁶ which are described in the next chapter—enforcement of section 504 would provide certain advantages not present in the Child Abuse Amendments alone. For one, section 504 reaches medical discrimination against people with disabilities of any age; unlike the Child Abuse Amendments, its coverage is not limited to children. For another, the Child Abuse Amendments apply only to States that choose to accept Federal funding for their child abuse programs.¹³⁷ In fiscal year 1988, four States—including California, the Nation's most populous—were not covered by the amendments.¹³⁸ Even in the other States, there are a number of ways in which the amendments are inferior to section 504 in protecting against medical discrimination. As James Bopp, Jr., a member of the President's Commission on Mental Retardation and the director of a legal services program specializing in denial of medical treatment to people with disabilities, testified:

[T]he remedies available in Section 504 are superior. The Child Abuse Amendments of 1984 require, at the pain of loss of Federal funds, State child protective service agencies to act. That is quite in contrast with the application of Section 504, which provides a substantive law standard for the entities that are discriminating against persons with disabilities in the delivery of medical care, which are hospitals and hospital employees and others who are recipients of Federal financial assistance. So the Child Abuse Amendments are quite indirect in their ability to influence the discrimination that is occurring within hospitals.

¹³⁶ Pub. L. No. 98-457, tit. 1, §§ 121-28, 98 Stat. 1749, 1752-55 (codified at 42 U.S.C.A. §§ 5101-5103 (West Supp. 1988)).

¹³⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 35 (1986) (vol. II) (testimony of James W. Ellis, School of Law, University of New Mexico). *Accord, id.* at 159 (testimony of James Bopp, Jr., President, National Legal Center for the Medically Dependent and Disabled).

¹³⁸ Telephone interview with Mary McKough, Program Analyst, National Center for Child Abuse and Neglect, Department

of Health and Human Services (Dec. 2, 1988). Ohio received funds in prior fiscal years, but was denied FY 1988 funds for reasons unrelated to the Baby Doe requirements. *Id.*

Third, actions by State child abuse and neglect agencies only occur on a case-by-case basis. Section 504, in contrast, can be the subject of a class action. . . . The Child Abuse Amendments only would involve a case-by-case protection of then-alive infants that are denied treatment, whereas under section 504 you can get injunctive relief to prohibit the hospital from using this form of criteria and protect all future infants.¹³⁹

The Commission heard revealing testimony from pediatric neurologist Dr. Patricia Ellison concerning the comparative effect of the section 504 regulations and those under the Child Abuse Amendments of 1984. When the section 504 rules were issued, she said, discussions about stopping lifesaving treatment in the neonatal intensive care unit "promptly ceased." Because physicians feared getting into trouble, "They treat[ed], and they continue[d] to treat." By contrast, under the Child Abuse Amendments, because physicians have "long worked with people in child abuse[.]. . . we would be surprised if it were an overwhelmingly interfering system. . . and one doesn't expect that they will be doing a lot of newborn investigation by and large."¹⁴⁰

It creates a strange anomaly for the Federal Government to mandate that State agencies enforce detailed national standards that forbid medical discrimination, while permitting Federal funds to be used for programs that are engaged in the same discrimination. The Federal Government enforces racial and sexual antidiscrimination standards for recipients of its funds; it should do the same to prevent medical discrimination against persons with disabilities.

Conclusion

The Commission's reading of the legislative history and plain meaning of section 504 persuade it that

of Health and Human Services (Dec. 2, 1988). Ohio received funds in prior fiscal years, but was denied FY 1988 funds for reasons unrelated to the Baby Doe requirements. *Id.*

¹³⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 162 (1986) (vol. II) (testimony of James Bopp, Jr., President, National Legal Center for the Medically Dependent and Disabled).

¹⁴⁰ *Id.* at 240-41 (testimony of Patricia Ellison, M.D.). Dr. Owens concurred. *Id.* at 241 (testimony of Walter Owens, M.D., Bloomington Obstetrics and Gynecology, Inc.).

the provision does cover discriminatory denial of medical treatment to people with disabilities. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a Federal financial assistance recipient's discriminatory denial of treatment to a person with a disability if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment. (The logic of the plurality opinion applies equally to such authorizations by other surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities.) In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

¹⁴¹ The Commission does not consider that this course of action would violate the decision of the Supreme Court in *Bowen*. First, the analysis in the plurality opinion depends almost entirely on the nature of the administrative record then before the Court. This report, by supplying information missing from that record, provides a basis for reopening many of the questions the plurality resolved against HHS. Second, this report provides a basis for concluding that the "decisions" by many parents to deny

The Commission's hearings and research summarized in chapter 2 supply information related to the issue that the Court considered not to have been satisfactorily addressed in the administrative record at the time *Bowen* was decided. Chapter 2 demonstrates that decisions nominally made by parents to deny treatment to children with disabilities often may, in fact, be generated by health care personnel who act as the agents of health care facilities. In such cases, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

In light of this, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends 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.¹⁴¹

treatment are not truly the product of informed consent; hence, it is questionable that they offer a legally valid or binding consent. Since the injunction bars investigation only of cases "in which parents have refused consent to treatment," *Bowen*, 476 U.S. at 625 n.11, investigations of instances in which it is suspected that parents have not given a legally binding consent to denial of treatment are not enjoined.

The Child Abuse Amendments of 1984

While HHS was responding to the public furor aroused by the Bloomington Infant Doe case by issuing its Notice to Health Care Providers and, later, the first version of the section 504 Baby Doe regulations,¹ Members of Congress were also reacting.² On May 26, 1982, Representative John Erlenborn introduced a bill to prevent denial of treatment to children with disabilities—a bill that, in substantially modified form, eventually became the Child Abuse Amendments of 1984.³ The bill was designed to create a private right of action against any person using the facilities of a health care facility who sought to “deprive a handicapped infant of nutrition which is necessary to sustain life, or deprive a handicapped infant of medical treatment which is necessary to remedy or ameliorate a life-threatening medical condition, if . . . any such deprivation is carried out for the purpose of causing or allowing the death of such infant; and . . . such nutrition or medical treatment generally is provided to similarly situated infants and handicapped infants.”⁴

The bill was not acted upon in 1982, but, on March 3, 1983, a significantly altered version was introduced by Representative Austin Murphy, Chairman of the House Select Education Subcom-

mittee, Representative John Erlenborn, the ranking minority member of the House Education and Labor Committee, and a number of other cosponsors.⁵ This bill would have required States receiving funds under the Child Abuse Prevention and Treatment Act⁶ to establish “procedures . . . to be followed by child protective service agencies, health care facilities, health and allied medical professionals, such other agencies or individuals as a State may deem appropriate, social service providers, and courts of competent jurisdiction, to insure that nutrition (including fluid maintenance), medically indicated treatment, general care, and appropriate social services are provided to infants at risk with life-threatening congenital impairments.”⁷

The House committee reported an amended version of the bill on May 16, 1983. Under this version, as described by the House committee report, the Secretary of Health and Human Services was to conduct a study of the incidence of denial of treatment and then:

[to] promulgate guidelines to encourage and assist the States in establishing local health care review mechanisms for health and allied professionals and facilities that provide care to those at risk infants. These local review mechanisms would include medical professionals, disability representatives, and persons concerned with the rights

child abuse and neglect. It also created the National Center on Child Abuse and Neglect to facilitate the gathering and dissemination of information on child abuse, as well as to keep records on the incidence of child abuse. The underlying act was amended and extended several times. Pub. L. No. 93-247, 88 Stat. 4 (1974), codified at 42 U.S.C.A. §§ 5101-5106 (West 1983 & Supp. 1988). See *id.* § 5101 note (West 1983 & Supp. 1988) for citations to other amending legislation.

⁷ H.R. 1904, 98th Cong., 1st Sess. sec. 103(a)(3) (1983).

¹ See chap. 6.

² See, e.g., *Newborn Baby Starves to Death in Bloomington, Indiana*, 128 Cong. Rec. 7143-44 (1982) (statement of Representative Hyde); *A Question of “Equal Justice Under Law,”* 128 Cong. Rec. 12171-72 (1982) (statement of Representative Erlenborn).

³ Pub. L. No. 98-457, tit. 1, §§ 121-28, 98 Stat. 1749, 1752-55, codified at 42 U.S.C.A. §§ 5101-5103 (West Supp. 1988).

⁴ H.R. 6492, 97th Cong., 2d Sess., sec. 3, § 202 (1982).

⁵ H.R. 1904, 98th Cong., 1st Sess. (1983).

⁶ This act established a program of Federal financial assistance to State agencies for the identification, prevention, and treatment of

of the infants. The review mechanism would provide special consideration of the uniqueness of each case while the child was being cared for, and would not prevent either the parents or health care professionals or others on the review mechanism from utilizing other procedures to appeal any findings and conclusions. In a case where the parents, attending physicians and review mechanism concur to not treat an infant, an automatic referral of the case shall be made to a child protection agency to assure that the decision was made on medical considerations and not solely based on other considerations such as the future quality of life or future disabling conditions.⁸

In an effort to satisfy objections from medical organizations, the principal sponsors and committee staff prepared amendments to the legislation after it was reported to delete the HHS incidence study, to make the "local review mechanisms" optional for each hospital, and to allow the required procedures to be incorporated into existing State child protective services procedures.⁹ Nevertheless, medical organizations lobbied against the bill,¹⁰ and the Waxman-Chandler amendment was proposed on the House floor "to eliminate the current Baby Doe provisions from the bill and to provide instead for local review committees to advise families and physicians on a case-by-case basis."¹¹ This amendment was defeated by a vote of 231 to 182, with 20 not voting.¹²

On September 28, 1983, the Senate Committee on Labor and Human Resources reported its version of the legislation. The committee report stated that the problems required "greater scrutiny and remedial action."¹³ Declaring that there was a "sufficient body of evidence" indicating that infants with disabilities were being denied treatment,¹⁴ it stated,

"this practice is not isolated to one or two instances."¹⁵ The Senate committee bill would have established an advisory committee to the Secretary of Health and Human Services to "conduct a comprehensive study of decision making procedures in health care facilities that involve the medical management of seriously ill handicapped infants."¹⁶ The advisory committee was to complete its study in 6 months, after which the Secretary could issue regulations "concerning the establishment of local decision-making procedures with regard to seriously ill handicapped infants which procedures will at a minimum guarantee that each health care facility will provide such infants proper feeding and appropriate medications for pain and sedation," regulations that the hospitals would have to follow or lose Federal financial assistance.¹⁷

Disability rights groups considered the Senate committee version unacceptable because it failed to provide what they considered adequate guarantees for treatment and because of its reliance on internal hospital self-policing. After these views were made widely known, six Senators whose views spanned the ideological spectrum (Orrin Hatch, Christopher Dodd, Jeremiah Denton, Alan Cranston, Don Nickles, and Nancy Kassebaum) and their staffs encouraged representatives of the interest groups involved to negotiate a compromise amendment.¹⁸ Thomas Nickels, legislative director and counsel to the American Nurses Association, told the Commission: "[I]t seemed to us [that] we perceived very clearly that there was a mood in the Congress that there should be some process by which reporting could

⁸ H.R. Rep. No. 159, 98th Cong., 1st Sess. 2-3 (1983).

⁹ Murphy, Committee Explanation of the Child Abuse Reauthorization, H.R. 1904 (undated) (letter to colleagues circulated shortly before House floor debate) (available in files of U.S. Commission on Civil Rights). See also 130 Cong. Rec. 1433 (1984).

¹⁰ See Letter to Members of Congress from American Academy of Pediatrics, American Association of Medical Colleges, American Psychiatric Association, National Association of Children's Hospitals and Related Institutions, American Academy of Family Physicians, American Medical Association, American Hospital Association, Federation of American Hospitals, and American College of Obstetricians and Gynecologists (Nov. 4, 1983); letter to Members of Congress from American College of Obstetricians and Gynecologists (Nov. 7, 1983); Letter to Members of Congress from American Hospital Association (Jan. 31, 1984) (available in files of U.S. Commission on Civil Rights).

¹¹ Letter to Colleagues from Reps. Henry Waxman, John Dingell, Rod Chandler, James Quillen, and J. Roy Rowland (Nov. 14, 1983) (available in files of U.S. Commission on Civil Rights).

¹² 130 Cong. Rec. 1442-43 (1984).

¹³ S. Rep. No. 246, 98th Cong., 1st Sess. 11, reprinted in 1984 U.S. Code Cong. & Admin. News 2918, 2928.

¹⁴ *Id.*

¹⁵ *Id.* at 16, 1984 U.S. Code Cong. & Admin. News at 2933.

¹⁶ *Id.* at 16, 1984 U.S. Code Cong. & Admin. News at 2933.

¹⁷ *Id.* at 17, 1984 U.S. Code Cong. & Admin. News at 2934.

¹⁸ Interview with Thomas Nerney, disability rights group representative present at the negotiations (Sept. 19, 1988). Staff from the office of Sen. Edward Kennedy were also involved in the negotiations. *Id.* Gary J. Caruso, former Legislative Director of the House Select Subcommittee on Education of the Committee on Education and Labor, told the Commission: "[A] number of Democrats and Republicans on both sides. . . felt that this was a civil rights matter that should be addressed. And when all the groups finally saw that the Democrats and Republicans. . . were going to act on something, they got involved." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 234* (1985) (vol. I).

occur. . . . We got involved because we wanted to have a say in how that process worked. . . .”¹⁹

A precedent existed for negotiations among medical and disability rights groups in connection with the Baby Doe issue. In 1983, under the auspices of the Office for Special Education and Rehabilitative Services in the Department of Education,²⁰ disability rights and medical groups negotiated a set of “Principles of Treatment of Disabled Infants.” The document was signed on November 29, 1983, after 7 months of discussions. With respect to medical care, it provided:

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration[s] such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual’s medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

¹⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 57 (vol. I) (1985). Dr. James Strain, past president of the American Academy of Pediatrics, testified: “I think we became aware, as the discussion went on, that there was a growing need to have something in place. We weren’t terribly enthusiastic about this to begin with, frankly. But when it became apparent that there was a good deal of concern. . . [w]e felt it was better to get in and make our suggestions to try to develop a law that would be workable.” *Id.* at 56.

²⁰ Interview with Thomas Nerney, former expert consultant, Office for Special Education and Rehabilitation Services, U.S. Department of Education (Sept. 19, 1988).

²¹ *Joint Policy Statement: Principles of Treatment of Disabled Infants*, 73 *Pediatrics* 559 (1984) [hereinafter *Principles of Treatment*]. The signatories were the Association for Retarded Citizens, the National Down’s Syndrome Congress, the American Coalition of Citizens with Disabilities, Inc., the Association for Persons with Severe Handicaps, the American Association on Mental Deficiency (now the American Association on Mental Retardation), the American Association of University Affiliated Programs, Persons with Developmental Disabilities, the Spina Bifida Association of America, the National Association of Children’s Hospitals and Related Institutions, Inc., and the American Academy of Pediatrics.

²² Among groups represented at one time or another in the negotiations were the American Medical Association (which

In cases where it is uncertain whether medical treatment will be beneficial, a person’s disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.²¹

These principles were to be referred to frequently in the negotiations over the Child Abuse Amendments. Those negotiations were lengthy and intense.²² They eventually produced an agreement that was announced in the *Congressional Record* on June 29, 1984, in the form of proposed statutory language and a “Joint Explanatory Statement” by the principal sponsors of the compromise amendment.²³ This statement was to serve the legislative history function of a committee report.

The Senate passed the compromise amendment on July 26, 1984, by voice vote and the amended bill by a vote of 89–0.²⁴ On September 19, 1984, the conference committee reported an agreed bill that essentially incorporated the Senate-passed compromise version. Furthermore, the conference committee report included most of the Principal Sponsors’ Statement.²⁵ The conference committee version was adopted by the House on September 26 and by the Senate on September 28.²⁶ The President signed it into law on October 9, 1984.²⁷

ultimately actively opposed the compromise), the American Hospital Association, the American Academy of Pediatrics, the American Nurses Association, the National Association of Children’s Hospitals and Related Institutions, the American College of Obstetricians and Gynecologists, the Nurse’s Association of the American College of Obstetricians and Gynecologists, the American College of Physicians, the California Association of Children’s Hospitals, the Catholic Health Association, the National Right to Life Committee, the American Life Lobby (which ultimately actively opposed the compromise), the Christian Action Council, the Association for Retarded Citizens of the United States, the American Association on Mental Deficiency, the Spina Bifida Association of America, the Down’s Syndrome Congress, People First of Nebraska, the Association for Persons with Severe Handicaps, the Disability Rights Center, and Operation Real Rights.

²³ 130 Cong. Rec. S8951 (daily ed. June 29, 1984) [hereinafter *Principal Sponsors’ Statement*]. See also Association for Retarded Citizens of the United States, *Compromise Reached on “Baby Doe” Legislation*, Press Release (July 2, 1984) (available in files of U.S. Commission on Civil Rights).

²⁴ 130 Cong. Rec. S9307, S9328 (daily ed. July 26, 1984).

²⁵ H.R. Conf. Rep. No. 1038, 98th Cong., 2nd Sess. 40 (1984), reprinted in 1984 U.S. Code Cong. & Admin. News 2947, 2969 [hereinafter *Principal Sponsors’ Statement*].

²⁶ 1984 U.S. Code Cong. & Admin. News 2918.

²⁷ 98 Stat. 1749 (1984).

Under the law, the Department of Health and Human Services was obligated to promulgate regulations to implement the act and to publish model guidelines for hospital-based infant care review committees.²⁸ These committees are voluntary under the 1984 amendments, as are the guidelines suggested for them.²⁹ A proposed implementing regulation was published by HHS on December 10, 1984.³⁰ In excess of 116,000 comments, most of them favorable, were received on the proposed regulation.³¹

On April 15, 1985, the HHS promulgated the Final Rule. In addition to the regulation itself, HHS published an appendix containing "Interpretative Guidelines." The Interpretative Guidelines were in large part derived from part of the proposed regulation. In response to critical comments from medical organizations, HHS decided to remove the clarifying definitions from the final regulation itself. However, because HHS continued "to believe that guidance relating to interpretations of key terms. . . will aid in effective implementation of the statute (a belief shared by many commenters)," it incorporated its understanding of them into the appendix.³² HHS wrote:

In publishing these interpretative guidelines, the Department is not seeking to establish them as binding rules of law, nor to prejudge the exercise of reasonable medical judgment in responding to specific circumstances. Rather, this guidance is intended to assist in interpreting the statutory definition so that it may be effectively and rationally applied in specific cases so as to fully effectuate the statutory purpose of protecting disabled infants.³³

Thus, the Interpretative Guidelines give "all parties the benefits of very relevant interpretations of the statute by the agency charged with its implementation."³⁴

²⁸ Child Abuse Amendments of 1984, 42 U.S.C.A. §5103 note (West Supp. 1988).

²⁹ See chap. 11 for a detailed consideration of the HHS model guidelines for infant care review committees issued in accordance with the amendments.

³⁰ Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48160 (1984) (to be codified at 45 C.F.R. pt. 1340) (proposed Dec. 10, 1984) [hereinafter Proposed Rule (CAA)].

³¹ Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14879 (1985) (codified at 45 C.F.R. pt. 1340) [hereinafter Final Rule (CAA)].

³² *Id.* at 14880.

³³ *Id.*

³⁴ *Id.* at 14882.

³⁵ *Id.* at 14878.

³⁶ Telephone interviews with Mary McKeough, Program Analyst, National Center for Child Abuse and Neglect, Office of

The relevant provisions of the Child Abuse Amendments of 1984 and their implementing regulation became effective on October 9, 1985.³⁵ As of December 1988, four States—California, Indiana, Ohio, and Pennsylvania—did not receive funds under the Child Abuse Prevention and Treatment Act, and the law did not apply to them.³⁶ The remaining 46 States, the District of Columbia, and Puerto Rico receive grants under the act, and the provisions of the amendments apply in these jurisdictions.³⁷

A sizable number of children with disabilities, those in the States that do not receive funds under the act, are not protected by the Child Abuse Amendments. Moreover, the funding the Federal Government provides through the underlying act is meager in comparison to that under other Federal programs: in fiscal year 1988, each compliant eligible jurisdiction received an annual base of \$35,000 and an additional amount depending on the number of residents under the age of 18. Payments ranged from a high of \$739,006 (Texas) to a low of \$35,980 (Commonwealth of the Northern Mariana Islands).³⁸

As a result, the financial incentive for States to comply is not very great.³⁹

The Standard of Care

As noted by the six principal Senate sponsors, each word in the standard of care enacted by the amendments "was chosen with utmost care."⁴⁰ Their nuances require careful analysis.⁴¹ Under the law, for a State to be eligible for Federal funds, it must have in place procedures to respond to reports of medical neglect; the definition given to medical neglect in the context of denial of treatment to children with disabilities is the meticulously negotiated federally required standard of care.

Human Development Services, Department of Health and Human Services (Dec. 2 & 5, 1988).

³⁷ *Id.*

³⁸ *Id.* The former trust territory is funded under a different formula. *Id.*

³⁹ In the words of Commissioner Blandina Cardenas Ramirez: "When I was in HHS, which was HEW at the time, the Child Abuse Act was one of the ones I was responsible for. . . . [I]t was very difficult to get the States to comply because you had no stick and very little carrot." Transcript, Meeting of the United States Commission on Civil Rights 142 (Nov. 18, 1988).

⁴⁰ Final Rule (CAA), *supra* note 31, at 14879.

⁴¹ See generally Mumaw, *The Child Abuse Amendments of 1984: The Infant Doe Amendment*, 18 Akron L. Rev. 515 (1985); Bopp & Balch, *The Child Abuse Amendments of 1984 and their Implementing Regulations: A Summary*, 1 Issues in L. & Med. 91 (1985).

Perhaps the best short statement of the medical standard of care established by the Child Abuse Amendments of 1984 is found in the Supplemental Information HHS published with the Proposed Rule:

[F]irst, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication. Second, all such disabled infants must be given medically indicated treatment. Third, there are three exceptions to the requirement that all disabled infants must receive treatment, or, stated in other terms, three circumstances in which treatment is not considered "medically indicated."⁴²

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."⁴³

Disabled

"Disabled" is not expressly defined in the statute, its implementing regulations, or the HHS Interpretative Guidelines. However, some light is cast upon its

meaning by the legislative history. The original formulation of what became "disabled infants with life-threatening conditions" in the statute was "infants at risk with life-threatening congenital impairments" in the House-passed bill.⁴⁴ Concern was expressed that this language would be interpreted to cover only those disabled infants whose life-threatening condition arose directly from a congenital impairment.⁴⁵ The enacted language clarifies that the 1984 amendments protect all infants with a disability, including those who develop a disability after birth, from withholding of medically indicated treatment for any life-threatening condition, regardless of whether the condition is related to the disability.

Model Procedures developed under a Federal grant by the American Bar Association's Commission on the Mentally Disabled and the National Legal Resource Center for Child Advocacy and Protection suggest the following meaning for the term "disabled":

"Disabled infant" means an infant with a physical or mental impairment which substantially limits or holds 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.⁴⁶

The Model Procedures explain that this definition is based on the definitions of "[h]andicapped person," "[p]hysical or mental impairment," and "[m]ajor life activities" in the implementing regulations for section 504 of the Rehabilitation Act of 1973,⁴⁷ except

⁴² Proposed Rule (CAA), *supra* note 30, at 48163.

⁴³ The statute prohibits "withholding of medically indicated treatment from disabled infants with life-threatening conditions," 42 U.S.C.A. § 5103(b)(2)(K) (West Supp. 1988), and defines the key term as follows:

[T]he term "withholding of medically indicated treatment" means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment, (A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the

provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id. § 5102(3).

⁴⁴ The House Committee report interpreted this original language to mean that those to be protected by the law were infants who are "born with a medically-identifiable handicapping condition and a life-threatening condition, the latter of which requires medical intervention in order to increase the infant's chances [sic] of survival." H.R. Rep. No. 159, 98th Cong., 1st Sess. 2 (1983).

⁴⁵ Bopp & Balch, *supra* note 41, at 107.

⁴⁶ 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) [hereinafter *Model Procedures*].

⁴⁷ *Id.* These definitions are found in 45 C.F.R. § 84.3 (j) (1987). They are not part of the "Baby Doe" regulations enjoined by the U.S. Supreme Court in *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986), but are part of the preexisting 1977 regulation implement-

that "the phrase 'or holds the reasonable prospect of in the future substantially limiting [a major life activity]' is added. This reflects the fact that infants and young children, in the normal course of development, do not yet possess the capability of performing many of the enumerated 'major life activities.'"⁴⁸

In addition to one who actually *has* such an impairment, the Rehabilitation Act includes one who "is [erroneously] regarded as having such an impairment."⁴⁹ That category was incorporated in the amended Rehabilitation Act to ensure that those subjected to discrimination because they are erroneously believed to have a disability receive the same protection under the law as those who actually have a disability. If this group were not included among those protected by the Child Abuse Amendments, then when lifesaving treatment is denied a child based on a mistaken prognosis of degree of disability, the very fact that the prognosis is mistaken might prevent the denial of treatment from being overturned.

Infant

Those protected by the standard of care are disabled infants with life-threatening conditions. The term "infants" includes, but is not limited to, children under 1 year of age. The first birthday is not an automatic cutoff from protection under the statute. The Principal Sponsors' Statement stated that although the law was intended primarily to protect infants under 12 months, it was not to be construed to justify discontinuance of otherwise mandated treatment at that age.⁵⁰ Accordingly, the Final Rule provides that the law "shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections

available under State laws regarding medical neglect of children over one year of age."⁵¹

Again tracking the Principal Sponsors' Statement, the Final Rule also provides that the standard of care "should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability."⁵² The Supplemental Information HHS published with the Final Rule explained this definition by noting that, as a condition of receiving child abuse and neglect grants, States must have procedures that protect children of all ages from medical neglect.

[A]s a general rule, issues of medical treatment for infants over one year of age are to be considered under the less precisely defined, but clearly applicable, standards of "medical neglect." Issues of medical treatment for disabled infants under one year of age with life-threatening conditions must be considered under the more precisely defined standards of the definition of "withholding of medically indicated treatment."

[But f]or certain infants over one year of age, the Conference Committee believed the more precisely defined standards of the definition of "withholding of medically-indicated treatment" might be more appropriate to use in considering the question of medical treatment than the more general standards of "medical neglect." . . . The apparent Congressional intent is to recognize that these three categories of infants, although over one year of age, share important characteristics with those infants under one year of age who are the principal focus of the statutory provision.⁵³

It is noteworthy that the third category, those over 1 year of age who have "a long-term disability," is extremely broad. Thus, it is arguable that under the law the more precise standards should be consulted concerning medical treatment decisions for practi-

ing section 504 in general. They are based on the statutory language of the Rehabilitation Act of 1973 itself. 29 U.S.C.A. §706 (West Supp. 1988).

⁴⁸ *Model Procedures*, *supra* note 46, at 228.

⁴⁹ 29 U.S.C.A. §706(8)(B)(iii) (West Supp. 1988).

⁵⁰ Principal Sponsors' Statement, *supra* note 25, at 41, 1984 U.S. Code Cong. & Admin. News at 2970.

⁵¹ 45 C.F.R. §1340.15(b)(3)(i) (1987).

⁵² *Id.*

⁵³ Final Rule (CAA), *supra* note 31, at 14882.

cally all children with disabilities, of whatever age.⁵⁴

Life-Threatening Conditions

Under the Interpretative Guidelines, a life-threatening condition includes a condition that, in the physician's "reasonable medical judgment, significantly increases the risk of the onset of complications that may threaten the life of the infant."⁵⁵ The intent of this clarification was to deal with circumstances in which a condition does not in and of itself threaten life but, unless corrected, poses the danger of a life-threatening condition developing. The Supplementary Information published with the Proposed Rule gave the example of spina bifida, in which the open lesion on the back does not, of itself, threaten life, but a failure to close the lesion surgically leaves an open pathway for a life-threatening infection.⁵⁶

Nutrition, Hydration, and Medication

"Appropriate" nutrition, hydration, and medication must always be supplied, even when one of the three exceptions to required maximal treatment applies.

⁵⁴ Presumably the term "infant" itself puts some limits on such a construction. Indeed, HHS suggested as much:

[N]o revision is necessary to clarify that "infant" does not include older children and adults. The potential appropriateness of applying the more precisely stated standards of the definition of "withholding of medically indicated treatment" to certain infants over one year of age is still stated, as it was in the proposed rule and in the Conference Report, in terms of *infants* over one year of age. Older children and adults are not "infants over one year of age."

Id. at 14882. However, "infant" can encompass a broad gamut of ages, especially in its use as a legal term. Black's Law Dictionary defines "infancy" as "Minority; the state of a person who is under the age of legal majority,—at common law, twenty-one years; now, generally 18 years." Black's Law Dictionary 699 (5th ed. 1979). Webster's gives a range of meanings for the term, including not only "a child in the first year of life" and "a child several years of age" but also "a person who is not of full age: minor" and "common law: a person under the age of 21." Webster's Third New International Dictionary 1157 (P. Grove ed. 1986) (emphasis in original). The Oxford English Dictionary includes the definition, "A person under (legal) age; a minor. In common law, one who has not completed his or her twenty-first year. . . ." Oxford English Dictionary 1426 (1971). When the applicability of legal standards is at stake, ambiguity of the sort that now exists in the definition of those covered by the Child Abuse Amendments is regrettable.

⁵⁵ 45 C.F.R. pt. 1340 App. Interpretative Guideline 2 (1987); see Bopp & Balch, *supra* note 41, at 107.

⁵⁶ Proposed Rule (CAA), *supra* note 30, at 48163. *But cf.* note 96, *infra*.

In cases concerning adults, a considerable number of courts have rejected any distinction between the provision of nourishment and the provision of maximal treatment: when it would be inappropriate to cut off the latter, they have ruled, it is equally appropriate to terminate the former.⁵⁷ In clear contrast to this approach, Congress plainly placed itself on the side of the dissenting judge in the 1986 Massachusetts case *Brophy v. New England Sinai Hospital* who wrote, "The process of feeding is simply *not* medical treatment. . . . Food and water are basic human needs."⁵⁸ Surgeon General C. Everett Koop had testified before the Senate Committee on Labor and Human Resources:

[T]he bottom line. . . is that you must nourish the patient. Whether an infant in a hospital is denied food and care, or whether an infant at home is denied food and care, the result is the same; it is child abuse.⁵⁹

On the Senate floor, one of the principal sponsors of the 1984 amendments affirmed that "the words 'appropriate nutrition [and] hydration'. . . are not meant to sanction outright denial of all nutrition and hydration but are intended only to affirmatively require appropriate nutrition and hydration in all cases[.] In other words, nothing in this amendment

⁵⁷ See *Corbett v. D'Alessandro*, 487 So.2d 368 (Fla. App. 2 Dist.), *review denied*, 492 So.2d 1331 (1986); *In re Drabick*, 245 Cal. Rptr. 840 (Cal. App. 6 Dist.), *cert. denied*, 57 U.S.L.W. 3347 (1988); *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (Del. Supr. 1980); *In re Gardner*, 534 A.2d 947 (Me. 1987); *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626 (1986); *In re Hier*, 18 Mass. App. 200, 464 N.E.2d 959, *rev. denied*, 392 Mass. 1102, 465 N.E.2d 261 (1984); *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *Delio v. Westchester County Medical Center*, 129 App. Div. 2d 1, 516 N.Y.S.2d 677 (2d Dept. 1987); *In re Grant*, 109 Wash.2d 545, 747 P.2d 445 (1987), *corrected*, 757 P.2d 532 (Wa. 1988); see also cases dealing with persons who expressed their wishes while competent: *Bouvia v. County of Los Angeles*, 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (2d Dist. 1987); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. App. 2d Dist. 1986); *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987); *cf.* *Leach v. Akron General Medical Center*, 68 Ohio Misc. 1, 426 N.E.2d 809 (1980) (the court did not make a decision on whether nutrition and hydration could be removed); later proceeding, *Estate of Leach v. Shapiro*, 13 Ohio App. 3d 393, 469 N.E.2d 1047 (Summit Co. 1984); *contra In re Steinhilber*, No. J-86-92, Amended Findings of Fact and Order at 3 (Redwood County Ct. Fam. Div. Minn. Oct. 13, 1986) (court ruled that nutrition, hydration, or medication could not be withdrawn from an infant who was chronically and irreversibly comatose, although resuscitation could be, in light of the 1984 Child Abuse Amendments and conforming Minnesota legislation).

⁵⁸ 398 Mass. 417, 497 N.E.2d 626, 640 (1986) (Nolan, J., dissenting).

⁵⁹ Quoted in S. Rep. No. 246, 98th Cong., 1st Sess. 10, reprinted in 1984 U.S. Code Cong. & Admin. News 2918, 2927.

allows an infant to be denied nutrition and hydration. . . .”⁶⁰ In addition, the HHS Interpretative Guidelines affirm:

[I]t should be clearly recognized that the statute is completely unequivocal in requiring that all infants receive “appropriate nutrition, hydration, and medication,” regardless of their condition or prognosis.⁶¹

It 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. Instead, the legislation requires that basic sustenance be provided in the form “appropriate” to the patient’s condition. For example, if a patient is incapable of receiving food and liquids orally, the patient might most appropriately receive nutrition and hydration through such measures as intravenous fluids, nasogastric or gastric tube feedings, or hyperalimentation.⁶²

The same absolute requirement that applies to nourishment also applies to “medication.” It seems clear that the congressional intent was to require that pain-relieving and other palliative medicine be given even to those children from whom maximal medical treatment is withheld. Before the final legislation was drafted, Dr. George Little testified:

Obligations to comfort and respect a dying person remain, and infants whose lives are destined to be brief are owed whatever enhancement and relief from suffering that can be provided, including medication for pain and sedation, as appropriate.⁶³

⁶⁰ 130 Cong. Rec. S9322 (daily ed. July 26, 1984) (Colloquy between Senators Helms and Hatch). The Principal Sponsors’ Statement said: “[T]he six principal sponsors of this compromise measure. . . [intend] that this statement. . . be the definitive legislative history in the Senate on it. Any remarks of individual Senators, including the principal sponsors, on this legislation express only their personal views and do not, therefore, constitute authoritative interpretation or explanation of the measure.” 130 Cong. Rec. S9319 (daily ed. July 26, 1984). However, the interpretation of Senator Hatch was never challenged by any other sponsor and appears to parallel the unequivocal language of the statute itself. It is useful primarily as an aid in understanding the importance attached to this aspect of the legislation at the time of passage.

⁶¹ 45 C.F.R. pt. 1340 App. Interpretative Guideline 10 (1987).

⁶² Major disability organizations strongly oppose starvation or dehydration of people with disabilities. For example, the Association for Retarded Citizens of the United States, noting that “debate is currently taking place concerning the appropriateness of withdrawing food and fluids from some persons labeled ‘comatose’ or ‘in a permanent vegetative state’” and recognizing that persons so labeled “may appear to share many characteristics with some persons labeled ‘profoundly mentally retarded’” resolved that the group “opposes the cessation of nutrition and/or

The Principles of Treatment adopted by medical and disability groups articulated a similar baseline standard of care:

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected.⁶⁴

In the case of *In re Steinhaus*, a Minnesota court held that antibiotics to deal with infection are included in the required medication.⁶⁵

Treatment Most Likely to Be Effective in Ameliorating or Correcting All Life-Threatening Conditions

The centerpiece of the Child Abuse Amendments’ standard of care is found in this phrase. It is the care that must be provided to all children covered by the law unless one of the three exceptions to be discussed below applies.

The history of the wording is instructive. Soon after Senate negotiations began on the standard of care, staff of the Senate Committee on Labor and Human Resources suggested a definition for the “medically indicated treatment” to be required that sought to incorporate the nondiscrimination approach of section 504. It required “treatment which would normally be provided to infants without regard to the presence of disabling conditions and includes treatment specifically designed to ameliorate a disabling condition.”⁶⁶ Later drafts also

hydration for the purpose of hastening or causing the death of persons with mental retardation.” *ARC Resolution on Cessation of Nutrition and/or Hydration*, 3 Issues in L. & Med. 313 (1987) (resolution adopted Oct. 25, 1986). Similarly, the Association for Persons with Severe Handicaps adopted a resolution stating that the group “strongly opposes any cessation of nutrition and hydration for people who are incapacitated. . . .” *TASH Resolution on Nutrition and Hydration*, 3 Issues in L. & Med. 315 (1987) (resolution adopted Nov. 15, 1986).

⁶³ Quoted in S. Rep. No. 246, 98th Cong., 1st Sess. 10, reprinted in 1984 U.S. Code Cong. & Admin. News 2918, 2927.

⁶⁴ *Principles of Treatment*, supra note 21, at 559.

⁶⁵ *In re Steinhaus*, No. J-86-92, slip op. at 10 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), reprinted in *Order in the Steinhaus Case*, 2 Issues in L. & Med. 241, 246-47 (1986).

⁶⁶ Gerry & Nimz, *The Federal Role in Protecting Babies Doe*, 2 Issues in L. & Med. 339, 345 (1987), quoting Senate Labor and Human Resources Staff Discussion Draft of Proposed Amendments to S. 1003 (May 18, 1984). An earlier draft from Sen. Edward Kennedy’s staff would have required “that all such newborns be provided treatment provided to other similarly situated children without congenital impairments that is necessary to correct or ameliorate a life-threatening condition, relief from suffering including feeding, and medication for pain and sedation

incorporated the nondiscrimination approach with various modifications.

When face-to-face negotiations among advocacy groups began, however, medical groups instead proposed language requiring "medical or surgical treatment, including treatment specifically designed to ameliorate a disabling condition, when such failure is clearly contrary to the best interests of the infant."⁶⁷ The "best interests" language was rejected because it would have allowed consideration of projected quality of life,⁶⁸ but the approach of requiring specifically defined treatment, instead of simply employing the nondiscrimination or equal protection approach of the earlier drafts, was retained. Further negotiations resulted in the language used in the statute as adopted: "'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions."⁶⁹

This definition creates a high standard of care—indeed, a higher standard of care than would equal protection language alone. 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. This places a responsibility on physicians to become knowledgeable about and employ the best available treatment rather than simply to avoid discriminating on the basis of disability.

The Interpretative Guidelines issued by the Department of Health and Human Services contain a number of clarifications of the scope of the standard of care. The Department emphasized:

as appropriate." Gerry & Nimz, *supra*, at 345, quoting Second Draft of Proposed Amendments to S. 1003 from Sen. Edward Kennedy's Staff (late April 1984).

⁶⁷ Gerry & Nimz, *supra* note 66, at 347, quoting Memorandum to Staff/Organizations re S. 1003 from Susanne Martinez (June 19, 1984).

⁶⁸ Gerry & Nimz, *supra* note 66, at 347.

⁶⁹ *Id.* at 348. The language now appears at 42 U.S.C.A. §5102(3) (West Supp. 1988).

⁷⁰ 45 C.F.R. pt. 1340 App. Interpretative Guideline 1 (1987).

⁷¹ *Id.*, Interpretative Guideline 4.

⁷² *Id.*, Interpretative Guideline 3.

⁷³ *Id.*, Interpretative Guideline 7. This interpretation is discussed more fully below in the context of the futility exception.

⁷⁴ 42 U.S.C.A. §5102(3) (West Supp. 1988).

⁷⁵ In *Maine Medical Center v. Houle*, Civ. No. 74-145 (Me. Super. Ct., Feb. 14, 1974), reprinted in *Trial Court Decision in*

[T]he definition's focus on the potential effectiveness of treatment in ameliorating or correcting life-threatening conditions makes clear that it does not sanction decisions based on subjective opinions about the future "quality of life" of a . . . disabled person.⁷⁰

The Interpretative Guidelines stated that treatment means more than a "particular medical treatment or surgical procedure"; it refers to a "complete potential treatment plan," including "multiple medical treatments and/or surgical procedures over a period of time. . . designed to ameliorate or correct a life-threatening condition or conditions."⁷¹ Treatment also includes diagnostic procedures to evaluate the need for medical intervention, including, as appropriate, "further evaluation by, or consultation with, a physician or physicians whose expertise is appropriate to the conditions(s) involved or further evaluation at a facility with specialized capabilities regarding the condition(s) involved. . . ."⁷² Finally, if palliative treatment makes a condition more tolerable, even though the condition will not be cured, that treatment is required.⁷³

Reasonable Medical Judgment

Under the 1984 amendments, the determination of what "will be most likely to be effective in ameliorating or correcting all [life-threatening] conditions" is to be made "in the treating physician's or physicians' reasonable medical judgment."⁷⁴ By requiring that the physician determine what the most effective treatment will be, the provision avoids the problem encountered in some cases in which the physician determined not what would be the treatment most likely to preserve life, but whether the treatment would produce a child with an acceptable quality of life.⁷⁵

Deference to "reasonable medical judgment" was not intended to authorize physician discretion to

Houle Case, 2 Issues in L. & Med. 237 (1986), for example, the pediatrician for a child with disabilities who in addition had a tracheoesophageal fistula testified:

I feel he [the infant] has already endured much insult to his brain and that considering the total child, I do not believe he will be able to function as a reasonable, normal child in late life. I honestly believe that with the insults of the last twenty-four hours, that he will be severely both motor and mentally retarded.

Quoted in Brown & Truitt, *Euthanasia and the Right to Die*, 3 Ohio N.U.L. Rev. 615, 633 (1976). The judge rejected the physician's quality of life analysis, holding that "the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise." *Houle*, slip op. at 4, 2 Issues in L. & Med. at 238-39.

avoid the explicit standards set forth in the legislation, but only to recognize the role of technical medical judgment in determining whether the conditions to which the legal standards refer exist in particular cases.⁷⁶ This distinction has been described by Loretta Kopelman, Ph.D., Thomas Irons, M.D., and Arthur Kopelman, M.D.:

[The law] only indicates that physicians are permitted to use reasonable medical judgment to determine whether the guidelines' conditions have been met. . . . [T]he guidelines must allow such appraisals by physicians if they are to be applied. In contrast, the traditional understanding of reasonable medical judgment includes not only such technical or scientific assessments but moral judgments about what is in the patients' best interests. The Baby Doe guidelines do not allow doctors, nurses, review committees, or state investigators to use their own views about which exceptions constitute reasonable medical judgment. Permitted exceptions to the provision of maximal treatment are spelled out in the rules; other behavior is defined as medical neglect. Hence, no deference is shown to reasonable medical judgment as traditionally understood—a judgment that includes moral as well as technical considerations of the proportional benefits of alternative treatments in alleviating suffering and in prolonging life.⁷⁷

While rejecting the incorporation of nonmedical factors into “reasonable medical judgment,” the law creates a high standard for that judgment on the technical level. Testifying before the Senate Committee on Labor and Human Services, Surgeon General Koop said:

The physician must know a great deal about the infant's disease process or disabling condition. As science and medicine continue to evolve, this is an ever-growing responsibility and requires that physicians must have great knowledge about and experience with the [condition] in question. . . .⁷⁸

⁷⁶ In the words of the Model Procedures developed by the American Bar Association: “[T]he decision to withhold medical treatment or care from a disabled infant with life-threatening conditions is to be made only in terms of the statutory definition. This definition does not include nonmedical factors in the ‘reasonable medical judgment’ used to determine ‘withholding of medically indicated treatment.’” *Model Procedures*, *supra* note 46, at 227. The Model Procedures point out that principles of treatment jointly adopted by medical and disability groups state: “considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decision concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.” *Id.*, quoting *Principles of Treatment*, *supra* note 21, at 559.

⁷⁷ Kopelman, Irons, & Kopelman, “*Baby Doe*” Regulations (letter to the editor), 319 *New Eng. J. Med.* 726 (1988).

Accordingly, the Principal Sponsors' Statement provided: “The reference to ‘reasonable medical judgment’ of the treating physician or physicians means a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.”⁷⁹ HHS adopted this definition verbatim in the Final Rule.⁸⁰ For the physician to be knowledgeable about the case and treatment possibilities, information which surpasses that with which the ordinary physician is familiar may be required. Reasonable judgments in life and death situations often will decree consultation and further evaluation.⁸¹ Nevertheless, as the American Bar Association's Model Procedures pointed out: “This standard of care is used widely in other treatment contexts, and only its application to the issue of withholding of medically indicated treatment from disabled infants with life-threatening conditions is new.”⁸²

Exceptions to Providing Treatment

The Child Abuse Amendments create three exceptions to the requirement to provide the treatment most likely to correct or ameliorate a child's life-threatening conditions (maximal treatment)—although “appropriate nutrition, hydration, and medication” must always be provided.

The Comatose Exception

The first exception applies when a child is “chronically and irreversibly comatose.”⁸³ The medical groups originally proposed an exception to cover those who are “permanently and completely unconscious.”⁸⁴ “Unconscious” is defined as “insensible” or “not conscious.”⁸⁵ The disability rights groups rejected this proposal as too broad and

⁷⁸ Quoted in S. Rep. No. 246, 98th Cong., 1st Sess. 10, reprinted in 1984 U.S. Code Cong. & Admin. News 2918, 2927.

⁷⁹ Principal Sponsors' Statement, *supra* note 25, at 41, 1984 U.S. Code Cong. & Admin. News at 2970.

⁸⁰ 45 C.F.R. § 1340.15(b)(3)(ii) (1987).

⁸¹ See *supra* note 72 and accompanying text.

⁸² *Model Procedures*, *supra* note 46, at 227. The Model Procedures paraphrase W. Prosser, *Handbook of the Law of Torts* § 32, at 161 (1982): “[P]hysicians who undertake work requiring special skill are required to possess a minimum standard of special knowledge and ability.” *Model Procedures*, *supra* note 46, at 246 n.28.

⁸³ 42 U.S.C.A. § 5102(3)(A) (West Supp. 1988).

⁸⁴ Gerry & Nimz, *supra* note 66, at 349, quoting Proposed Amendment to S.1003 by Medical Groups (June 25, 1984).

⁸⁵ *Stedman's Medical Dictionary* 1512 (24th ed. 1982).

proposed the more restrictive language now in the law.⁸⁶ "Coma" has a precise meaning:

Coma was defined operationally as a sleeplike, unarousable, unresponsive state in which the patient shows no awareness of self or environment. Such patients (1) do not open their eyes either spontaneously or in response to any verbal stimulus, (2) utter no comprehensible words, and (3) neither obey commands nor move their extremities appropriately to localize or to resist noxious stimuli.⁸⁷

In the 1986 Minnesota case *In re Steinhaus*, the court ruled that although the statute makes an exception for those who are "chronically and irreversibly comatose," it makes no exception for those in a "persistent vegetative state."⁸⁸ In an article on persistent vegetative state, Dr. Philip Hansotia wrote that, in contrast to those in a coma:

Patients in the PVS [persistent vegetative state], . . . are awake without being aware. They open their eyes and look about randomly but do not follow objects or respond to verbal command. The eyes open and blink spontaneously and to menace but are unattentive. Patients may sleep at times. Chewing and bruxism [grinding of teeth] are common, and a grasp reflex is often present.⁸⁹

The Futility Exception

The second exception applies when:

[T]he provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant. . . .⁹⁰

When 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 period longer. The HHS Interpretative Guidelines state that the exception does not "apply 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."⁹¹

In its proposed rule, HHS used the word "imminent" to define the period within which death must be expected in order to make the exception applicable.⁹² However, the Senate sponsors of the compromise legislation wrote a joint letter objecting to the term:

In the negotiations leading to the final language, there was much discussion about whether or not to include the word "imminent" in the statutory definition. It became apparent that "imminent" would create undue confusion both because it was ambiguous and because the expected time of death cannot be predicted with precision. A decision was made, therefore, not to include "imminent," and we urge that it be dropped in the regulations as well.⁹³

Accordingly, in the Interpretative Guidelines accompanying the Final Rule, HHS retracted the term "imminent" and indicated that the precise determination of what is a "near" versus a "more distant" future was left to reasonable medical judgment.⁹⁴

The second category of the second exception specifically addresses circumstances in which death will inevitably occur shortly even though some life-threatening conditions could be cured. As two legal commentators have noted:

In HHS' view, this [exception] was intended to apply to situations in which an infant suffers from several life-threatening conditions, some of which can be treated effectively, but at least one of which cannot. If and only if the untreatable condition will produce death in the near

⁸⁶ Gerry & Nimz, *supra* note 66, at 349.

⁸⁷ Hansotia, *Persistent Vegetative State*, 42 Arch. Neurol. 1048, 1048 (1985) (emphasis in original).

⁸⁸ Transcript at 73, *In re Steinhaus*, No. J-86-92 (Minn. Redwood County Ct., Fam. Div., Oct. 6, 1986); *In re Steinhaus*, No. J-86-92, slip op. at 11-12 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), reprinted in *Order in the Steinhaus Case*, 2 Issues in L. & Med. 241, 247-48 (1986). The court later ruled that the child was in fact chronically and irreversibly comatose. *In re Steinhaus*, No. J-86-92, Amended Findings of Fact and Order 3 (Minn. Redwood County Ct., Fam. Div. Oct. 13, 1986). Lance Steinhaus received serious injuries when just over a month old and became unconscious. After a decision was made not to give him antibiotics and to place a "Do Not Resuscitate" order on his medical chart, the county welfare department petitioned the court to prevent the withholding of antibiotics. After the court ruled that he was chronically and irreversibly comatose and that treatment other than nutrition, hydration, and medication could

legally be withheld, the "Do Not Resuscitate" order was restored. *Agreement Will Allow Comatose Baby to Die*, The Sun, Oct. 25, 1986, at A10. He subsequently died. *Baby Who Was Subject of Right-to-Live Case Dies*, Minneapolis Star and Tribune, Feb. 11, 1987, at 1A, col. 1.

⁸⁹ Hansotia, *supra* note 87, at 1048. See also Levy, *The Comatose Patient*, in I The Clinical Neurosciences 955, 956 (R. Rosenberg ed. 1983):

The patient in the *vegetative state* appears awake but shows no evidence of content, either confused or appropriate. He often has sleep-wake cycles but cannot demonstrate an awareness either of himself or his environment.

Id. (emphasis in original) (footnote omitted).

⁹⁰ 42 U.S.C.A. §5102(3)(B) (West Supp. 1988).

⁹¹ 45 C.F.R. pt. 1340 App. Interpretative Guideline 5 (1987).

⁹² Proposed Rule (CAA), *supra* note 30, at 48164, 48167.

⁹³ Quoted in Final Rule (CAA), *supra* note 31, at 14879.

⁹⁴ 45 C.F.R. pt. 1340 App. Interpretative Guideline 5 (1987).

(as opposed to the far) future, then treatment need not be provided for the other life-threatening conditions which theoretically could be treated. In other words, if the child is going to die shortly anyway from ailment A, it makes no sense (and is not required) to treat ailments B, C, or D. If, on the other hand, the child is terminally ill from ailment A, but will not die from it for some time, this exception provides no excuse for failing to treat the immediate threats to life from ailments B, C, or D.⁹⁵

HHS also interpreted the law to require that palliative care, including treatment that goes beyond medication,⁹⁶ must be provided even when lifesaving treatment would not be effective:

If . . . palliative treatment will ameliorate the infant's *overall* condition, taking all individual conditions into account, even though it would not ameliorate or correct *each* condition, then this palliative treatment is medically indicated.⁹⁷

The third category in the second exception applies if treatment would "otherwise be futile in terms of the survival of the infant." This category is simply a "cover all bases" logical extension of the other two categories, each of which describes circumstances in which treatment would be futile. The language, however, carefully ties futility to the "survival" of the infant, emphasizing that only the inevitability of death despite treatment, and not the persistence of disability despite treatment, renders the treatment legally futile.⁹⁸

The Virtually Futile and Inhumane Exception

The third exception reads:

[T]he 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.⁹⁹

The exception is phrased in the conjunctive: to remove the maximal treatment mandate, both of two requirements must be met.

⁹⁵ Bopp & Balch, *supra* note 41, at 112–13. See 45 C.F.R. pt. 1340 App. Interpretative Guideline 6 (1987).

⁹⁶ At the time it published the Proposed Rule, HHS gave the example of a child with an uncorrectable and life-threatening heart problem who also had an imperforate anus; in such a situation, the absence of effective treatment for the heart problem would not relieve physicians of the responsibility of providing a colostomy to relieve "the severe pain associated with the intestinal obstruction caused by the imperforate anus." Proposed Rule (CAA), *supra* note 30, at 48164. However, when HHS issued the Final Rule, it noted that commenters had "stated that, depending on medical complications, exact prognosis, relationships to other conditions, and other factors, the treatment

The first of the requirements is that the treatment be "virtually futile." The distinction between "futile" as used in the second exception and "virtually futile" as used in the third exception lies in the degree of probability or uncertainty in determining the futility of the treatment. Under the Interpretative Guidelines, the term "virtually futile" is understood to mean that treatment is "highly unlikely to prevent death in the near future."¹⁰⁰

The second requirement of this third exception is that the treatment itself be inhumane. The Interpretative Guidelines state that this is true only in the presence of "significant medical contraindications and/or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive."¹⁰¹

The Interpretative Guidelines note that although the initial two exceptions concerned themselves with the expected results of treatment, the third exception focused on the process of possible treatment:

It recognizes that in the exercise of reasonable medical judgment, there are situations where, although there is some slight chance that the treatment will be beneficial to the patient (the potential treatment is considered *virtually* futile, rather than futile), the potential benefit is so outweighed by negative factors relating to the process of the treatment itself that, under the circumstances, it would be inhumane to subject the patient to the treatment.¹⁰²

Enforcement of the Child Abuse Amendments

While the 1984 amendments were in the process of negotiation under the auspices of Senate staff, Senator Kennedy's office suggested an approach to enforcement that would have "required states, as a condition of continued receipt of federal child abuse funds, to create an ombudsman program for the purpose of protecting and advocating for the interests of newborn infants with life-threatening congen-

suggested. . . might not necessarily be the treatment that reasonable medical judgment would decide would be most likely to be effective. In response to these comments, specific diagnostic examples have not been included in this discussion. . . ." 45 C.F.R. pt. 1340 App. Interpretative Guideline 7 (1987).

⁹⁷ 45 C.F.R. pt. 1340 App. Interpretative Guideline 7 (1987) (emphasis in original).

⁹⁸ See Gerry and Nimz, *supra* note 66, at 349.

⁹⁹ 42 U.S.C.A. 5102(3)(C) (West Supp. 1988).

¹⁰⁰ 45 C.F.R. pt. 1340 App. Interpretative Guideline 8 (1987).

¹⁰¹ 45 C.F.R. pt. 1340 App. Interpretative Guideline 9 (1987).

¹⁰² *Id.* (emphasis in original).

ital impairments and infants or children with special needs.”¹⁰³ This was rejected by the medical groups on the ground that it would lead to undue intrusion. Instead, the American Academy of Pediatrics made a counterproposal giving enforcement authority to State child protective services agencies, the framework that was eventually adopted.¹⁰⁴ Under the statute as enacted, within 1 year after the act became law, such agencies desiring to receive Federal funds would have to:

have in place for the purpose of 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 service system to pursue any legal remedies, including the authority to initiate legal proceedings in a court of competent jurisdiction, as may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.¹⁰⁵

The Principal Sponsors’ Statement of the Senate sponsors adopted by the conference committee noted that preexisting law required recipient State agencies “to provide certain mechanisms for the reporting of abuse or neglect cases. The same reporting mechanisms and standards set forth in the Act and existing regulations would be applicable to the reporting of cases of medical neglect. . . .”¹⁰⁶

Those preexisting regulations establish a State duty to create classes of individuals legally required to report both known and suspected cases of child abuse and neglect, a State duty to permit all other persons to submit such reports,¹⁰⁷ and a State duty to investigate promptly to substantiate the accuracy of all such reports.¹⁰⁸

The HHS Final Rule implementing the Child Abuse Amendments is largely built on these require-

ments. To ensure that health care facilities take seriously their obligation to designate individuals with the specific responsibility to report known or suspected withholding of medically indicated treatment and to serve as a point of contact and coordination during investigations, it mandates that State agencies contact each health care facility annually to identify the names, titles, and telephone numbers of the designated individuals.¹⁰⁹ It requires that States demonstrate, through statute, regulation, or the opinion of the State attorney general, that their State laws give adequate authority to enable them to prevent violations of the federally defined standard of care.¹¹⁰

Perhaps the most important feature of the Final Rule pertaining to enforcement was its emphasis on providing the mechanisms necessary to ensure an independent medical evaluation of circumstances that give rise to a report of suspected medical neglect. As the American Bar Association’s Model Procedures point out: “The judgment of physician(s) who specialize in the medical problems and disabling conditions of newborn infants is necessary to assess whether reasonable medical judgment was employed in a decision to withhold medical treatment or care from a disabled infant.”¹¹¹ A social worker or other child protective services specialist is rarely equipped to make an accurate judgment about whether legally required treatment is being withheld. Short of outright admissions by medical staff, detection of such withholding normally requires a specialist’s knowledge of the appropriate level of care for the life-threatening condition, so as to judge whether the treatment being accorded by the health care facility falls short of it. Furthermore, a judgment about what care is appropriate necessarily depends on an accurate diagnosis of the child’s condition. Without the assistance of a consultant qualified to make an independent evaluation of that condition, a child protective services worker would in most cases be reduced to relying solely upon the unconfirmed representations of the very physicians whose conduct is the subject of investigation.¹¹²

¹⁰³ Gerry & Nimz, *supra* note 66, at 344.

¹⁰⁴ *Id.*

¹⁰⁵ 42 U.S.C.A. § 5103(b)(2)(K) (West Supp. 1988).

¹⁰⁶ H.R. Conf. Rep. No. 1038, 98th Cong., 2d Sess. 41, *reprinted in* 1984 U.S. Code Cong. & Admin. News 2947, 2970. It made special mention of the requirement that a guardian *ad litem* be appointed for children in the course of all judicial proceedings relating to abuse or neglect. *Id.*

¹⁰⁷ 45 C.F.R. § 1340.14(c) (1987).

¹⁰⁸ *Id.* § 1340.14(d).

¹⁰⁹ 45 C.F.R. § 1340.15(c)(3) (1987).

¹¹⁰ *Id.* § 1340.15(d)(2)(ii) (1987).

¹¹¹ *Model Procedures, supra* note 46, at 229.

¹¹² The analogy in a more “traditional” child abuse case, one in which someone reports that a neighboring child has been severely beaten by her parents, would be a child protective services

It was recognized, therefore, that the key to effective enforcement would be resort to physicians who were at the same time specialists in the field of treatment alleged to have been denied and persons committed to the standards of treatment embodied in the Federal law. HHS sought to provide them the key tools—access to medical records and the ability to conduct an independent medical examination—necessary to enable them to obtain the information essential to make an independent evaluation. Under this approach, there is no need to find a “smoking gun” in the form of proof that treatment has been intentionally denied in order to cause the child’s death. It need only be determined, by the consulting expert or experts, that in order to meet the federally defined standard of care, the child needs treatment she or he is not getting.

worker restricted to asking the parents to describe the child’s wounds, without being able to look at the child.

Accordingly, the Final Rule required that State agencies specify procedures they will employ to obtain access to medical records when necessary for an appropriate investigation of a report of medical neglect, and a court order for an independent medical examination when necessary for an appropriate resolution of such a report.¹¹³

Conclusion

The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

¹¹³ 45 C.F.R. §1340.15(c)(4) (1987). The regulation permitted States to show that they may obtain an independent medical examination in some manner other than with a court order.

Constitutional Issues

Since the record developed by the Commission demonstrates that persons with disabilities have been denied necessary medical care on the basis of their disabilities,¹ and that neither Federal, State, nor local protective agencies make it a practice to intervene on their behalf,² two constitutional questions arise:

First: whether constitutional rights are at stake in disputes over the denial of medical treatment for newborns and other persons with disabilities; and **Second:** if so, whether there exist under State and Federal law adequate substantive and procedural safeguards (including a forum) to protect those rights.

Such an inquiry can be obscured by the technical nature of the medical decisionmaking process, the deference the law gives to parental choices alleged to be in the best interests of their children, and the power of the States over matters of family law. Nonetheless, it is important to note that the factual setting of denial of treatment cases is critical to an analysis of their constitutional aspects. Based on the

record developed during the Commission's inquiry, at least four basic types of denial of treatment cases can be identified:³

1. Cases where the denial of treatment reflects the medical judgment of the attending physicians that the treatment would not be useful to the patient, and that the parents or guardians have given a fully informed consent to the denial of treatment;
2. cases where medical professionals present inadequate or prejudiced information concerning the future quality of life of individuals with the particular disability in question, and the refusal by the parent or guardian to consent to otherwise useful treatment is based on such information;
3. cases where medical and other qualified professionals make a full and fair presentation of the child's present medical needs, the limitations associated with the disability, and the rehabilitation and support services resources available, but the parents refuse consent based on either their own view of the future quality of life of individu-

discrimination on the basis of handicap influenced the parental choice to refuse consent. 476 U.S. at 636 & n.22 (Stevens, J., plurality opinion). See also, 476 U.S. at 653-54 & n.7, 656-63 (White, J., dissenting). Given the breadth of the injunction that limits the power of the Secretary of Health and Human Services to intervene under section 504 on behalf of infants with disabilities, it is arguable that *Bowen* itself is a legal development that may have the effect of leaving unregulated acts which do, in fact, "constitut[e] discrimination or a denial of equal protection of the laws under the Constitution, because of race, color, religion, sex, age, handicap, or national origin or in the administration of justice." 42 U.S.C.A. § 1975c(2) (1988). See *Am. Hosp. Ass'n v. Heckler*, 585 F.Supp. 541 (S.D.N.Y., 1984), *aff'd in reliance on* *United States v. Univ. Hosp.*, 729 F.2d 144 (2d. Cir, 1984), 794 F.2d 676 (2d. Cir, 1984). For a full discussion of the *Bowen* case see chap. 6.

¹ See chaps. 1, 9.

² See chaps. 10-12. See also *United States v. Univ. Hosp.*, 729 F.2d 144 (2d Cir. 1984); *Am. Academy of Pediatrics v. Heckler*, 561 F.Supp. 395 (D.D.C. 1983); *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom. State of Indiana on Relation of Infant Doe by Guardian*, No. 482 S139 (Ind. S.Ct, May 27, 1982), No. 482 S.140 (Ind. S.Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

³ That the factual record is significant to a complete understanding of both the statutory and constitutional policy issues which can arise in denial of treatment cases is illustrated by the U.S. Supreme Court's ruling in *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986). Justice Stevens' opinion for the plurality rested its holding that section 504 of the Rehabilitation Act of 1973 did not apply to denial of treatment cases, where parental consent was refused, where there was a lack of a clear factual record that

als with the particular disability in question or their view of the burden that caring for such a child will place on them or their family; and

4. cases where agencies charged with the protection of children or persons with disabilities have reason to believe that a disability, rather than the need for and usefulness of treatment, was the determinative factor in the decision to deny treatment, and the agency declines to intervene, even though it would do so if the child in question did not have a disability.

Part one of this chapter, therefore, examines the nature and extent of the equal protection and procedural due process constitutional rights at stake in the types of denial of treatment cases raised above. Part two examines the interests and rights of parents as potential substantive limitations on the recognition and protection of such rights, and part three discusses the ability and willingness of courts to protect the rights of newborns denied treatment on the basis of disability. The chapter concludes with a discussion of whether or not there is a need for Federal legislative, administrative, or judicial intervention on behalf of newborn children who are denied treatment on the basis of disability.

The Constitutional Rights of Newborn Children with Disabilities

The constitutional right of newborn children to due process and equal protection of the law is not

open to question. Section 1 of the 14th amendment provides in relevant part that:

All persons born or naturalized in the United States and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.⁴

As persons who are also citizens, persons with disabilities, including newborn children,⁵ are entitled to the same legal protection of their lives, physical integrity, and procedural due process rights as infants, children, and adults without disabilities.⁶

Equal Protection of the Laws

The legal standards governing discrimination on the basis of handicap or disability are undergoing rapid development as developments in vocational rehabilitation, biotechnology, and medicine influence changes in public attitudes toward those with disabilities.⁷ Federal law requires, among other things, that any federally funded program or activity must refrain from discriminating against an "otherwise qualified" individual "solely on the basis of his handicap"⁸ and that children with disabilities must be offered equal educational opportunities.⁹ Many

⁴ U.S. CONST. amend. XIV, § 1. Although this language applies only to the States, the Supreme Court has held that "[t]he federal sovereign, like the States, must govern impartially. The concept of equal justice under law is served by the Fifth Amendment's guarantee of due process, as well as by the Equal Protection Clause of the Fourteenth Amendment." *Hampton v. Mow Sun Wong*, 426 U.S. 88, 100 (1976). *Accord*, *United States Dep't of Agriculture v. Moreno*, 413 U.S. 528, 533, n. 5 (1973); *Bolling v. Sharpe*, 347 U.S. 497, 499 (1954).

⁵ *In re Gault*, 387 U.S. 1, 13 (1967) ("[W]hatever may be their precise impact, neither the Fourteenth Amendment nor the Bill of Rights is for adults alone."). *Accord* *Thompson v. Oklahoma*, 108 S.Ct. 2687 (1988) (death penalty for minors); *Goss v. Lopez*, 419 U.S. 565 (1975) (procedural due process). The liberty interests of children are also protected, though, in some cases, to a lesser degree than for adults. *See, e.g.*, *Hazelwood School Dist. v. Kuhlmeier*, 108 S.Ct. 562 (1988); *Tinker v. Des Moines School Dist.*, 393 U.S. 503 (1969); *West Virginia Bd. of Educ. v. Barnette*, 319 U.S. 624 (1943).

⁶ *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985) [hereinafter *Cleburne Living Center*].

⁷ *See, e.g.*, *Cleburne Living Center*, 473 U.S. 432 (1985) (constitutional standard for discrimination against the persons with disabilities in cases involving exclusionary zoning); *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (coverage of funded programs); *Alexander v. Choate*, 469 U.S. 287 (1985)

(application of "disparate impact" theory as a matter of law or regulation); *Smith v. Robinson*, 468 U.S. 992 (1984) (relationship of the Education of the Handicapped Act, 20 U.S.C.A. §§ 1400-1485, (1982) [hereinafter cited as E.H.A.] to section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794 (1982) and the 14th amendment); *Bd. of Educ. v. Rowley*, 458 U.S. 176 (1982) (extent of rights under E.H.A.); *Southeastern Community College v. Davis*, 442 U.S. 397 (1979) (limits on reach of section 504). *See also*, *Americans with Disabilities Act of 1988*, S. 2345, 100th Cong., 2d Sess.

⁸ Section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794 (1988) provides, in relevant part:

No otherwise qualified individual with handicaps. . . shall, solely by reason of his handicap, 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. . . .

See *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (Federal funds need not be given with the "primary objective" of promoting employment to subject the recipient to the requirements of section 504). The definition of the term "handicapped individual" is found in 29 U.S.C.A. § 706(8)(B) (1988): "the term 'individual with handicaps' means. . .any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

State and local laws provide similar protection.¹⁰ The appropriate place to begin¹¹ an analysis of the appropriate equal protection standard for “disability” cases is Congress’ prohibition against discrimination against those with disabilities in federally funded programs, including its expression of particular concern about medical care discrimination against infants with disabilities.¹²

In a series of cases elaborating on various Federal laws governing the rights of persons with disabilities,¹³ the United States Supreme Court has held that the intent of these laws is twofold:¹⁴ to protect those with disabilities from the discriminatory acts of others¹⁵ and to eliminate what might be called “benign neglect” based on “thoughtlessness and indifference.”¹⁶ The Court has also held that discrimination on the basis of disability is a violation of the equal protection clause of the 14th amendment when the government is unable to demonstrate that its rationale for the challenged discriminatory activity is grounded in an unprejudiced evaluation of the differences caused by the disability itself.¹⁷

¹⁰ See, e.g., Fla. Stat. Ann. § 760.10 (West Supp. 1985); N. Dak. Cent. Code §§ 14-02.4-03 to 4-06, 14-02.4-08 (1981); Ohio Rev. Code § 4112.02 (Page 1984); Tenn. Code Ann. § 8-50-103, 104 (1979). Unlike the Federal Government, the States are not constrained by a Federal constitutional requirement that nondiscrimination provisions relating to private sector discrimination on the basis of disability must be tied to a funding source or some matter of Federal concern such as interstate commerce. As a result, they may, and do, prohibit private sector discrimination directly.

¹¹ This is not to say that constitutional and legislative standards are the same, but merely to point out that, whatever the constitutional standard of protection, Congress retains the ability to mandate a minimum level of additional protection which is not otherwise inconsistent with the Constitution. U.S. CONST. amend. XIV, § 5. *Katzenbach v. Morgan*, 384 U.S. 641, 651-52 n.10 (1966).

¹² Child Abuse Amendments of 1984, 42 U.S.C.A. §§ 5101-5103 (Supp. 1988). For a full discussion of the law, see chap. 7.

¹³ See cases cited *supra* note 7.

¹⁴ That the congressional concern was for both the social welfare and the civil rights of persons with disabilities is critically important to an understanding of the Supreme Court’s approach to disability cases, and to the approach taken by this Commission in this report and others. See U.S. Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities* (1983). There is an inherent relationship between civil rights law and social welfare policy, yet they address separate problems. Persons in need of material or economic assistance often need the legal protection afforded by the civil rights laws. Proof of material need, however, is not necessary to state a claim under the civil rights laws.

¹⁵ See *Alexander v. Choate*, 469 U.S. 287 (1985) (holding that section 504 would clearly cover cases of intentional discrimination against the persons with disabilities, but refusing to hold either that the regulations promulgated under the statute are

Cleburne v. Cleburne Living Center

In *City of Cleburne v. Cleburne Living Center*,¹⁸ a unanimous¹⁹ Supreme Court ruled that the equal protection clause forbids exclusionary zoning that would make it impossible for people with mental retardation to live in a neighborhood group home environment.²⁰ The Court began its discussion of the constitutional standards that govern legislation having an adverse impact on the mentally retarded with a review of the general standards that are applicable to cases raising equal protection claims, and held that mental retardation is not a “quasi-suspect classification calling for a more exacting standard of judicial review than is normally accorded economic and social legislation.”²¹ Instead, the Court chose a minimum rationality standard, and highlighted the obvious relationship between the social and constitutional concerns that motivated its choice:

First. . . those who are mentally retarded have a reduced ability to cope with and function in the everyday world. . . . [T]hey range from those whose disability is not immediately evident to those who must be constantly

limited to such cases or that the statute necessarily comprehends the use of “disparate impact” analysis); *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (coverage of funded programs); *Smith v. Robinson*, 468 U.S. 992 (1984).

¹⁶ *Alexander v. Choate*, 469 U.S. 287, 295 & nn. 12-16. (1985). The sources cited in the Court’s footnotes make it clear that a bright line was drawn between “thoughtlessness and indifference” which, though neglecting the needs of the persons with disabilities, might be considered “benign” in that they are not intentional or “invidious”:

To be sure, well-catalogued instances of invidious discrimination against the handicapped do exist. See, e.g., United States Commission on Civil Rights, *Accommodating the Spectrum of Individual Abilities*, Ch. 2 (1983); Wegner, *The Antidiscrimination Model Reconsidered: Ensuring Equal Opportunity Without Respect to Handicap Under Section 504 of the Rehabilitation Act of 1973*, 69 *Cornell L. Rev.* 401, 403 n.2 (1984).

469 U.S. at 295, n. 12. Intentional neglect of the needs of persons with disabilities—such as denying food and water (nutrition and hydration) or necessary medical care because the disability is alleged to cause a diminished quality of life—are not “benign.”

¹⁷ *Cleburne Living Center*, 473 U.S. 432 (1985).

¹⁸ 473 U.S. 432 (1985).

¹⁹ Justice Stevens and Chief Justice Burger joined the opinion of the Court, but also filed a concurring opinion advocating a new single tier standard for equal protection analysis. Justices Brennan and Marshall filed an opinion concurring in part and dissenting in part, which argues that the proper standard for disability cases is heightened scrutiny, and that the ordinance should have been declared invalid on its face.

²⁰ See chap. 4.

²¹ *Cleburne Living Center*, 473 U.S. at 442. For a general discussion of these standards, see *supra* note 7.

cared for. They are thus different, immutably so, in relevant respects, and the States' interest in dealing with and providing for them is plainly a legitimate one. How this large and diversified group is to be treated under the law is a difficult and often a technical matter, very much a task for legislators guided by qualified professionals and not by the perhaps ill-informed opinions of the judiciary. Heightened scrutiny inevitably involves substantive judgments about legislative decisions, and we doubt that the predicate for such judicial oversight is present where the classification deals with mental retardation. . . .²²

Because mental retardation is a characteristic that the government may legitimately take into account in a wide range of decisions, and because both state and federal governments have recently committed themselves to assisting the retarded, we will not presume that any given legislative action, even one that disadvantages retarded individuals, is rooted in considerations that the Constitution will not tolerate.²³

Although the practical effect of the Court's refusal to deal with equal protection cases involving persons with disabilities at a heightened level of scrutiny is arguably to make it more difficult to challenge State or Federal policies that are alleged to be discriminatory, the majority opinion by Justice White makes it clear that "refusal to recognize the retarded as a quasi-suspect class does not leave them entirely unprotected from invidious discrimination."²⁴ Even though the Court refused to "presume that any given legislative action, [including] one that disadvantages retarded individuals, is rooted in considerations that the Constitution will not tolerate,"²⁵ the standard actually applied in *Cleburne* is quite similar to that applied in gender cases: it explicitly requires lower courts to focus on the real reasons behind the challenged unequal treatment and

²² *Cleburne Living Center*, 473 U.S. at 442-43 (footnotes omitted).

²³ *Id.* at 446 (footnotes omitted).

²⁴ *Id.* at 446. Justice White's opinion for the Court was joined by Chief Justice Burger and Justices Powell, O'Connor, Rehnquist, and Stevens.

The lower court opinions in *Cleburne Living Center* are instructive as to the operation of the standards of review in practice. The district court was criticized by the Fifth Circuit for using a "minimum rationality" test to uphold the ordinance, both on its face and as applied. The Court of Appeals for the Fifth Circuit held that the proper equal protection test was "heightened scrutiny," and ruled that the ordinance was invalid, both on its face and as applied. 726 F.2d 191 (1984).

²⁵ *Cleburne Living Center*, 473 U.S. at 446.

²⁶ The area in question was zoned "R-3" (apartment house district) and the ordinance permitted the following uses:

1. Any use permitted in District R-2.
2. Apartment houses, or multiple dwellings.
3. Boarding and lodging houses.

to analyze whether the discriminatory policy is actually related to a legitimate government purpose.

The Supreme Court undertook such an analysis in *Cleburne* and found that the zoning ordinance²⁶ was invalid under the equal protection clause. It found that the reason for the discriminatory treatment was "the negative attitude of the majority of the property owners located within 200 feet of the . . . facility, as well as the fears of elderly residents of the neighborhood."²⁷ In short: "an irrational prejudice against the mentally retarded."²⁸

Denial of Treatment to Newborn Children with Disabilities

The record of the Commission's inquiry leaves no doubt that newborn children have been denied food, water, and medical treatment solely because they are perceived to be disabled. It is undisputed that the purpose of the denial of treatment was to end the lives of these children because of social, economic, or eugenic factors unrelated to the child's medical need or ability to benefit from the proposed treatment. In some cases, the discriminatory denial of treatment was based on ignorance and false stereotypes about the "quality of life" of persons with disabilities, and in others, about the nature of the particular disability the child would have if he or she were permitted to survive. The testimony of Dr. Walter Owens, the physician who treated the original Baby Doe in Bloomington, Indiana,²⁹ illustrates the point.

COMMISSIONER DESTRO. . . How was the issue of recommending [a] course of treatment posed to the parents?

4. Fraternity or sorority houses and dormitories.
5. Apartment hotels.
6. Hospitals, sanitariums, nursing homes or homes for convalescents or aged, other than for the insane or feeble-minded or alcoholics or drug addicts.
7. Private clubs or fraternal orders, except those whose chief activity is carried on as a business.
8. Philanthropic or eleemosynary institutions, other than penal institutions.
9. Accessory uses customarily incident to any of the above uses.

Cleburne Living Center, 473 U.S. at 436 n.3.

²⁷ *Id.* at 448.

²⁸ *Id.* at 450.

²⁹ *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.* State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S.Ct. May 27, 1982), No. 482 S.140 (Ind. S.Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

DR. OWENS. I think that's a little distortion. They were not recommended courses of treatment but simply alternatives. As I indicated earlier, the pediatrician and Dr. Schafer and the family physician, Dr. Wenzler, were simply saying to them, "This child must go to Riley Hospital to be operated on tonight." I'm not sure they even mentioned the Down's syndrome or they certainly downplayed it and were giving the impression to the family that surgery would make the child okay. Those were their words: "The baby will be okay."

My words to the family were simply, as I said before, that "I think you must realize that if the child has the surgery, and if the surgery is successful, that this child will still be a Down's syndrome child with all that that implies," and as I indicated earlier, the parents were pretty well-acquainted and had a good knowledge of what this implied. I said to them, "There is the alternative of doing nothing, in which case the child will survive a few days and will die." These were not recommendations in that sense at all. These were alternatives presented to the family of what could be done. They chose not to treat the child.

COMMISSIONER DESTRO. Is it fair to say, then, that the decision not to treat was based on the fact that the child had Down's syndrome?

DR. OWENS. I think it was, and all that this implied. In other words, that the gain, if you want to say this, that to go through all of this, to treat such a child with everything that's involved in that, and then to do all that with such a dreary, hopeless outlook as to the future, the parents felt this was not indicated either for themselves or the child.³⁰

The significance of Dr. Owens' approach to the treatment of persons with disabilities was echoed in the statements of other witnesses, and therein lies the crux of the constitutional problem. It occurs in light of a history of discrimination against persons with mental disabilities that has been described by each Justice of the United States Supreme Court as "grotesque."³¹ More important, what is at stake in denial of treatment cases is not merely "equal protection of the laws" but protection of life itself.³²

Thus, when medical care decisionmaking is based on little more than personal experience and hearsay regarding the capabilities and 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

³⁰ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights*, 228–29 (1986) (vol. II).

³¹ *Cleburne Living Center*, 473 U.S. at 438, 454 (Stevens, J., concurring), 461 (Marshall, J., concurring and dissenting in part).

forbids government action that either rests on such stereotypes or affirms them.

Procedural Due Process

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 the fairness and lawfulness of the proposed deprivation. The procedure required is determined by weighing several factors:

First, the private interest that will be affected by the official action; second, the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any, of additional or substitute procedural safeguards; and finally, the Government's interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirements would entail.³³

Disabled infants who are denied food, water, and medical care on the basis of their disability are denied both life and liberty. At a minimum, the 5th and 14th amendments require that they be afforded procedural due process, but in many of the cases brought to the Commission's attention, there was no procedural protection afforded at all. Potential advocates for the child were not identified and notified of the denial of treatment, nor were they given adequate opportunity to present the case for providing care that children without disabilities would be provided as a matter of course.

A thorough evaluation of the type of procedural protection that should be provided is beyond the scope of the Commission's inquiry, but the factors addressed by the Supreme Court in *Mathews v. Eldridge*³⁴ counsel that careful and informed evaluation of each case by independent and disinterested decisionmakers is required.³⁵ Evidence in the record supports a finding that the risk of erroneous determinations regarding the nature and extent of future disability is extremely high. The record also supports a finding that children have been deprived of treatment based on both uninformed and biased

³² See *Furman v. Georgia*, 408 U.S. 238, 272 (1972) (Brennan, J., concurring) (the right to life is the "right to have rights").

³³ *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976).

³⁴ 424 U.S. 319 (1976).

³⁵ See chaps. 10–13.

medical advice. Given the magnitude of the child's interest and the risk of error to life and health, no argument has been made that there even exists a substantial government financial interest that would preclude a hearing.³⁶ Instead, it has been argued that the private nature of most medical care decisionmaking, as well as the substantial deference accorded parents in the care and upbringing of their children counsels against government intervention on behalf of newborn children with disabilities.

Factors Limiting the Rights of Newborn Children with Disabilities

Relevance of "Privacy"

Although the term "privacy" appears in several State constitutions,³⁷ it does not appear in the Constitution of the United States. As commonly understood in constitutional law, the term "privacy" refers to two distinct concepts: (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

³⁶ There are, in fact, existing mechanisms for such hearings. The question for present purposes is whether they should be required as a matter of procedural due process. See chaps. 10-13.

³⁷ E.g., ARIZ. CONST. art. II, sec. 8; FLA. CONST. art. I, sec. 23 (1980) WASH. CONST. art. 1, sec. 7.

³⁸ See generally, *Whalen v. Roe*, 429 U.S. 589 (1977).

³⁹ U.S. CONST. amend. IV: "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probable cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized."

⁴⁰ U.S. CONST. amend. XIV, sec. 1: "nor shall any State deprive any person of life, liberty, or property, without due process of law; . . ."

⁴¹ See, e.g., *Meyer v. Nebraska*, 262 U.S. 390 (1923) (autonomy to make educational decisions; invalidating State law which forbade teaching any language other than English); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (autonomy of married persons to use contraceptives; invalidating State laws prohibiting the use of birth control devices); *Roe v. Wade*, 410 U.S. 113 (1973), *reh'g denied*, 478 U.S. 1039 (1986) (autonomy to choose abortion; invalidating State laws protecting the unborn). *But see Bowers v. Hardwick*, 478 U.S. 186 (1986), *reh'g denied* 410 U.S. 959 (1973) (refusing to recognize autonomy of homosexuals to engage in consensual sodomy, but reserving decision with respect to sodomy by married couples).

⁴² E.g., *Am. Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402-03 (D.D.C. 1983) (dictum). Another example is found in *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674, 682 (1987) in which the Arizona Supreme Court construed article 2, section 8, of the Arizona Constitution, which provides that "No person shall be disturbed in his private affairs, or his home invaded, without authority of law," to include the right of a competent adult to grant another a proxy to refuse medical treatment on the grantor's behalf should he or she become incompetent.

(e.g., marriage, sex, childbearing).³⁸ The protection for the locational aspect of privacy is found in the 4th amendment,³⁹ whereas the due process clause of the 14th amendment⁴⁰ is generally held to be the basis of the rights of individual autonomy that the United States Supreme Court has recognized over the years.⁴¹ It is in the latter sense—individual autonomy—that the term "right to privacy" is used in cases involving the right to refuse medical treatment for oneself or others.⁴²

Control and Upbringing of Children

It has long been held that parents have constitutionally protected interests in the custody, care, and control of the upbringing of their children.⁴³ It is also well-settled that the government may override parental decisions when the life, health, or safety of the child is endangered.⁴⁴ The reluctance of courts to intervene in disputes involving parental authority over children is evident in several of the reported cases involving denial of medical treatment to infants and children with disabilities.⁴⁵ Nevertheless,

⁴³ See, e.g., *Smith v. Org. of Foster Families*, 431 U.S. 816 (1977); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (education); *May v. Anderson*, 345 U.S. 528 (1953) (custody); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); (education); *Behn v. Timmons*, 345 So.2d 388, 389 (Fla. App. 1977) ("a natural, God-given right"); *New Hampshire v. Robert H.*, 118 N.H. 713, 393 A.2d 1387 (1978). See generally, B.C. Hafen, *The Constitutional Status of Marriage, Kinship, and Sexual Privacy—Balancing the Individual and Social Interests*, 81 Mich. L. Rev. 463 (1983).

⁴⁴ See, e.g., *Prince v. Massachusetts*, 321 U.S. 158 (1944) (child labor). In *In re Rinker*, 117 A.2d 780 (Pa. Super. 1955), for example, the court discussed the policy considerations supporting involuntary deprivation of child custody for neglect as follows:

It is a serious matter for the long arm of the state to reach into a home and snatch a child from its mother. It is a power which a government dedicated to freedom for the individual should exercise with extreme care, and only where the evidence clearly establishes its necessity. . . .

Under our system of government children are not the property of the state to be reared only where and under such conditions as officials deem best.

The power of the juvenile court is not to adjudicate what is for the best interests of a child, but to adjudicate whether or not the child is neglected. *In re Rose Child Dependency Case*, 161 Pa. Super. 204, 208, 54 A.2d 297 (1947).

Accord *Petition of Kauch*, 358 Mass. 327, 264 N.E.2d 371 (1970). *Cf.*, *In the Matter of Baby M*, 109 N.J. 396, 537 A.2d 1227 (1988) (rejecting both the right of parental consent and an absolute right of procreational autonomy where important State and child interests are at stake.) See generally, Thomas, *Child Abuse and Neglect Part I: Historical Overview, Legal Matrix, and Social Perspectives*, 50 N.C. L. Rev. 293 (1972); Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 Stan. L. Rev. 1383 (1974).

⁴⁵ See, e.g., *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610 (1986); *United States v. Univ. Hosp.*, 729 F.2d 144 (2d Cir. 1984); *Am.*

the Supreme Court's concern for parental prerogatives has always been tempered by the recognition that there is broad legislative authority to protect children from the misguided, negligent, or harmful acts of parents.⁴⁶

Parental Autonomy and Medical Decisionmaking

The testimony developed during the course of the Commission's two hearings on the protection of newborns with disabilities left no doubt that parental choice in medical decisionmaking is strongly influenced by attitudes and prejudices reflected in the suggestions of attending physicians, medical staff, and others close to the family, such as clergymen and other family members.⁴⁷ Parents generally strive to act in the best interests of their children, whether those children have disabilities or not, and seek out medical advice to assist them in the difficult decisionmaking process which surrounds any medical care decision of consequence.⁴⁸ Thus, the first situation described in the introduction to this chapter—fully informed parents who refuse consent to medical treatment that is either not useful or burdensome to their child—was not the subject of any part of the Commission's inquiry.

It is only when parents are alleged to be neglecting the child's health interests that the cause for governmental intervention on behalf of the child arises. To speak of parental or familial autonomy or "privacy" in such a situation would be to argue that governmental intervention is inappropriate even in the face of a charge of parental neglect. The fact that the child is born with a disability does not change the analysis.

The significant issues for constitutional purposes arise when parental or guardian refusal to consent to medical treatment for a person with a disability is not based on a medically defensible difference of opinion about the harmful or useless nature of the proposed treatment. Instead, it is based on either: (1) lack of adequate, accurate information about the disability itself; or (2) irrational or negative attitudes and prejudices about the quality of life of persons

with disabilities generally, or of persons with similar disabilities.⁴⁹

The record explicitly supports a finding that medical care decisions affecting persons with disabilities—particularly mental disabilities—are strongly influenced by a lack of adequate information about such important matters as rehabilitation opportunities, costs, and community support.⁵⁰ Physicians and medical personnel often do not provide the information parents need, and many times the information that is provided is simply wrong or out of date.⁵¹ State child protective agencies have an educational intervention role to play in such cases.⁵² In the small, but significant, number of cases that are also influenced by negative attitudes about persons with disabilities,⁵³ State refusal to intervene to protect their interests raise serious equal protection problems.

The medical neglect statutes discussed in chapters 5 and 7 address each of these concerns, and they need not be repeated here. The important point is that parental and legal guardianship rights to make medical care decisions for dependent persons are subject to government oversight on behalf of the dependent. There is simply no other way to protect a dependent's interests.

For purposes of making policy, however, the difference between an argument based on an alleged constitutional right to parental autonomy and one based on the common law or statutory right of parents or guardians to refuse medical treatment is that the autonomy argument is far broader. In a case asserting the common law or statutory right to refuse treatment, the best interests of affected individuals are the central issues, and appropriate guidelines can be written to protect both the parental or guardianship relationship and the interests of the child or ward. As a matter of common or judge-made law, such standards can be modified in whole or in part by legislation. Constitutional rights to privacy (autonomy), however, operate as limits on the power of the government to make any regula-

Academy of Pediatrics v. Heckler, 561 F.Supp. 395 (D.D.C. 1983); Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 456 N.E.2d 1186 (1983), *aff'g*, 95 A.D.2d 587, 467 N.Y.S.2d 685 (App. Div. 2d Dept. 1983); *In re Phillip B., A Minor*, No. 66103 (Super. Ct., Santa Clara County, Cal., Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796 (1979), *cert. denied*, 445 U.S. 749 (1980).

⁴⁶ Parham v. J.R., 441 U.S. 584 (1979); Prince v. Massachusetts, 321 U.S. 158 (1944).

⁴⁷ See chap. 2.

⁴⁸ *Id.*

⁴⁹ See, *supra*, text accompanying notes 13-16 (distinguishing between actions based on "thoughtlessness and indifference" and those based on prejudice).

⁵⁰ See chaps. 2, 3, and 9.

⁵¹ See chaps. 2 and 3.

⁵² See chap. 10.

⁵³ See chaps. 1-4 and 9.

tions at all regarding the subject matter.⁵⁴ Decisions based squarely on constitutional concepts of parental autonomy reflect a policy position that seeks to remove the issues from legislative or executive competence altogether.⁵⁵ Such a proposition finds little, if any, support in the case law.⁵⁶

“Substituted Judgment”: The Right to Refuse Medical Treatment by Proxy

Often raised in denial of treatment cases is the right of an individual to consent to or refuse medical treatment. This right, however, is not absolute, even for a competent adult who seeks to refuse personal treatment.⁵⁷ It must give way in the face of important governmental interests in protecting others:

1. The preservation of life;
2. the protection of interests of innocent third parties (e.g., children and other dependents);
3. the prevention of suicide; and
4. the maintenance of the ethical integrity of the medical profession.⁵⁸

In the case of newborns with disabilities, this interest manifests itself in the principle that parents and legal guardians may give or withhold consent to medical treatment for their children or wards, subject to the power of the government to prevent medical neglect.⁵⁹ By definition, an infant is incapa-

ble of making individual decisions or exercising autonomy. Thus, to the extent that courts might rely on the infant's asserted right to individual autonomy as the basis for parental decisionmaking,⁶⁰ such courts are operating in the realm of legal fiction.⁶¹

Issues of Cost

Because the issues in deprivation of treatment cases involve such a massive deprivation of life and liberty in the form of withholding food, water, and needed medical treatment, the cost of such treatment alone is an insufficient reason for denial of treatment. There is no question that the added financial and other burdens that a child with a disability may place on other members of the family are serious issues of social welfare policy,⁶² but these burdens alone cannot justify deprivation of life through either design or neglect.

The Ability and Willingness of Courts to Provide Protection

Although the Supreme Court has held that persons with mental retardation are not entitled to the benefit of “heightened [judicial] scrutiny” when they complain of discriminatory treatment by the government,⁶³ the Court was motivated by concern that legislative and administrative judgments affecting persons with mental retardation involve sensitive

⁵⁴ Cf. *In the Matter of Baby M*, 109 N.J. 396, 537 A.2d 1227 (1988) (holding that where important interests of the child are at stake, parental consent is not the determinative consideration; rejecting absolute right of procreational autonomy which would support an absolute parental discretion over the health and welfare of the child).

⁵⁵ See, e.g., *In re Peter*, 108 N.J. 365, 529 A.2d 419, 427 (1987) (decided on nonconstitutional grounds); *In re Colyer*, 99 Wash.2d 114, 119–21, 660 P.2d 738 (1983) (decided, in part, on constitutional grounds). For an interesting discussion of the relationship between the concepts of consent and constitutionally based privacy or autonomy, see *In the Matter of Baby M*, 109 N.J. 396, 468 n.16, 537 A.2d 1227 (1988).

⁵⁶ See, e.g., *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1976) (parents' statutory right to refuse consent to minor's abortion overridden on constitutional grounds); *Prince v. Massachusetts*, 321 U.S. 158 (1944) (State interest in health of children outweighs guardian's right to employ the child in a manner the State has determined to be harmful). See also cases cited *supra* note 55.

⁵⁷ *In re Conroy*, 98 N.J. 321, 346, 348–54, 486 A.2d 1209, 1222, 1223–26 (1985). See also *Roe v. Wade*, 410 U.S. 113 (1973) (rejecting absolute right to control one's body).

⁵⁸ E.g., *Brophy v. New England Sinai Hosp.*, 398 Mass. 417, 497 N.E.2d 626, 634 (1986). See also *In re A.C.*, 533 A.2d 611 (D.C. App. 1987) *reh'g granted en banc*, 539 A.2d 203 (D.C. App. 1988) (protection of others); *In re E.G., a Minor*, 161 Ill. App. 3d 765, 515 N.E.2d 285 (1987) (prevention of suicide: right of minor to reject blood transfusion for religious reasons).

⁵⁹ See chap. 5.

⁶⁰ See, e.g., *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716, 722–23 (1984); *In re P.V.W.*, 424 So.2d 1015, 1020 (La. 1982).

⁶¹ *In re Conroy*, 98 N.J. 321, 486 A.2d. 1209, 1246 (1985) (Handler, J., dissenting).

⁶² While it is also possible to argue that resource allocation issues affecting persons with disabilities should also be analyzed under the equal protection clause, such arguments are beyond the scope of the analysis presented here. There has been considerable debate among Supreme Court Justices concerning the propriety of using the equal protection clause to analyze eligibility criteria for social welfare programs. Compare, e.g., *San Antonio Indep. School Dist. v. Rodriguez*, 411 U.S. 1 (1973) (guarantee does not prohibit classifications having differential impact on the poor), with, e.g., *Dandridge v. Williams*, 397 U.S. 471, 521 (1970) (Marshall, J., dissenting) (when analyzing classifications affecting receipt of governmental benefits, a court must consider “the character of the classification in question, the relative importance to individuals in the class discriminated against of the governmental benefits that they do not receive, and the asserted state interests in support of the classification.”). See also *Plyler v. Doe*, 457 U.S. 202 (1982) (though guarantee does not prohibit classifications based on aliens' legal status, State refusal to permit undocumented alien children to attend public schools is invalid). The discussion presented here, however, deals only with denial of either treatment or legal protection usually available to all on the basis of simple need.

⁶³ *Cleburne Living Center*, 473 U.S. 432, 443 (1985).

policy judgments related to their needs.⁶⁴ The Court's deference to legislative judgment, however, places a particularly heavy burden on Congress and the State legislatures to protect the rights and interests of persons with disabilities by statute.

State Action Issues

The obligations of decisionmakers whose actions are fairly attributable to the government⁶⁵ are governed directly by the Constitution. Among those whose actions are subject to scrutiny under the equal protection and due process clauses are: (1) Federal,⁶⁶

State, and local hospitals and their employees (including staff physicians when their decisions are governed by hospital policy),⁶⁷ even though the action in question is taken at the request of the parents;⁶⁸ (2) State and local child protective agencies; (3) Federal, State, and local agencies charged with the enforcement of laws prohibiting discrimination on the basis of disability; and (4) State and Federal courts.

Although the Supreme Court's "state action" jurisprudence has been described as a "conceptual disaster area" and "a 'doctrine' without shape or line,"⁶⁹ several of its holdings are relevant to questions involving discriminatory denials of medical care by physicians. First, and perhaps most important, substantial government funding or regulation of an institution, program, or activity will not transmute what is otherwise a private decision into one which "may be fairly treated as that of the state itself."⁷⁰ The key is whether the decisionmaker is acting in his or her private capacity. In *Blum v. Yaretsky*,⁷¹ for example, the plaintiffs complained that physicians responsible for the discharge or transfer of Medicaid patients were "state actors"

because their activities were almost fully subsidized by government. The Court stated:

[A]lthough the factual setting of each case will be significant, our precedents indicate that a state normally can be held responsible for a private decision only when it has exercised coercive power or has provided such significant encouragement, either overt or covert, that the choice must in law be deemed to be that of the state.⁷²

Thus, while the facts in each case must be examined to determine whether or not physicians and other medical care personnel are chargeable with constitutional violations if they engage in discrimination in the provision of medical care,⁷³ it goes without saying that when State child protective agencies, civil rights enforcement agencies, and courts act or fail to act on the grounds that an individual has a disability, such acts or omissions are subject to examination under the equal protection clause. The more difficult question arises when the government knowingly acquiesces in private discrimination or deprivations of life and liberty.⁷⁴ There are circumstances where the Court has held that government inaction—declining to act to prevent private conduct—may constitute government action, particularly where there is some indication of public encouragement of the private conduct in question.⁷⁵ As the Supreme Court noted in *Palmore v. Sidoti*: "The Constitution cannot control such [private] prejudices, but neither can it tolerate them. Private biases may be outside the reach of the law, but the law cannot, directly or indirectly, give them effect."⁷⁶

Conclusion

The record developed during the Commission's two hearings and continuing investigation demon-

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794 (Supp. 1988), however, protects an "otherwise qualified handicapped individual" from discrimination or denial of benefits "solely by reason of his handicap. . . under any program or activity receiving Federal financial assistance. . . ."

⁷¹ 457 U.S. 991 (1982).

⁷² *Id.* at 1004.

⁷³ *Burton v. Wilmington Parking Auth.*, 365 U.S. 715, 722 (1961) ("Only by sifting facts and weighing circumstances can the nonobvious involvement of the State in private conduct be attributed its true significance.")

⁷⁴ *See, e.g., Deshaney v. Winnebago County Dep't of Social Services*, 812 F.2d 298 (7th Cir., 1987) *cert. granted*, 108 S.Ct. 1218 (1988) (No. 87-154).

⁷⁵ *See, e.g., Reitman v. Mulkey*, 387 U.S. 369 (1967); *Shelley v. Kraemer*, 334 U.S. 1 (1948).

⁷⁶ 466 U.S. 429, 433 (1984).

⁶⁴ *See supra*, text at notes 13-15.

⁶⁵ *See supra* notes 7-10.

⁶⁶ *See supra* note 3.

⁶⁷ *See, e.g., Johnson v. Sullivan*, Civ. No. 85-2434 A (W.D. Okla., filed Oct. 3, 1985). *See also, S. Paulus, Suit Filed in Oklahoma Alleging Twenty-Four Infants Died After Being Denied Beneficial Medical Treatment*, 1 Issues in L. & Med. 321 (1986).

⁶⁸ *Parham v. J.R.*, 442 U.S. 584, 606-07 (1979).

⁶⁹ C. Black, *State Action, Equal Protection and California's Proposition 13*, 81 Harv. L. Rev. 69, 95 (1967).

⁷⁰ *Jackson v. Metropolitan Edison Co.*, 419 U.S. 345, 351 (1974) (extensive regulation); *Blum v. Yaretsky*, 457 U.S. 991 (1982) (State subsidy of more than 90 percent of the medical expenses of patients insufficient). "The ultimate issue in determining whether a person is subject to suit under [42 U.S.C.A.] § 1983 is the same question posed in cases arising under the Fourteenth Amendment: is the alleged infringement of federal rights 'fairly attributable to the state?'" *Rendell-Baker v. Kohn*, 457 U.S. 830 (1982), *citing* *Lugar v. Edmundson Oil*, 457 U.S. 922, 938 (1982).

strates that there is a grave danger to the constitutional rights of newborn children in cases where food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. 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

⁷⁷ 476 U.S. 610 (1986).

often absent completely or is woefully inadequate to the task of sifting the facts.

Since the Supreme Court's decision in *Bowen v. American Hospital Association*,⁷⁷ it has been clear that judicial action is insufficient to protect newborn children with disabilities. The task of protecting such children from discrimination and neglect, whether based on ignorance or outright prejudice, thus falls to Congress and to the State legislatures.

The Incidence of Discriminatory Denial of Medical Treatment

How frequently in contemporary America are people denied medical treatment for treatable life-threatening conditions, or life-preserving food and fluids, because they have disabilities? The answer to this question is of great importance. If discriminatory denials of treatment in general occur only in isolated and unusual instances, the need for any government intervention in treatment decisions might be questioned, especially the need for a Federal role. If it were the case that there was a significant incidence of such discrimination before the effective date of the Child Abuse Amendments of 1984,¹ but that since then the incidence had greatly shrunk, that might imply that the amendments themselves are adequate to address the situation and that they are being effectively enforced. Such conclusions would suggest that there is little need for a change in the status quo.

Suppose, on the other hand, the evidence shows that there has been a significantly high incidence of medical discrimination against children with disabilities that is part of a much larger pattern of medical care discrimination against people with disabilities generally, and that this incidence largely persists despite 3 years of experience under the Child Abuse

Amendments. Such a conclusion would suggest a need to examine critically the current approach to implementing the amendments with a view to seeing how it might be improved and whether other instruments are needed to protect the medical treatment rights of children with disabilities.

Difficulties of Estimation

Any attempt to quantify denial of treatment, now or in the recent past, is subject to inherent limitations. When health care personnel and parents agree to reject a course of lifesaving 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.² There have been isolated instances of treatment denials being publicly announced in medical journal articles, including one article that reported decisions to withhold lifesaving treatment from a number of newborn children with disabilities at Yale-New Haven Hospital in the early 1970s³ and another describing similar decisions at Children's Hospital of Oklahoma in the 1980s.⁴ The physicians who authored these articles were crusading for open acceptance of denial of treatment practices by their fellow professionals.⁵

¹ 42 U.S.C.A. §§ 5101-5103 (West Supp. 1988). The 1984 law, discussed in detail in chap. 7, established standards of treatment for children with disabilities in all States that receive Federal funds for their child abuse and neglect programs.

² Nor is it usually reported to others within the hospital, such as members of an infant care review committee. A study of such committees in 10 hospitals in eight cities found that only one "requires [committee] review of any case where withdrawal of life support is proposed." Office of Inspector General, Department of Health and Human Services, *Infant Care Review Committees Under the Baby Doe Program* ii (1987). The other nine review such cases only when there is disagreement between the treating physician and parents or "the treating physician

requests advice." *Id.* Nor may incidence easily be estimated based on records from retrospective reviews of such instances. Only two of the committees studied have or are planning to have retrospective review of "selected" cases, although patient deaths may be reviewed by other quality assurance committees. *Id.* at 5.

³ Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 *New Eng. J. Med.* 890 (1973).

⁴ Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 *Pediatrics* 450 (1983).

⁵ For example, the Oklahoma health care personnel stated: "[D]ocumented suffering. . . is not only reduced but prevented, if one is persuaded that death is preferable to life under certain

Disincentives to Whistle Blowing

Denial of treatment cases typically come to public attention only when a "whistle blower"—usually a health care professional⁶ or a family member⁷ who is convinced the denial of treatment is wrong—reports the matter to a public agency or other rights advocate.⁸

There are substantial disincentives to whistle blowing whether it takes place among health care personnel or in the general population. A recent study of whistle blowers by Donald and Karen Soeken found that all of those studied who blew the whistle in the private sector lost their jobs. One-fifth of those surveyed (who also included Federal Government employees) were without jobs at the time of the study; 86 percent had "negative emotional consequences, including feelings of depression, powerlessness, isolation, anxiety and anger"; and 80 percent had physical deterioration. Mr. Soeken, a psychiatric social worker with a doctorate in human development, concluded (as paraphrased by a reporter) that "[T]here is so much retaliation against known whistle blowers [because]. . . it is associated with cultural taboos against tattling."⁹

Mr. Soeken said there are seven stages of life for the whistle blower: discovery of the abuse, reflection on what action to take, confrontation with superiors, retaliation, the long haul of legal or other action involved, termination of the case, and going on to a new life. "The last stage is the most difficult to reach," he said, "and most [of] them don't reach it."¹⁰

Bill Bush, himself a whistle blower who was demoted, maintains a computer file on whistle

circumstances. . . it is prima [facie] irresponsible to obtain knowledge about the results of surgery on high risk infants and then not to use the negative results in informing the parents and others of the consequences of surgery." *Id.* at 451, quoting with approval Fletcher, *Spina Bifida with Myelomeningocele: A Case Study in Attitudes Towards Defective Newborns*, in *Decision Making and the Defective Newborn* 281 (C. Swinyard ed. 1978).

⁶ Health care professionals did so in the "Baby Jane Doe" case. *Lawyer Fights on For Baby Doe*, USA Today, Dec. 13, 1983, at 2A, col. 1.

⁷ A family member did so in *In re T.A.P.*, No. 03231186 (Milwaukee County, Wis. Cir. Ct. July 31, 1987), *rehearing* (Aug. 12-13, 1987), a case involving denial of surgery to a child with spina bifida. Telephone interview with Thomas C. Potter, Assistant District Attorney, Milwaukee County, Wis. (Nov. 25, 1988).

⁸ Occasionally, unusual circumstances bring a case to public attention in other ways. In a Minnesota case, *In re Steinhaus*, No. J-86-92 (Minn. Redwood County Ct., Juv. Div. Sept. 11, 1986), *reprinted in* 2 *Issues in L. & Med.* 241 (1986), the child to whom treatment was being denied was in the legal custody of a child

blowers with 8,500 entries. "When individuals phone him with dark secrets he exhorts them to keep quiet unless they're independently wealthy. 'I want to emphasize this one thing,' he says. 'Whistle blowing is dangerous. I've seen people bloodied. And it's not going to get easier to do. Nobody wants a snitch.'" ¹¹ Sociology Professor Myron Peretz Glazer, an expert on whistle blowers, observes, "They break the unwritten law of social relationships. . . They break a norm—the norm of loyalty."¹²

These realities lead to the conclusion that counting the number of reported or publicized cases alone would underestimate the incidence of discriminatory denial of treatment. It is probable that such cases represent only the tip of the iceberg. It is necessary to turn, therefore, to methods other than counting the reported cases.

Surveys of Physician Attitudes

One method of judging the prevalence of denial of treatment is by examining the attitudes of treating physicians and other health care personnel. Although surveys of attitudes toward denial of treatment do not provide direct evidence of the number of actual cases, the statements of health care professionals do establish that a significant proportion of them would participate in denial of treatment in certain circumstances. Two surveys of pediatricians published in 1988 suggest that contemporary denial of treatment is not infrequent.

The November 1988 issue of the *Journal of Pediatrics* contains a report on a poll undertaken to learn how pediatricians would influence treatment

abuse agency (although the agency had placed him with his mother) because of previous abuse by his father. For that reason, the agency received information about the treatment denial. Telephone interview with Michael H. Boyle, attorney for Lance Steinhaus (Dec. 1, 1988). In the Idaho "Baby Ashley" case, the proposed denial of treatment evoked public attention and agency intervention because the child—whose disability was not initially apparent—was found in a trash can shortly after birth, an event that made the headlines and led to reporters' putting a spotlight on the case. Medical professionals openly deplored the public attention, and agency involvement focused on them because they believed that without the publicity treatment could have been quietly withheld. Telephone interview with James Baugh, Managing Attorney, Coalition of Advocates for the Disabled, *amicus curiae* in the case (Dec. 1, 1988).

⁹ Farnsworth, *Survey of Whistle Blowers Finds Retaliation but Few Regrets*, New York Times, Feb. 22, 1987, at 22, cols. 1-5.

¹⁰ *Id.* at col. 5.

¹¹ Kleinfeld, *The Whistle Blowers' Morning After*, New York Times, Nov. 9, 1986, sec. 3, at 1, col. 2, at 10, col. 2.

¹² *Id.* at 10, col. 2.

decisions based on the presence of varying degrees of hydrocephalus in children born with spina bifida.¹³ The subjects of the study were 604 Fellows of the American Academy of Pediatrics selected on a random basis from the membership. Of the 604 pediatricians contacted, 373 or 62 percent returned the questionnaires, although 56 were discarded due to incomplete information.¹⁴

The questionnaires were designed to determine what approach the doctors would take toward lifesaving treatment for children with spina bifida. Approximately half the physicians were asked about children with spina bifida but no hydrocephalus and those with both spina bifida and moderate hydrocephalus. The other half were asked about children with spina bifida but no hydrocephalus and those with both spina bifida and severe hydrocephalus.¹⁵ On the survey form, doctors could indicate that they would encourage surgery, be neutral, or discourage surgery. If the child were their own, the doctors could obtain all possible care, could provide only supportive care, or could answer that they were not sure what they would do.¹⁶

The authors wrote: "Previous experience with physician surveys suggests that the responses to surveys tend to be conservative. . . . Thus the results of this study would be more likely to err on the less controversial side (treatment of all infants)."¹⁷ Nevertheless, the results of this survey were significant: the presence of hydrocephalus (which the pediatricians perceived as related to mental retardation) would lead the doctors away from encouraging surgery toward discouraging surgery, a trend more marked as the degree of the hydrocephalus became more pronounced. If the child were the doctor's own, a similar trend toward choice of supportive care only, increasing with the degree of hydrocephalus, was evident. About a third of the doctors (34.2 percent) either would not know what to do or would provide only supportive care if the child were their own and only had spina bifida, with no hydrocephalus. If the same child were another's, 36 percent would be neutral or would discourage

surgery. The percentage of doctors who would either not know what to do or would provide only supportive care almost doubled (to 62 percent) for their own child with the presence of moderate hydrocephalus. In the same circumstances, 55.1 percent would be neutral or would discourage surgery for the child of another. With the presence of severe hydrocephalus, 75.7 percent would not know what to do or would provide only supportive care for their own child (49.7 percent were certain they would provide only supportive care), and 75.1 percent would be neutral or would discourage surgery for the child of another.¹⁸

Another survey, this one answered by 49 percent of the membership of the Perinatal Pediatrics Section of the American Academy of Pediatrics during fall 1986, disclosed widespread hostility to the standards of treatment adopted by the Child Abuse Amendments of 1984 and their implementing regulations.¹⁹ Sixty-six percent declared that the standards do not allow sufficient consideration of the parents' views, and 60 percent stated that they do not allow adequate consideration of the infant's suffering.²⁰

An attitude that discourages treatment is sometimes inculcated in medical school. Pediatric residents at Baylor College of Medicine in Houston, Texas, were asked the following questions both at the beginning and at the end of their 3-year residencies:

In which of the following situations would you employ heroic measures to save an infant's life; that is, would you resuscitate a child with:

Minor birth defects (eg, skin tags, extra digits)?

Major defects (eg, tracheoesophageal fistula, duodenal atresia)?

Birth weight less than 1000 g?

Severe defects (eg, congenital hydrocephalus myelomeningocele)?

Severe mental defects (eg, anencephaly, known severe brain damage)?²¹

¹³ Siperstein, Wolraich, Reed & O'Keefe, *Medical Decisions and Prognostications of Pediatricians for Infants with Meningomyelocele*, 113 *J. of Pediatrics* 835 (1988). See chap. 1, notes 9 and 14, for descriptions of spina bifida and hydrocephalus.

¹⁴ *Id.* at 837.

¹⁵ *Id.* at 836-37.

¹⁶ Siperstein, Wolraich, Reed & O'Keefe, *supra* note 13, at 836.

¹⁷ *Id.* at 840.

¹⁸ *Id.* at 837, table 1. Further discussion of the results of this survey appears in chap. 4, at the text accompanying notes 12-14.

¹⁹ The standard of treatment the act and regulation require is described in chap. 7, at the text accompanying notes 42-102.

²⁰ Kopelman, Irons & Kopelman, *Neonatologists Judge the "Baby Doe" Regulations*, 318 *New Eng. J. Med.* 677, 683 (1988). The survey authors agree with the majority, arguing that death is in the best interests of some infants who must be given life-preserving treatment under the Child Abuse Amendments.

²¹ Berseth, Kenny & Durand, *Longitudinal Development in Pediatric Residents of Attitudes Toward Neonatal Resuscitation*, 140 *Am. J. Diseases of Children* 766, 767, table 2 (1986).

Using a cumulative scaling procedure known as Guttman scoring, the authors were able to conclude that "residents demonstrated a significant increase in reluctance to resuscitate during the first year. . . of training. . . [and] a highly significant change during the third year. . . Both periods of change demonstrated increasing Guttman scale scores, indicating that residents had developed attitudes during those time intervals of increased reluctance to resuscitate. . . ."22 The authors attributed the increased reluctance to resuscitate to the assumption that "these residents may have been strongly influenced by faculty members and other role models who interacted with the residents."²³

Turnbull Analysis

Apart from these recently published studies, the most comprehensive and well-documented evaluation that has been done to date appears in the statement prepared for the Commission by H. Rutherford Turnbull, professor of Special Education and Law at the University of Kansas. It has been included as appendix B to this report. In it, Professor Turnbull evaluated the available polls of health care personnel, summarized relevant sociological research, and surveyed the professional literature. What follows is a brief synopsis of Turnbull's paper.

Turnbull summarized earlier polls of attitudes among health care professionals, incidence data, and recent trends in the literature on medical ethics. He concluded that these demonstrated the existence of "a contemporary attitude in the medical profession that supports discrimination in medical care against children, particularly newborns with moderate to severe/profound disabilities" that "has been linked to unwarranted deaths" and that justifies Federal action to prevent such discrimination from occurring.²⁴

Several polls have been conducted among pediatric surgeons, pediatricians, and nurses in neonatal intensive care units eliciting their responses to hypothetical treatment situations involving infants with medically correctable life-threatening condi-

tions who were also at risk for mental retardation or other disability after the treatment. Approximately 77 percent of the surgeons and 50 percent of the pediatricians in a 1975 survey conducted by the Surgical Section of the American Academy of Pediatrics said that they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia²⁵ if the infant also had Down's syndrome." Approximately 63 percent of the surgeons and 43 percent of the pediatricians indicated that in such cases they would also stop supportive services such as the provision of intravenous fluids and nasogastric suction.²⁶

A 1977 survey of Massachusetts pediatricians revealed that 51 percent of them believed that a Down syndrome child with intestinal block, whose parents rejected surgery, should not be operated on.²⁷ Even of the 46 percent of pediatricians in this Massachusetts survey who would recommend surgery, only 40 percent (approximately 18 percent of the entire group) would obtain a court order for treatment of the infant.²⁸ Sixty-seven percent of those surveyed would not recommend surgery for a baby with severe myelomeningocele, while 60 percent of those who would recommend surgery would nonetheless acquiesce in a parental decision not to authorize it.²⁹

A 1984 survey of nurses at neonatal intensive care units and intermediate care nurseries in Houston revealed the predominance of attitudes favorable to the denial of treatment to infants with disabilities. In this survey, approximately 71 percent of the nurses felt that nurses and physicians should never resuscitate an infant with severe mental disabilities (e.g., severe brain damage). For infants with such disabilities as myelomeningocele or congenital hydrocephalus, approximately 48 percent of the nurses said that nurses and physicians should only occasionally resuscitate, while approximately 13 percent of the nurses stated that infants with such disabilities should never be resuscitated.³⁰ Indeed, approximately 37 percent of the nurses in this study "felt that sometimes a doctor should act in such a way as

²² *Id.* at 767. Unfortunately, the authors provided no breakdown of the percentage of residents unwilling to resuscitate for any of the particular conditions listed.

²³ *Id.* at 768.

²⁴ App. B.

²⁵ Intestinal obstructions may occur as frequently as 1 in each 1,500 births. R. Behrman & V. Vaughan, *Textbook of Pediatrics* 780 (W. Nelson 13th ed. 1987).

If a complete obstruction is not corrected promptly, the infant's condition deteriorates rapidly, with persistent vomiting, loss of

weight, dehydration, and death, usually within a few days. Most cases of intestinal atresia and other obstructions of the intestines are susceptible to surgical correction. *Id.*

²⁶ App. B.

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

to cause an infant's death," and approximately 31 percent of them indicated that the decision whether to treat a sick newborn child should be influenced by whether or not there are healthy children at home.³¹

To test the view advanced by Dr. James Strain, former president of the American Academy of Pediatrics, that "shifts in attitude" in the medical community have resulted in more frequent treatment for infants with disabilities who have life-threatening conditions, making earlier studies obsolete,³² Turnbull surveyed more recent medical literature expressing contemporary health care providers' attitudes toward appropriate treatment responses to the birth of newborn children with disabilities. He found such literature to be "overwhelmingly in favor of denying treatment to those deemed to lack a sufficient 'quality of life.'"³³ Turnbull quoted from nearly two dozen articles and books, all authored by physicians, to show the predominance in the contemporary medical community of the belief that a "low quality of life ethically justifies or even mandates letting some children with disabilities die. . . ."³⁴

Turnbull focused on two examples reinforcing the conclusion that numerous unwarranted deaths of children with disabilities have resulted from the current hegemony of the "quality of life. . . over the equality of life" ethos in the medical community.³⁵ One was a study of the disparate treatment over a period of 6 years of two groups of individuals affected with a potentially life-shortening heart malformation. The prospects for successful surgical correction of this malformation decrease over time to the point of disappearance, making early action vital. The study found that all children with the heart malformation but without Down syndrome were referred for surgical correction or treatment at an appropriately early age. However, 10 out of 28 children who had both the heart problem and Down syndrome were not referred until they were beyond 1 year of age, with the result that half of these children with Down syndrome had deteriorated to the point that surgery for their heart condition could no longer be performed.³⁶

³¹ *Id.*

³² *Id.* (statements of Dr. James Strain, former President of the American Academy of Pediatrics, which conducted the 1975 poll cited in app. B).

³³ *Id.*

³⁴ *Id.* Articles and books excerpted at *id.*

³⁵ *Id.* (phrase used by Dr. Robert M. Blizzard, Chairman, Department of Pediatrics, University of Virginia School of Medicine).

The other example was the practice at Children's Hospital of Oklahoma in which a quality of life formula served explicitly as part of the basis for denying treatment to 24 of 69 infants with spina bifida, an approach that resulted in their death.³⁷ The Commission relies heavily on the material Turnbull assembled in assigning considerable weight to his conclusion that: "It is obvious that many health care professionals still feel that there are circumstances in which it is proper to deny medical care to children with disabilities. Overwhelmingly, these decisions appear to be based on the doctor's own opinion regarding the child's 'quality of life' after treatment."³⁸

Investigative Reporting

Professor Turnbull's conclusion is supported by other evidence obtained by the Commission. The Commission received detailed testimony from a Pulitzer and Peabody award-winning investigative journalist, Carlton Sherwood. He described the approach taken by himself and the teams working with him, as well as their findings.

Since 1983 I have authored three separate in-depth series dealing with so-called Baby Doe cases, two for television and one for print. Roughly speaking, I have devoted about 18 months of direct field research to the subject and perhaps another year of study on Babies Doe and the host of related medical, social, legal, and ethical issues.

During the course of my research, I traveled to 28 States, visited 19 intensive care hospital nurseries, 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.

In all, my research staffs and I reviewed upward of 700 cases where there was a probability that infants died as a result of decisions to withdraw medical treatment. From that number, we targeted 300 cases where there was an admitted or a high degree of certainty, based on first-hand eyewitness testimony, that nonheroic or extraordinary medical care had been withheld based solely on the real or perceived presence of a mental or physical handicap.

³⁶ *Id.* at 4-5; Sondheimer, Byrum, & Blackman, *Unequal Cardiac Care for Children with Down's Syndrome*, 139 *Am. J. Diseases of Children* 68 (1985).

³⁷ *Id.*

³⁸ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 45-46 (1986) (vol. II) (testimony of Carlton Sherwood).

Of that 300 we targeted, approximately 120 cases were acknowledged outright, sometimes in writing, by the physicians who actually took part in the process. . . .

On a secondary level, we were able to document through records and the supporting testimony of other physicians, nurses, and parents directly involved, an additional 27 incidents where beneficial medical care was withdrawn or withheld because of a real or perceived mental or physical handicap.³⁹

Sherwood described "the attitude that these children are disposable" as "pervasive" among the pediatricians with whom his teams spoke.⁴⁰

It is sometimes argued that in many instances in which treatment was denied to a child with a disability like spina bifida or Down syndrome, the real basis for denial was the existence of other anomalies or life-threatening conditions that severely complicated the case. This was a claim that Sherwood also frequently confronted.

On several occasions, however, I was fortunate enough to have the medical records. . . and let me tell you what some of the other anomalies. . . were.

According to the medical charts of one baby boy with spina bifida we looked at, there were the additional complications of a hernia and an ear infection, both of which went untreated.

Another spina bifida boy also developed bronchitis, but because antibiotics might have saved his life. . . , none was prescribed to alleviate his chest congestion. He died.

A Down's syndrome baby who had an esophageal atresia also suffered from a hernia and a kidney infection. This severely handicapped child died after 23 days; he died of [de]hydration which, I'm told, is a remarkable feat for any healthy baby.⁴¹

Testimony from People with Disabilities and Their Relatives

There is a strong impression among many people with disabilities that the medical profession in general is influenced by negative and inaccurate

³⁹ *Id.* at 51-52.

⁴⁰ *Id.* at 48-49.

⁴¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 103 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability). *See also id.* at 176 (testimony of Prof. Irving Kenneth Zola, Department of Sociology, Brandeis University) ("I think the medical profession may be less well-equipped than other segments of our society to make judgments as to what is the quality of life. This is based on at least a quarter of a century of experience of teaching at medical schools and looking at. . . who ultimately becomes a physician and the training to which they are exposed.")

stereotypes about them. Ed Roberts, who uses a wheelchair and a respirator, testified: "Disability creates its own stigma, [its] own fear; people react to it in different ways, but most of it often manifests itself in prejudice. . . . The medical profession is among the worst in this area; they see the worst."⁴² John Kemp, who also uses a wheelchair, presented a similar view:

[A]s chairman of the Board of Access Living, an independent living center in Chicago, I work very closely with the CEO of that organization, who is a quadriplegic [sic] female. We regularly conduct training programs for the University of Illinois Medical School for the doctors and to-be doctors there, and we are continually astounded at the naivete of the medical profession regarding the rights of and services for disabled individuals. Her problems, if they are female in nature, are usually referred to a physical medicine and rehabilitation person only because of her quadriplegia, and this phenomenon continues to astound her and infuriate her. That is symptomatic of the medical community, and I would say I have heard this comment on numerous occasions dealing with people who are disabled, that the disability becomes the primary focus of the medical attention, when, in fact, they may be in need of medical services unrelated to their physical disability or mental disability.⁴³

The Commission heard testimony reporting that physicians who diagnose muscular dystrophy around age 4 or 5 frequently describe it as a terminal disability, without revealing that if a respirator is used, the person might well live a normal lifespan.⁴⁴

Mental retardation evokes similar responses.

In a paper by Ann and H. Rutherford Turnbull on the ethics of early intervention, the authors talk about the parents of a profoundly retarded young man of 15 who were frequently asked by the physicians who were working with the. . . youngster, whether they really wanted to continue with kidney dialysis or blood transfusions.

Would those physicians have asked such a thing, even dared ask such a thing of the parents of any other 15-year-old minor child without a disability? Of course not.⁴⁵

⁴² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 123-24 (1986) (vol. II) (testimony of John Kemp, Director of Human Resources, National Easter Seal Society). *See also id.* at 132.

⁴³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 107 (1986) (vol. II) (testimony of Ed Roberts, President, World Institute on Disability).

⁴⁴ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 127 (1986) (vol. II) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

⁴⁵ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 8 (1985) (vol. I) (testimony of C.

Surgeon General Koop testified that most of the problems concern the child with mental retardation "who has a problem that will kill him without surgery. . . ."⁴⁶

There was particular objection to the terminology often used by health care personnel. "The absurdity of calling disabled people of any age defective is like calling us cars and. . .there is an implied warranty that's been breached in some way. We're not products or appliances, we're people, and I don't think we're defective."⁴⁷

Research by sociologist Dr. Rosalyn Benjamin Darling tends to confirm these impressions:

[P]hysicians lack information about the experience of living with disability. They too have been exposed to societal stigma towards the disabled, resulting in attitudes like these expressed by pediatricians I interviewed: "It is hard to find much happiness in this area. The subject of deformed children is depressing. Other problems I can be philosophic about; as far as having a mongoloid child, I can't come up with anything good it does. There's nothing fun or pleasant. It's somebody's tragedy. 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."⁴⁸

Darling pointed out that physicians are traditionally trained to seek to heal, and that when a disability will persist in spite of lifesaving treatment, some do not feel rewarded. She quoted a pediatrician she interviewed: "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."⁴⁹

The parent of a 24-year-old man who has mental retardation testified that in April 1986 she took him to an Ohio physician because he was experiencing severe side effects from medication: "[The physi-

cian] said it really wasn't important because he was mentally retarded. . . ."⁵⁰ She also described being on a panel with pediatric neurologists in Colorado in 1984 during which the physicians, when asked the conditions under which they would perform lifesaving surgery for any child, insisted that the criteria are different "when the child is mentally retarded."⁵¹

Recent Medical Literature

Another approach to determining the extent of the problem is to consider how pervasive articulated support for denial of treatment may be. The Turnbull testimony appended to this report documents with numerous quotations and citations his conclusion that in the recent medical literature the "commentary on the issue is overwhelmingly in favor of denying treatment to those deemed to lack a sufficient 'quality of life.'"⁵²

When made aware of the legal requirements concerning discriminatory denial of treatment, health care personnel sometimes seem more interested in ensuring that no one finds out about their violations than in implementing them. After a case in Danville, Illinois, in which Siamese twins were initially denied surgery, food, and water until public exposure by a whistle blower led to criminal proceedings, the *American Medical News* quoted Dr. L. W. Tanner as saying, "[I]f hospital business had stayed within hospital walls, perhaps the state would never have been called in." The article went on to report: "Since the twins' birth, the hospital has intensified its courses on confidentiality, particularly for new employes, and has reminded physicians to be cautious when discussing cases when they might be overheard."⁵³

Everett Koop, M.D., Surgeon General, U.S. Public Health Service).

⁴⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 133 (1986) (vol. II) (testimony of John Kemp, Director of Human Resources, National Easter Seal Society).

⁴⁷ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 181 (1986) (vol. II) (testimony of Dr. Rosalyn Benjamin Darling, Director, Early Intervention Services, City Council Clinic in Johnstown, Inc.).

⁴⁸ *Id.* at 181. Cf. Alexander, *Medical Science Under Dictatorship*, 241 *New Eng. J. Med.* 39, 45 (1949) ("The original concept of medicine and nursing was not based on any rational or feasible likelihood that they could actually cure and restore but rather. . .motivated by the compassion in alleviating suffering.").

⁴⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 257-58 (1986) (vol. II) (testimony of Margaret Burley, Director, Ohio Coalition for the Education of Handicapped Children).

⁵⁰ *Id.* at 259.

⁵¹ See app. B. It is noteworthy that, contrary to some suggestions, negative quality of life assessments continue to be given concerning those with Down syndrome and spina bifida, often characterized as the "easy cases." *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 44-45 (1986) (vol. II) (testimony of Prof. H. Rutherford Turnbull, Department of Special Education, University of Kansas).

⁵² *Siamese Twins' Case "Devastates" MDs*, *Am. Med. News*, Oct. 9, 1981, at 1, 15-16.

⁵³ App. B.

Conclusion

Thus, the surveys of health care personnel, the analysis submitted to the Commission by Professor Turnbull, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of

physicians set forth in their professional journals all combine to suggest the likelihood of widespread denials of lifesaving treatment to children with disabilities that have continued since implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

Child Protective Services Agencies and Enforcement of the Child Abuse Amendments of 1984

Principal enforcement responsibility for the Child Abuse Amendments (CAA) of 1984 resides with State Child Protective Services (CPS) agencies, the variously named entities that exist to administer each jurisdiction's child abuse and neglect laws.¹ Under current law, the fate of children with disabilities who are threatened with denial of lifesaving medical treatment, food, and fluids largely depends on how effectively CPS agencies carry out this responsibility.

Alternative avenues are scarce. Direct Federal efforts to prevent this type of medical discrimination to date have been stymied by the Supreme Court. Ruling in *Bowen v. American Hospital Association*, the Court enjoined the Federal Government from direct regulation and investigation, under section 504, of

"instances in which parents have refused consent to treatment."² The ability of private organizations or individuals to mount legal challenges to denial of treatment is restricted because in many States there are severe limitations on private standing to challenge threatened denials of treatment.³

CPS Delegation of Investigative Responsibility

Forty-eight jurisdictions receive Federal funds from the Department of Health and Human Services under the Child Abuse Prevention and Treatment Act. A review of their policies and procedures has shown that, on their faces, the policies of 14 of these States explicitly abdicate to internal hospital infant care review committees or hospital staffs the authority to decide whether illegal denial of treatment is

¹ Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14,878, 14,878 (1985).

² 476 U.S. 610, 625 n. 11 (1986). See chap. 6, text accompanying notes 109-135, and chap. 12, text accompanying note 65, for further discussion of this decision.

³ In forty-four . . . jurisdictions. . . anyone may bring the matter to the court's attention. However, [12 jurisdictions]. . . place some limitation upon who may bring the matter to the court's attention. Even in the other jurisdictions, just because the matter may be brought to the court's attention by an attorney or his or her client does not mean

that a hearing before a judge will necessarily be had. A little over half of the jurisdictions surveyed employ some type of petition screening process. . . . In some jurisdictions the state child protection agency investigates, in others the county attorney or district attorney. In yet others, a court staff person is charged with conducting the investigation. The investigator often has authority to dismiss the petition, allow the petition to be filed or "informally adjust" the matter. National Legal Center for the Medically Dependent and Disabled, *The Medical Treatment Rights of Children with Disabilities* § 8.01 (1987) (available from the Legal Services Corporation).

taking place when a report of suspected denial of treatment is received by the State agencies.⁴

Federal regulations, however, require that State CPS agencies make the determination whether treatment is medically indicated under the Child Abuse Amendments. The existence of hospital-administered infant care review committees (ICRC) does not relieve a State CPS agency of its responsibility to investigate suspected cases of withholding of medically indicated treatment or to employ its legal authority to prevent such withholding:

[T]he existence and activities of the ICRC do not amend the responsibilities under State law of medical professionals and the hospital to report to the child protective services agency suspected instances of medical neglect (including the withholding of medically indicated treatment from disabled infants with life-threatening conditions). . . . Although the child protective services agency and the ICRC are to be guided by similar principles and standards regarding the best interests of the child, the Department [of Health and Human Services] believes they have separate and distinct functions. The primary function of the ICRC in this context is to offer counsel to the attending physician(s), the hospital and the family to assure that the parents have the benefit of prudent, knowledgeable and professional evaluations, recommendations and services, consistent with appropriate medical standards, to assist them in making sound decisions regarding the welfare of their child. The function of the child protective services agency is to determine those circumstances in which the power of the State must be invoked to protect the infant, and then to take appropriate action to do so.⁵

Section 5103(2) of the Child Abuse Prevention and Treatment Act of 1978 provides: "In order for a State to qualify for assistance under this subsection,

such State shall . . . provide for the reporting of known and suspected instances of child abuse and neglect; . . ."⁶ The implementing regulations require that programs receiving Federal funds must provide for "[p]rompt notification by individuals designated by and within appropriate health care facilities of cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions); . . ."⁷ Subsection 1340.14(d) requires that "the State must provide for the prompt initiation of an appropriate investigation by a child protective agency or other properly constituted authority to substantiate the accuracy of all reports of known or suspected child abuse or neglect."⁸

Shortly after the adoption of the Child Abuse Amendments, Professors Nancy Rhoden and John Arras openly challenged hospital infant bioethics committees to "educate" local CPS agency personnel so that they "come to appreciate *all* of the morally relevant factors involved and will, accordingly, defer to the decisions made by parents, doctors, and committees, except in cases where the child's best interests are *clearly* being threatened." The objective of such "education" is to encourage hospital committees "occasionally [to] condone non-treatment in circumstances not contemplated" by the Child Abuse Amendments of 1984 and their implementing regulations.⁹

One State CPS worker told Commission staff that there had been "only one reported case in the 3 years I've been here. Of course, we hear through the

⁴ Ala. Dep't of Pensions and Sec., I Family and Children's Servs. Manual, Pt. VII-53 (Rev. May 1988); Alaska Division of Family and Youth Services, Child Protective Services Policy Manual tit. 300. § 5.045(c)(1) & (d)(1) (January 1987); Ariz. Dep't of Economic Sec. Policy 5-55-8.E.1 (May 1988); Del. Dep't of Servs. for Children, Youth and Their Families, Policy on Medical Neglect of Handicapped Infants at 2 (August 1986); Fla. Dep't of Health and Rehabilitative Servs., Health and Rehabilitative Services Pamphlet 175-1, § 3.4.17 (July 1988); Ga. Dep't of Human Resources, Guidelines for Medical Neglect of Disabled Infants, Introduction, ¶ 3 (undated); Haw. Dep't of Social Servs. and Housing Policy Manual Ch. 1100.9.2 (June 1987); Memorandum from Sandy Hodge, Me. Child Protective Servs. Program Manager, to Regional Program Managers for Child and Family Servs. (incorporating Action for Child Protection Fact Sheet at 3, question 7) (Apr. 16, 1985); Mich. Dep't of Social Servs. Manual Bulletin, Children and Youth, No. 86-11 at 46 (Rev. Nov. 3, 1986); Nev. State Welfare Div. Serv. Manual § 417.11(c)(4) (September 1985); N.M. Human Servs. Dep't., Social Servs. Div. Procedure § 4.8.3.2.1. (Oct. 1, 1987); Wash. Dep't of Social and Health Servs., Div. of Children and Family Servs. Manual ch. 26.33 F.(5)(b) (March 1987); Memorandum from Rozella Archer,

Director, Servs. to Families and Children, W. Va. Dep't of Human Servs. to Area Administ., Social Serv. Coordinators [and] Child Protective Servs. Supervisors, Child Protective Servs. Policy pt. 2 ¶ 2, pt. 3 (Aug. 28, 1986).

⁵ *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers To Establish Infant Care Review Committees*, 50 Fed. Reg. 14,893, 14,900-01 (1985).

⁶ 42 U.S.C.A. § 5103(b)(2)(B) (West 1983).

⁷ 45 C.F.R. § 1340.15(c)(2)(ii) (1987).

⁸ 45 C.F.R. § 1340.14(d) (1987). The entity being investigated is hardly a "properly constituted authority" to conduct the investigation.

⁹ Rhoden & Arras, *Withholding Treatment From Baby Doe: From Discrimination to Child Abuse* 63 Milbank Mem. Fund. Q. 18, 47-48 (1985) (emphasis in original). Similarly, Thomas Murray had confidently predicted that the Child Abuse Amendments of 1984 and their implementing regulations would be of purely "symbolic" importance because in practice "the impact of the legislation and rule will be minimal." Murray, *The Final Anti-Climactic Rule on Baby Doe*, Hastings Center Rep., June 1985, at 5, 6-7.

grapevine from medical personnel of cases that go unreported."¹⁰ A Florida administrator stated, "I suspect that these cases are occurring in the State of Florida, but that the hospitals are handling the situations appropriately—which is the best of all worlds, really."¹¹ An administrator for the District of Columbia declared that "all of these cases have been resolved at the hospital level and we have not been called in."¹²

When State CPS agencies do not delegate their authority to internal hospital committees, they sometimes delegate it to the same organized elements of the medical profession who have strongly objected to the Child Abuse Amendments. In Nebraska, the State CPS agency simply turned over principal responsibility for evaluating reports of such denial to the State chapter of the American Academy of Pediatrics.¹³

On September 30, 1985, Dr. Kenton Shaffer, on behalf of the Committee on Maternal and Child Health of the Nebraska Medical Association and the Fetus and Newborn Committee of the Nebraska Chapter of the American Academy of Pediatrics, notified the Nebraska Department of Social Services (DSS) that an Ad-Hoc Resource Committee had been formed to offer assistance to DSS in evaluating cases of suspected medical neglect of infants born with a handicapping condition. . . .

Gina Dunning, state director of the DSS, accepted this offer on October 8, 1985, and entered into an agreement. . . . The DSS will refer all reports to the Ad-Hoc Resource Committee, which will supply consultative services 24 hours a day, at no charge to the department.¹⁴

¹⁰ Telephone interview with Michelle Gore, CPS Specialist, Kentucky Department for Social Services (July 21, 1988).

¹¹ Telephone interview with Chris Christmas, Senior Human Services Specialist, Florida Department of Health and Human Services (July 25, 1988).

¹² Telephone interview with Carolyn Smith, Chief of Intake for Protective Services, District of Columbia Department of Human Services (Aug. 9, 1988).

¹³ See chap. 6, and text accompanying notes 59–62, 70, for a description of the position taken by the American Academy of Pediatrics on government intervention to protect children with disabilities.

¹⁴ Eggert, Shaffer & Bausch, *Baby Doe—The Saga Continues*, Neb. Med. J., April 1986, at 103, 103–104. Commenting on a draft of this report, the Nebraska Department of Social Services took issue with the "inaccuracy" of these statements, stating: "While this Committee of experts MAY provide consultation to the Department regarding planning for and intervention steps of the investigation, by no means has the . . . state CPS agency simply turned over principal responsibility for evaluating reports of such denial to the state chapter of the American Academy of Pediatrics." Letter from Kermit R. McMurry, Director, Nebraska Department of Social Services, to William J. Howard, General Counsel, U.S. Commission on Civil Rights (Oct. 3, 1988) (emphasis in original). However, the letter concedes that cases

The Arkansas Department of Human Services, Division of Children and Family Services, seems to rely almost entirely for enforcement on the Arkansas Children's Hospital. The hospital has estimated it "treat[s] 90–95 percent of the 'Baby Doe' cases in the entire state."¹⁵ The State agency even contracted with the hospital to provide training workshops for its own "agency attorneys and child protective service workers."¹⁶ It worked with the hospital in developing its procedures, without input or consultation from disability groups.¹⁷ The "independent" physician who advises the State agency about whether medically indicated treatment is in fact being withheld is also selected by the hospital.¹⁸ In other words, in 90 to 95 percent of the cases, the hospital under investigation for medical neglect is permitted to name the "independent" medical authority who will rule on whether the course of treatment or nontreatment is proper.

Special Relationship Among CPS Agencies and Doctors

This widespread and remarkable readiness of CPS agencies to surrender their arms-length oversight responsibility concerning medical neglect appears in part to be rooted in the special relationship that has developed between CPS workers and many members of the medical profession. In dealing with traditional forms of child abuse and neglect, CPS agencies rely primarily on health care professionals for diagnosis and reporting. These include situations

"may require independent consultation from practicing, specialized physicians which are available to the Department under an agreement with the Committee on Maternal and Child Health of the Nebraska Medical Association." *Id.* Furthermore, the Nebraska "Central Office Procedures in Regard to a Report of Suspected Medical Neglect of an Infant Born with Handicapping Conditions" state that upon receiving notification of such a report CPS agency staff "will immediately contact a representative of the Ad-Hoc Resource Committee for consultation of the report" and that based on "discussion and consultation with the Ad-Hoc Resource Committee" the agency general counsel will be contacted for a legal opinion. These procedures do not make involvement of the Ad-Hoc Resource Committee optional; they make it mandatory. It is clear that the agency's reaction to any report is heavily dependent on the advice of the Ad-Hoc Resource Committee.

¹⁵ Letter from Bobbie Ferguson, Acting Administrator, Child Protective Services, to Mr. Tommy Sullivan, Regional Director, Administration of Children, Youth and Services 2 (Apr. 10, 1986) (available in files of U.S. Commission on Civil Rights).

¹⁶ *Id.* at 1.

¹⁷ Telephone interview with Sandra Haden, Arkansas Department of Human Services, by Dr. Leon Bourke (June 10, 1987).

¹⁸ *Id.*

where the parents say “the child fell down the stairs” but the bones were in fact broken by the parents, or where the child has been neglected to the point of exhibiting “failure to thrive” syndrome. Medical witnesses before the Commission repeatedly emphasized this point. An attorney for the American Hospital Association (AHA) testified:

from the internal hospital’s point of view, one of the reasons AHA participated in the Child Abuse Amendments—after filing suit, of course, on 504—was the fact there was a possibility of dealing with these difficult decisions by building upon existing collaborative relationships within the hospital between the social workers and the child protective agency people.¹⁹

The contrast between the receptivity of most CPS agencies to views from medical organizations—some of whose numbers were responsible for abuses the Child Abuse Amendments were enacted to curtail—and to views from disability organizations—the groups representing those whom the amendments were designed to protect—is striking. According to a survey conducted by the journal *Issues in Law and Medicine*, of 37 responding jurisdictions, 34 said that they had consulted with medical representatives in formulating their implementing procedures, while only 11 said they had consulted with disability groups.²⁰

CPS agencies have clearly been anxious not to offend the physicians whose discrimination they are supposed to be preventing. When the law that became the Child Abuse Amendments of 1984 was first proposed, the CPS agencies’ national lobbying

organization, the National Council of State Public Welfare Administrators, opposed it in part because “the good working relationship between social workers and physicians could be jeopardized.”²¹ Any belief that the amendments would lead to the development of an oversight (let alone an adversary) relationship with the medical profession hardly seems to have been justified. One physician who testified before the Commission was openly confident that, despite the Child Abuse Amendments, CPS agencies would do little to question nontreatment decisions:

In terms of the workings of the Child Abuse Amendments, many of us have long worked with people in child abuse. We’re used to that system and we would be surprised if it were an overwhelmingly interfering system. That is to say, they have their hands full with child abuse in the community as it is, and one doesn’t expect that they will be doing a lot of newborn investigation by and large.²²

Indeed, in over a third (17) of the jurisdictions receiving Federal funding, the State CPS agencies told the Health and Human Services Office of Inspector General either that “Baby Doe funds could be put to better use on general child protective programs, medical neglect or other priorities identified by States” or that the “Baby Doe problem is too small to warrant special Federal funds or attention.”²³

¹⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 54 (1985) (vol. I) (testimony of Mary Ahern, Attorney, American Hospital Association). Accord Testimony of Dr. James Strain, American Academy of Pediatrics (“We, the medical profession, have a good relationship with child abuse agencies in the State. We have worked closely with them in the past. Of course, the reporting many times of child abuse comes from physicians.”) *Id.* at 45. Testimony of Evan J. Kemp, Jr., Director, Disability Rights Center (“I think there’s a bit of a problem in basing too [many] resources in the child abuse statute. Basically those statutes were set up so that doctors could report on parents that abuse their children, and this situation is sort of the reverse. We’re asking them now to report on doctors who are denying treatment, and I think this whole setup is bad for the protection of infants born with disabilities.”) *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 36 (1986) (vol. II); testimony of Carlton Sherwood (“In my experience, the State child abuse . . . workers . . . work hand-in-glove with the local hospitals for child abuse reports; they’re one and the same. Some of the State child abuse agencies actually have offices in the hospitals where they actually work right there so the physicians can report something. They know these guys, they work with them.”) *Id.* at 61.

²⁰ Interview with Dr. Leon Bourke, *Issues in L. & Med.* (Nov. 30, 1987). All the jurisdictions which consulted disability representatives also consulted medical representatives. One additional responding jurisdiction indicated it “probably” had contacted disability representatives. Those responding on behalf of three other jurisdictions said either that the jurisdiction had consulted no one or that they didn’t know who, if anyone, had been consulted. *Id.*

²¹ Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations: A Summary*, 1 *Issues in L. & Med.* 91, 104 n.66 (1985).

²² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 240–41 (1986) (vol. II) (testimony of Patricia Ellison, M.D.). Dr. Walter Owens, the physician in the Bloomington Infant Doe case, was on the same panel as Dr. Ellison. He immediately said, “I would endorse Dr. Ellison’s statement completely.” *Id.* at 241. Cf. testimony of Carlton Sherwood (“Why do you think the AMA and the rest of these organizations are willing to let the State child abuse agency come in and look at anything they want to but not somebody from HHS? They’re friends. They work together. . . .”) *Id.* at 61.

²³ Office of Inspector General, Department of Health and Human Services, Survey of Baby Doe Programs 11 (1987).

CPS Agencies' Failure to Comply with Federal Regulations

The delegation of significant investigational responsibility by watchdog agencies to those they are supposed to be watching is perhaps the most serious form of widespread noncompliance by CPS agencies with the medical discrimination regulations it is their duty to implement. It is not, however, the only one.

In direct contravention of the governing regulations, six States' CPS agencies have no written policy specifying the manner in which they would obtain medical records to investigate a report of medical neglect.²⁴

In addition, Federal regulations require that State CPS systems must have the ability to obtain: "[a] court order for an independent medical examination of the infant, or otherwise effect such an examination in accordance with processes established under State law, when necessary to assure an appropriate resolution of a report of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life threatening conditions)."²⁵ Yet 10 States' CPS agencies have policies that fail to provide for securing an independent medical examination of a child with a disability about whom a report of a suspected medical neglect has been filed.²⁶

The impression that some States pay little or no attention to the standards of treatment embodied in the Federal law and regulations is reinforced by the fact that 11 States' CPS agencies have policies that either misdefine the term "withholding of medically indicated treatment," do not define it at all, or define the term in such an abbreviated fashion as to invite ambiguity and uncertainty.²⁷ In fact, Utah's CPS agency went so far as to create a new exception. Under its procedures, medical treatment need not be provided when "in the treating physician's judg-

ment. . . the treatment itself under such circumstances would be inhumane."²⁸

A majority of the States reviewed are not even clear in their policies concerning who is covered by the standards of treatment in the act. The Child Abuse Amendments standard of treatment applies to "disabled infants with life-threatening conditions."²⁹ 45 C.F.R. §1340.15(b)(3)(i) (1987) provides:

The term "infant" means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should be changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth in paragraph (b)(2) of this section [defining "withholding of medically indicated treatment"] should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

Twenty-four State CPS agencies have policies that either do not define the term "infant" or—in direct contravention of the governing regulations—define the term to encompass only infants of less than a year in age.³⁰

CPS Attitudes to Treatment Principles

There 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.

When a bill that, in modified form, would become the Child Abuse Amendments was first before Congress, the national organization which represents CPS agencies conceded that "child protective service agencies should appropriately intervene in cases where it is alleged that medically beneficial treatment is being denied to handicapped infants."

²⁴ These States are Alabama, Arkansas, Connecticut, Georgia, Mississippi, and New York.

²⁵ 45 C.F.R. §1340.15(4)(ii) (1987). The term "independent" connotes an individual free from the influence, guidance, or control of another. A hospital's own physicians, such as those serving on its ICRC, therefore cannot qualify as an "independent" source for the CPS agency. Each State's CPS system must construct its own bank of independent medical consultants.

²⁶ These States are Arkansas, Connecticut, Florida, Georgia, Hawaii, New York, Mississippi, Oklahoma, Utah, and Washington. Missouri's CPS agency will secure a court order for an independent medical examination only if the parent(s) do not consent and/or the attending physician disagrees with the recommendation of the ICRC. Missouri Division of Social Services, Division of Family Services, Children's Section Special

Child Abuse/Neglect Investigation Procedure: Baby Doe, A-7, ¶8 (Oct. 1, 1986) (available in files of U.S. Commission on Civil Rights).

²⁷ These States are Arizona, Iowa, Mississippi, Montana, New Jersey, New York, Oklahoma, Oregon, Utah, Washington, and West Virginia.

²⁸ Utah Division of Family Services, Department of Social Services, Division of Family Services Policy and Procedures for Implementation of "Baby Doe" Legislation Pt. II-B (3).

²⁹ 45 C.F.R. §1340.15(a) (1987).

³⁰ These States are Alabama, Alaska, Arizona, Delaware, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, New Jersey, New York, North Dakota, Ohio, Oklahoma, Oregon, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, and West Virginia.

Nevertheless, the organization opposed the bill, emphasizing that:

Cases involving the denial of health care for handicapped infants should not automatically be defined as child abuse or neglect. These decisions are most often the result of difficult medical/ethical judgments made by both the parents and doctors, and not instances of willful abuse or neglect resulting from malice or ignorance.³¹

A 1987 Health and Human Services Inspector General's report found that personnel at 11 of 49 State CPS agencies took the position that "[b]ecause of medical and ethical issues involved, CPS responsibility for Baby Doe cases is not appropriate," and 10 others were unwilling to state whether they regarded such responsibility as appropriate or not.³²

CPS agencies are largely staffed by social workers. A witness before the Commission, Mary Jane Owen, director of Disability Focus, Inc., reviewed the literature of the social work profession. Although she found articles that discussed how to help "so-called healthy families deal with the tragedy of having a flawed infant or child," she found no material giving any positive picture of life with disabilities or describing the maximization of the potential of people with disabilities.³³ Social psychologist Adrienne Asch testified:

[S]ocial workers, like everybody else, are brought up in a culture that devalues people with disabilities. And there's no reason to think that they're not going to bring that devaluing right to their work and they say, "These poor parents, I really understand why they don't want to treat this child. It's not really child abuse. I don't care what the law says. It is really understandable. The child is going to be a great burden."³⁴

Individual expressions of a negative attitude by CPS personnel toward the mission implicit in their responsibilities under the Child Abuse Amendments of 1984 are not hard to find. For example, when asked if there had been any reports of withholding of medically indicated treatment in Texas in the pre-

ceding year, the CPS administrator there replied, "Are you kidding?" and described the Baby Doe question as "a misunderstood issue caused by an extraordinary event in Bloomington, Illinois. This issue is primarily an issue related to parents' and physicians' decisions concerning treatment of the child—it is a medical issue, not a political issue."³⁵

Similarly, when a court action was initiated in Oregon to prevent the starvation of a terminally ill child with a disability, the CPS reaction was hostile:

Karen Green, a state assistant attorney general for the Children's Services Department, said the reaction to the intervention. . . was "outrage. . . that a family which had the trauma of having a deformed child in the first place should then be dragged into court and have it suggested that they are not being proper parents. . . . The people I have spoken to are unhappy," she said.³⁶

Even in well-publicized cases, State CPS agencies have repeatedly been reluctant or unwilling to act to protect children with disabilities from denial of life-preserving treatment. In the original "Infant Doe" case in Bloomington, Indiana, the local CPS agency was appointed by the trial judge to act as the child's guardian *ad litem* for the purpose of considering whether to appeal from his ruling supporting the death of the child. The agency considered the case and declined to appeal it.³⁷

The Connecticut CPS agency has an agreement for shared responsibility with the Connecticut Department of Health Services "with regard to coordination and consultation with health care facilities providing inpatient newborn care and response to reports of medical neglect (including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions). . . ." Under that agreement, the health services department has the responsibility to "[r]eview and approve health care facility policies concerning the care of critically ill/handicapped newborns."³⁸

ny of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

³⁵ Telephone interview with David Brock, Child Protective Services Manager, Texas Department of Human Services (July 29, 1988).

³⁶ Hiltz, *Brain-Damaged Baby Dies Amid Court Fight Over Treatment*, Washington Post, Apr. 23, 1983, at A2, cols. 1-5, col. 3.

³⁷ Telephone interview with James Bopp, Jr., Attorney for Robert and Shirley Wright, a couple who sought to adopt Infant Doe (Nov. 30, 1988).

³⁸ Connecticut Department of Children and Youth Services, Agreement Between the Connecticut Department of Health Services and the Connecticut Department of Children and Youth

³¹ *Statement of the Role of Child Protective Services Agencies in Cases Involving Denial of Health Care for Handicapped Infants*, Resolution of the National Council of State Public Welfare Administrators of the American Public Welfare Association, May 11, 1984, cited in Bopp & Balch, *The Child Abuse Amendments of 1984 and Their Implementing Regulations*, 1 Issues in L. & Med. 104 n.66 (1985).

³² Office of Inspector General, Department of Health and Human Services, Survey of Baby Doe Programs 11 (1987).

³³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 146 (1986) (vol. II) (testimony of Mary Jane Owen, Director, Disability Focus, Inc.).

³⁴ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 147-48 (1986) (vol. II) (testimo-

In 1981 a State legislative committee asked the Connecticut Department of Health Services to investigate denials of treatment at Yale-New Haven Hospital and in other hospitals around the State after hearings the committee held, stimulated by the investigative reporting of the *Hartford Courant*, documented a pattern of such denial. That pattern included the starvation of children with Down's syndrome (in one case taking 23 days), the provision of lethal overdoses to parents to give to children with disabilities, and the falsification of death certificates to cover up such deaths.³⁹ Instead of acting to stop such practices, the agency responded with a report that took the following positions:

Parents may have to choose between caring for a devastated infant and maintaining food, shelter and clothing for the rest of the family.

No one reviewing or making these decisions will be able to ignore economic considerations of some kind.

. . . .

The state, acting through the legislature, should not attempt to define or interfere with medical practice;

. . . The state, acting through the legislature, cannot establish ethical or moral standards for its citizens to observe, because of the enormous variety of personal feelings on the subject which are present in our society. Such laws would be ignored and ineffective. . . .⁴⁰

Confronted with denial of lifesaving surgery to a child with spina bifida in Robinson, Illinois, the Illinois CPS agency acted to protect the child only under threat of a Federal lawsuit.⁴¹ In the "Baby Jane Doe" case, not only did the CPS agency refuse to act, but it provided a letter to the attorneys defending the denial of treatment stating that the denial constituted "no credible evidence of neglect."⁴²

Although some of the examples above of attitudes of CPS workers antedate the Child Abuse Amend-

Services Regarding Medical Neglect of Infants in Connecticut Health Care Facilities 1 (Oct. 9, 1985).

³⁹ See chap. 12 and text accompanying notes 12-33.

⁴⁰ Connecticut Department of Health Services, *Infant Death: Life and Death in Newborn Special Care Units*, 46 Conn. Med. 589, 594-95 (1982).

ments, there is little reason to conclude that such attitudes have changed dramatically, given people's general reluctance to change their views.

Conflict of Interest

CPS agencies are part of the State government, often in the same department that runs hospitals and other institutions that provide medical treatment to children with disabilities. This can create a direct conflict of interest for the CPS agency. The "Baby Jane Doe" incident is a case in point. Jane Doe was denied treatment at University Hospital of the State University of New York at Stony Brook. The State attorney general represented the hospital—arguing not only against treatment, but even against governmental investigation of the situation. Similarly, the Oklahoma CPS agency never investigated or acted to thwart the course of selective denial of treatment to children with spina bifida at Oklahoma Children's Memorial Hospital. As James Bopp, Jr., testified, it had a strong incentive not to do so:

In the Oklahoma case. . . the Oklahoma child abuse and neglect State authority is the very same State authority that operates the hospital at which the children were denied medically indicated treatment. You then have a situation in which the two agencies which may be involved, one in denying medical treatment and the other in enforcing and insuring that medical treatment is provided, are within the same department of the State government. It is difficult to believe in that circumstance that child abuse and neglect agencies would take enforcement action against a hospital that is a member agency of its own State department.⁴³

Conclusion

In sum, the close working relationship between some CPS personnel and members of the medical profession has resulted in the substantial failure of many State child protective service agencies to effectively enforce the Child Abuse Amendments of 1984.

⁴¹ Telephone interview with Robert D'Agostino, former Deputy Assistant Attorney General, Civil Rights Division, Department of Justice (Dec. 1, 1988).

⁴² Letter from William Larson and Jane Raven, Suffolk County Child Protective Services, to Paul Gianelli (Nov. 7, 1983).

⁴³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 156 (1986) (vol. II) (testimony of James Bopp).

The Role and Performance of Infant Care Review Committees

The establishment of infant care review committees—internal hospital committees that consider instances in which life-preserving medical treatment is being or may be withheld from infants with disabilities—is encouraged by the Child Abuse Amendments of 1984,¹ as it was by the final regulations the Department of Health and Human Services issued under section 504.² A 1986 survey found that 51.8 percent of hospitals with either a neonatal intensive care unit or over 1,500 births annually had established such committees, and an additional 8.9 percent were in the process of forming them.³

Many maintain that using infant care review committees⁴ for advice when denial of treatment is being considered is preferable to governmental involvement. Robert Weir makes a typical argument:

Simply put, such a committee can work as the third stage of a four-stage process of decision making and review—consisting of parents, physicians, the committee, and the courts as a seldom-used final stage. The committee can function as an advisory board to pediatricians making difficult decisions in the neonatal intensive-care unit, an internal appeals and review board, and an institutional

check on abusive practices. This procedural process is preferable to having moral decisions in neonatal intensive care units hamstrung by governmental regulations, and it will achieve basically the same end: the provision of medical treatment to handicapped newborns who need and will on balance benefit from such treatment.⁵

On the other hand, some disability rights advocates are skeptical about the effectiveness of such committees in protecting the medical treatment rights of people with disabilities. For example, Professor James Ellis told the Commission:

[A]necdotal evidence suggests they are very hit-and-miss as to whether or not they effectively investigate cases that are like the ones that have been under discussion here, and there is anecdotal evidence to suggest that some of them have not been very effective. And to place all of our civil rights enforcement resources in such a hit-and-miss kind of mechanism when the stakes are so high for the kids involved is distressing.⁶

History

The genesis of these committees may probably be traced to suggestions made in a 1975 law review article by pediatrician Dr. Robert Teel.⁷ The concept was given impetus the following year by the New Jersey Supreme Court in its *In re Quinlan*

¹ 42 U.S.C.A. § 5103 note (West Supp. 1987) (see generally chap. 7).

² 45 C.F.R. §§ 84.55(a) & (f) (1986) (see generally chap. 6, and the text accompanying notes 72–77).

³ University of Connecticut Health Center, Pediatric Research and Training Center, National Collaborative Survey of Infant Care Review Committees in United States Hospitals 6 (1987) (available from American Academy of Pediatrics) [hereinafter National Collaborative Survey]. The survey, largely funded by the National Institute for Disability and Rehabilitation Research of the U.S. Department of Education, was conducted by the University of Connecticut Pediatric Research and Training Center and the American Academy of Pediatrics. It was sent to

870 hospitals in 48 States, of which 643 (73.9 percent) responded. *Id.*, app. D at 1.

⁴ They are also frequently called “ethics committees” and sometimes “patient care review committees.”

⁵ Weir, *Sounding Board*[:] *The Government and Selective Nontreatment of Handicapped Infants*, 309 *New Eng. J. Med.* 661, 663 (1983).

⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 35–36 (vol. II) (1986) (testimony of Prof. James W. Ellis, School of Law, University of New Mexico).

⁷ Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 *Baylor L. Rev.* 6, 8–10 (1975).

decision.⁸ The court wrote that the establishment of such committees “would be protective to the hospital as well as the doctor in screening out, so to speak, a case which might be contaminated by less than worthy motivations of family or physician.”⁹

However, a study published in March 1983 concluded that as of that date ethics committees had “not been widely adopted as a means of handling medical ethical problems. Only 1 percent of the hospitals in this country. . . have such committees.”¹⁰

Widespread advocacy and then implementation of ethics committees came only in reaction to the public outcry over the Bloomington Infant Doe case and the Federal response under section 504 of the Rehabilitation Act of 1973 as contemplated by the then recently promulgated Department of Health and Human Services’ “Baby Doe” regulations.¹⁵ Instead, it proposed a process of internal hospital review, including the use of ethics committees:

Under assault from the federal government. . . the American Academy of Pediatrics (AAP) has quietly but significantly changed its position.

In the last several months, the AAP has come forward to say that hospitals should establish ethics committees made up not only of hospital staffers but also of community members. These committees would establish procedures to review cases in which doctors and parents have decided to forego life-sustaining measures.

“Historically, the American Academy of Pediatrics has been unwilling to allow outsiders to participate in the difficult decisions these newborns bring up,” said Thomas Murray of the Hastings Center in Hastings-on-Hudson, N.Y., an ethics think tank.

. . . .

Yet, given recent government attempts to intervene in treatment decisions, the medical profession now views “the ethics committee route as the lesser of the evils,” Murray said.¹²

In 1983 the ethics committee concept was championed by two important sources: the President’s Commission for the Study of Ethical Problems in

Medicine and Biomedical and Behavioral Research, and the American Academy of Pediatrics. In March 1983, the President’s Commission issued its report, *Deciding to Forego Life-Sustaining Treatment*. While condemning the denial of lifesaving surgery to a child with Down syndrome¹³ (in apparent reaction to the Bloomington Infant Doe case¹⁴), the President’s Commission rejected resort to government enforcement of section 504 of the Rehabilitation Act of 1973 as contemplated by the then recently promulgated Department of Health and Human Services’ “Baby Doe” regulations.¹⁵ Instead, it proposed a process of internal hospital review, including the use of ethics committees:

This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases [including] those in which a decision to forego life-sustaining therapy has been proposed because of a physical or mental handicap, as well as cases where a dispute has arisen among care givers and surrogates over the proper course of treatment.

Such a review could serve several functions. . . . First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate. Such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested “representative of the public” and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.¹⁶

When it filed its legal challenge to the first set of “Baby Doe” rules, the American Academy of Pediatrics also promoted medical ethics committees as an alternative.¹⁷ An article by Dr. Norman Fost,

⁸ 70 N.J. 10, 355 A.2d 647 (1976), cert. denied, 429 U.S. 922 (1976).

⁹ *Id.* at 669. Other courts subsequently spoke with approbation of ethics committees, primarily in the context of cases of potential termination of treatment for older patients. See, e.g., *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

¹⁰ Youngner, Jackson, Coulton, Juknialis & Smith, *A National Survey of Hospital Ethics Committees*, in President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 443, 448 (1983).

¹¹ See, e.g., Cranford & Doudera, *The Emergence of Institutional Ethics Committees*, L., Med. & Health Care, February 1984, at 13, 14.

¹² Herskowitz, *The ‘Baby Doe’ Dilemma: The Ethics of Life and Death*, Philadelphia Inquirer, Nov. 20, 1983, at 1D, cols. 1–2.

¹³ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 6 (1983) [hereinafter President’s Commission Report].

¹⁴ *Id.* at 224 & n. 92.

¹⁵ *Id.* at 225–27.

¹⁶ *Id.* at 227.

¹⁷ American Academy of Pediatrics, News Release: Pediatricians Oppose Federal Rule on Handicapped Newborns 2 (Mar. 18, 1983) (available in files of U.S. Commission on Civil Rights).

a member of the American Academy of Pediatrics' Infant Bioethics Task Force, which played a key role in proposing such committees, makes clear that they were designed less to enforce the treatment standards of the law than to protect doctors and hospitals from "intrusion" by the government or other outsiders:

The theoretic basis for ethics committees is that they should be better able to emulate the "ideal ethical observer" than could any single individual. Even if they did not achieve this ideal, however, they might serve the following purposes.

Political. They offer a mechanism for accountability that could avoid less desirable alternatives.

Therapeutic. They offer a forum for nurses and others who are aggrieved by decisions to express their concerns and feel part of the decisionmaking process. This not only helps professionals who experience suffering, but it may avoid the whistle-blowing that leads to unwelcome publicity and intrusion.

Legal. The risks of civil or criminal liability would presumably be fewer if the responsible physician could show his or her decision was reached after extensive consultation and deliberation. Consultation should reduce the chance of making decisions that create actual civil or criminal liability. It is also less likely that charges will be brought if decisions are seen as resulting from extensive consultation and deliberation. Even if charges are brought, the risk of conviction is reduced by demonstrating that due care was taken in making a decision.

Educational. By increasing sensitivity within the institution, committees can presumably improve the ethical acceptability of complex decisions.¹⁸

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. The President's Commission argued that there are three categories of situations in which choices between provision and denial of lifesaving treatment are made: those in which treatment is clearly beneficial, those in which it is clearly futile, and a gray area in between.¹⁹ The content of these broad categories was left deliberately vague. Beyond stating that treatment is clearly beneficial for those with Down syndrome, the President's Commission rejected the use of "[s]upposedly objective criteria [which] seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers."²⁰ In effect, the President's Commission concluded that because no hard and fast rules should be established for the gray area, the best approach to making appropriate decisions in individual cases would be to foster a process in which all information would be weighed by compassionate and knowledgeable individuals from a variety of backgrounds. This could best be achieved through the use of hospital ethics committees.

The American Academy of Pediatrics grounded its support for ethics committees in a similar analysis. "[I]t is impossible to develop a consensus on which infants within a broad range should be treated," the organization's president, Dr. James Strain, wrote. "The academy believes these difficult medical decisions should be made only after a thorough review, including consultation with a local medical review committee."²¹ Dr. Strain emphasized that the committees should operate in the area of ambiguity: "It is the management of the . . . 'in between' group where indications for unusual medical or surgical care are uncertain. . . . which should be reviewed by an ethics committee at the local hospital level."²²

Strain's perspective on the role of ethics committees did not change following the adoption of the Child Abuse Amendments of 1984. Addressing a December 1985 Colorado conference intended to examine implementation of the regulations issued under the amendments, he did not discuss the standard of care established by the amendments as the basis for committee deliberations, but rather repeated the view that treatment decisions fall into the categories of "clearly beneficial, . . . futile[.], . . . and that in which the burden of treatment must be weighted against the benefits—that 'gray area' of decisionmaking. Parents, physicians and IBCs will be called on to determine the best course of treatment." Strain, *Bloomington to Here: A Brief History of the Baby Doe Regulation*, in The Center for Applied Biomedical Ethics at Rose Medical Center, *Medical Neglect and the Disabled Infant: The Impact of the Baby Doe Regulation* 12, 14 (rev. ed. 1987).

¹⁸ Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 *Critical Care Clinics* 149, 157 (1986) (emphasis in original). Dr. Fost's justification has been given in its entirety. Three out of four of the purposes described relate to fending off perceived threats to medical autonomy.

¹⁹ President's Commission Report, *supra* note 13, at 217-23.

²⁰ *Id.* at 223. See the more detailed discussion of the President's Commission's approach in chap. 6 at the text accompanying notes 40-59.

²¹ Strain, *AAP Will Fight Rule*, *Milwaukee Sentinel*, July 22, 1983, at 6, col. 5.

²² Strain, *The Handicapped Infant*, *AAP News and Comment*, July 1983, at 15. The AAP developed guidelines for such committees. Infant Bioethics Task Force and Consultants, *Guidelines for Infant Bioethics Committees*, 74 *Pediatrics* 306 (1984) [hereinafter *Infant Bioethics Task Force and Consultants*]. Dr.

From this perspective, as Carl Schneider has observed:

[T]he wide range of deeply held opinions about neonatal euthanasia. . . presses us to take the problem. . . outside the sphere of substantive social rules by seeking ways to make decisions about neonatal euthanasia which do not require social conclusions about its underlying questions. Where there is pressure of this kind, the law. . . seeks procedural devices that obviate the need for substantive rules. For neonatal euthanasia, the nonsubstantive solution has commonly been to establish hospital committees to decide case by case whether neonatal euthanasia is appropriate.²³

Thus, the proponents of ethics committees sought to shift the question from the substantive one of *whether* treatment should be withheld to the procedural one of *who should decide* whether treatment should be withheld.

As a substitute for HHS's proposed "Baby Doe" rule to implement section 504, the AAP submitted a detailed proposal for mandatory infant bioethics committees in each hospital.²⁴ Before promulgating the Final Rule, HHS conducted negotiations with the AAP, other medical groups, and disability rights groups, negotiations that soon focused on incorporating some modification of the AAP proposal.²⁵

As a result of these discussions, the Final Rule included a recommendation that hospitals establish what HHS called "Infant Care Review Committees." However, HHS recognized that the original rationale for ethics committees stood in stark contrast to the approach embodied in the nondiscrimination tenets of section 504.²⁶ Inherent in reliance on section 504 was the assumption that the law establishes a societally defined basis for determining when life-preserving treatment must be provided to children with disabilities and when it may be withheld from them. In contrast, inherent in the original rationale for ethics committees was the assumption that such determinations should be decided on a

case-by-case basis varying from hospital to hospital. Because of this dichotomy, the Supplementary Information published with the Final Rule explained that HHS had "revised the Academy's model somewhat to underscore that the purpose of the ICRC is to advance the basic principles embodied in section 504."²⁷

In the words of bioethicist Thomas Murray, a proponent of ethics committees and an opponent of the Final Rule:

[A]lthough the hospital committee described in the rule is closely modeled on the one suggested by the American Academy of Pediatrics, its name has been changed from "Infant Bioethical Review Committee" to "Infant Care Review Committee"—substituting a medical for a moral term. And one type of member recommended by the Academy is absent from the HHS version—"the ethicist or member of the clergy."²⁸

The 504 Final Rule was promulgated in January 1984. In October the Child Abuse Amendments of 1984 were signed into law. This legislation directed HHS to publish model guidelines for infant care review committees,²⁹ and when the Department did so in April 1985, the model guidelines were quite similar to those promulgated as a part of the Final Rule under section 504.³⁰ Before issuing the model rules, the Department had published interim model guidelines on December 10, 1984, and provided a 60-day period for public comment.³¹ Responding to views expressed during this comment period by medical groups, the Department noted:

Some commenters suggested a different name for the committee, such as "Infant Bioethics Committee" or some other term that emphasized the committee's function of considering questions of medical ethics. The Department has not changed the title of the committee because nothing in the authorizing statute corroborates the notion that the focus of the committee should be "medical ethics," at least to the extent that term connotes considerations different than those involved in evaluating medical treatment

²³ Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 Calif. L. Rev. 151, 153-54 (1988). See also Fost, *Putting Hospitals on Notice*, Hastings Ctr. Rep., August 1982, at 5, 7 ("[T]he search for substantive criteria may be too difficult, and procedural safeguards may prove more serviceable. The government could, for example, require the establishment of a local review process, similar to the institutional review boards. . . .").

²⁴ *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1622, 1623 (1984) [hereinafter Final Rule (504)].

²⁵ Hilts, *HHS Moves to End "Baby Doe" Controversy on the Handicapped*, Washington Post, Aug. 24, 1983, at A2, cols. 1-5.

²⁶ The hospital ethics committee was understood by its proponents to be an alternative rather than a complement to enforce-

ment of section 504. See, e.g., Fleischman & Murray, *Ethics Committees for Infants Doe*, Hastings Ctr. Rep., December 1983, at 5, 6-8.

²⁷ Final Rule (504), *supra* note 24, at 1625.

²⁸ Murray, *At Last, Final Rules on Baby Doe*, Hastings Ctr. Rep., February 1984, at 17, 17 (emphasis in the original).

²⁹ 42 U.S.C.A. §5103 note (West Supp. 1988).

³⁰ *Services and Treatment for Disabled Infants; Model Guidelines for Health Care Providers To Establish Infant Care Review Committees*, 50 Fed. Reg. 14893 (1985) [hereinafter HHS Model ICRC Guidelines].

³¹ *Services and Treatment for Disabled Infants; Interim Model Guidelines for Health Care Providers to Establish Infant Care Review Committees*, 49 Fed. Reg. 48170 (1984).

possibilities that “will be most likely to be effective in ameliorating or correcting” all life-threatening conditions.³²

As contemplated by the model guidelines, “the basic policy [of infant care review committees (ICRCs)] should be to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.”³³ The Department envisioned that ICRCs would serve essentially as prognosis committees, marshalling and evaluating specialized medical opinion to determine whether the facts in particular cases placed them within the categories of the Child Abuse Amendments that require treatment or within the exceptions that make the provision of treatment (other than nutrition, hydration, or medication) legally discretionary.

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 enactment of the law, but would instead focus on an analysis of how the law should properly be applied to the facts of that case. The “ethical issues” concerning what circumstances justify withholding of treatment were not to be up for reconsideration on a case-by-case basis; they were to be regarded as settled by the provisions of the Child Abuse Amendments.³⁴ Dr. Richard Barthel, chair of the Ethics Advisory Committee at Children’s Hospital of Wisconsin, commented: “What does an ethics committee do at this point? Does it say, ‘People, follow the law?’ Then they put themselves out of business, frankly. Because the law is pretty clear. You probably don’t have to debate many of these issues. . . .”³⁵

³² HHS Model ICRC Guidelines, *supra* note 30, at 14897.

³³ *Id.* at 14894.

³⁴ The HHS guidelines have no mandatory force. No hospital is required to establish an infant care review committee. Any hospital that does is not required to follow the Federal guidelines, nor will it receive any reward for doing so. HHS Model ICRC Guidelines, *supra* note 30, at 14893. However, to qualify for Federal funds, each State must have in place procedures that provide for prompt notification by health care facilities of suspected withholding of medically indicated treatment, as defined by the Federal standards. 45 C.F.R. § 1340.15(c)(2)(ii) (1987). An infant care review committee following the President’s Commission/AAP model instead of the HHS model would not report cases which the committee judged to be within the “gray area” and in which, upon consideration, it considered withholding of treatment ethically acceptable. If such withholding could

Infant Care Review Committees in Action

Are the infant care review committees serving as prognosis committees, providing advice on whether or not the facts in particular cases bring them within the circumstances the Child Abuse Amendments define as requiring treatment as contemplated by the HHS model guidelines? Or do they act as “ethics” committees, making quality of life judgments about whether or not treatment should be withdrawn without reference to detailed legal standards—the role originally envisioned for them by the President’s Commission and the American Academy of Pediatrics? A limited number of accounts describing the functioning of committees have appeared since the effective date of the Child Abuse Amendments.

A May 1986 article coauthored by the chair of the Children’s Hospital of Wisconsin Ethics Advisory Committee described its functioning.³⁶ He and his coauthor advocated a model State statute that would give absolute and unreviewable authority to a unanimous hospital ethics committee (provided that parents and treating physicians agree) to choose to deny treatment to any newborn child “who allegedly has substantial physical and/or mental deficiencies that cannot be significantly cured or alleviated by surgery or other medical treatment.”³⁷ This position is self-evidently closer to the President’s Commission/AAP model than to the Department of Health and Human Services’ model. Nevertheless, the authors stated that “[i]n making many of [its] determinations,” the Children’s Hospital committee “was guided by the Baby Doe regulations,” which they then paraphrase, including this description of the third exception to required treatment: “treatment would be virtually futile in terms of the survival of the infant and, under the circumstances, inhumane.”³⁸ However, in describing four cases in which the committee agreed with parents and

be suspected of transgressing the Federal standards, this failure to report would violate the law.

³⁵ Address by Dr. Richard Barthel, Interpreting the Law: The Roles of the Hospital, Child Protective Services, and Legal System in “Baby Doe” Cases, Conference on ‘Baby Doe’ Ethical, Legal, and Child Protection Issues in Medical Treatment of Infants with Disabilities (Oct. 6, 1987) (videotape in files of U.S. Commission on Civil Rights).

³⁶ Shapiro & Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?* 37 *Hastings L.J.* 827 (1986). Dr. Richard Barthel chaired the committee; Robyn Shapiro is a bioethicist and attorney.

³⁷ *Id.* at 859.

³⁸ *Id.* at 855 n. 164. *Cf.* discussion in chap. 7, text accompanying notes 99–102.

treating physicians that life-preserving treatment should be withheld, they wrote: "In each case, the committee determined that the treatment either was futile, only prolonged the dying process, or was *inhumane and not in the best interests of the child.*"³⁹ This third category is far broader than the Child Abuse Amendments exception and effectively reintroduces a panoply of subjective judgments about the projected quality of life of a child with a disability.⁴⁰

The authors said the committee reviewed other cases "in which the parents, the physician, or other caregivers questioned whether the child's quality of life merited continued support or treatment."⁴¹ In one such instance, the treating physician wanted to terminate ventilation for a child with congenital paralysis.

The EAC [Ethics Advisory Committee] split strongly on the answer to this question because of the members' differing perspectives on the child's quality of life. Some felt that the child's inability to move and to communicate rendered the quality of his life negligible. Others felt unable to make such a judgment given the infant's age and the unpredictability of treatment outcome. Because the EAC could not reach a consensus, it advised continued ventilator support.⁴²

On the basis of the facts given, it is hard to see even a colorable basis under the Child Abuse Amendments that would have justified denial of lifesaving treatment in this case.⁴³ Nevertheless, it was the subject of intense discussion and division on the committee. More to the point, even those supporting continued treatment did so apparently based only on their differing judgments concerning the child's projected quality of life—a factor emphatically excluded from consideration under the Child Abuse Amendments.⁴⁴

³⁹ Shapiro & Barthel, *supra* note 36, at 855 (emphasis added).

⁴⁰ See the extended discussion of this point in chap. 7 at the text accompanying notes 83–102.

⁴¹ Shapiro & Barthel, *supra* note 36, at 854–55.

⁴² *Id.* at 856.

⁴³ As with all the cases discussed, it is not clear whether this one occurred before or after the effective date of the Child Abuse Amendments. The article described the committee's functioning "over its three-and-one-half years of existence prior to the passage of the Child Abuse Regulations and during the six months following the law's implementation." *Id.* at 853. It is noteworthy that the authors made no mention of a significant change in the methodology of the committee during the last 6 months. Moreover, the article presented the committee's approach to the cases they describe as a model in general worth emulating, not as a methodology that should be radically altered in light of the entrance into effect of the Child Abuse Amendments.

In another case, "consultants" and "the majority of the nursing staff" wanted to terminate treatment for a child whose "prognosis included blindness, deafness, seizures, and negligible developmental potential."⁴⁵ The child's parents strongly supported continuation of treatment.

The committee reached a consensus that further care was not ethically mandatory. There was a strong minority opinion that further care violated the child's best interests and that the mother's "abusive" stance should be reported and the case should be "taken to court." The committee's recommendations were entered into the child's chart, but there was no change in care.⁴⁶

In this instance, it appears from the facts available that the committee supported denial of treatment that would have violated the standards of treatment in the Child Abuse Amendments.⁴⁷ There is no indication that the child was chronically and irreversibly comatose, that the treatment would have merely prolonged dying, that treatment would have been ineffective or otherwise futile in terms of the survival of the child, or that the treatment would have been "virtually futile in terms of the survival" of the child—a prerequisite to any legally valid consideration of whether "the treatment itself under such circumstances would be inhumane."⁴⁸ Had it not been for the insistence of the child's parents that treatment be provided, it seems evident that the committee would have sanctioned—and certainly not reported—denial of treatment of the sort now required by the law.

The committee did support treatment in two cases in which physicians and parents wanted to stop it and in all three cases in which parents wanted to stop it but physicians wanted to continue it, as well as in two cases in which the physician was uncertain.⁴⁹ Although the published record does not

⁴⁴ The HHS Interpretative Guidelines state: "*The Department strongly believes such an interpretation [consideration of the infant's future 'quality of life'] would be inconsistent with the statute.*" 45 C.F.R. Pt. 1340 App. Interpretative Guideline 9 (1987) (emphasis in original).

⁴⁵ Shapiro & Barthel, *supra* note 36, at 857.

⁴⁶ *Id.* at 857–58. Because the parents refused to accept the negative prognosis for their child, physicians went to the extent of ordering a psychiatric assessment of the mother. It concluded "that she was under stress but competent, well informed but unable to accept the medical information." *Id.* at 857. *Cf.* chap. 2.

⁴⁷ It is unclear, however, whether the case occurred before or after the Child Abuse Amendments of 1984 took effect in October 1985.

⁴⁸ 45 C.F.R. § 1340.15(b)(2) (1987).

⁴⁹ Shapiro & Barthel, *supra* note 36, at 855–57.

clearly indicate that the committee's deliberations actually resulted in the denial of treatment to any child in violation of the Child Abuse Amendments,⁵⁰ it does establish that during the period described in the article the committee gave consideration to factors impermissible under the Child Abuse Amendments. Rather than regarding itself as a prognosis committee with the role of making judgments about the medical facts and then applying the decided legal principles to them, it conducted itself, at least to some extent, as an autonomous ethical arbiter. In significant respects, therefore, the Children's Hospital of Wisconsin Ethics Advisory Committee appears in practice to have acted in a manner more closely approaching the President's Commission/AAP model than the HHS model.

The infant bioethical review committees of the Albert Einstein College of Medicine-Montefiore Medical Center affiliated hospitals have not only been the subject of published accounts,⁵¹ but have also been held up as "a useful reference for hospitals considering the establishment of similar committees" by the HHS Inspector General.⁵² Dr. Alan Fleischman, director of the Division of Neonatology and professor of pediatrics at the Albert Einstein College of Medicine and Montefiore Medical Center, has written about their operation. Although he noted and quoted the standards of treatment embodied in

the Child Abuse Amendments,⁵³ he described the approach the committees take in language that could have come from the President's Commission report:

We believe that the proper role of the ethics committee is to "decide who should decide"; that is, ethics committees should not . . . [arrogate] all decisions to themselves. . . . Our committee believes that there are three types of cases. First are those instances where treatment is clearly required based on the best interests of the infant and the future assessment of the benefits of that treatment. Second are cases where nontreatment is morally indicated—when infants are in the process of dying or when treatments would be clearly futile. Third are the cases where in our imperfect wisdom we honestly do not know what is in the best interests of the infant. This third "gray area" comprises a significant share of the morally problematic cases in newborn nurseries. . . . On these occasions when the principle of best interests of the infant cannot tell us what to do, we honor two other principles—respect for the autonomy of the family and letting those who bear the burdens make the choice; in other words, the parents who bear the burdens ought to make a decision consistent with the range of reasonable alternatives provided by the treating physicians. Thus, our ethics committee has agreed to differing outcomes in similar cases based on parental discretion within the range of the alternatives presented by the treating physicians.⁵⁴

Fleischman stated that: "Although the federal regulations provided certain standards or guidelines, we have proposed. . . principles that might be utilized as the basis for decision making in complex cases and

⁵⁰ With regard to the four reported instances in which the committee agreed with the physicians and parents that treatment should be withheld (see *supra* note 39 and accompanying text), the article is ambiguous about how many of the cases involved treatment that would merely prolong dying—a legal basis for termination of treatment—as opposed to circumstances in which life could be preserved but treatment was considered "inhumane" for quality of life reasons. It is also unclear which, if any, of these cases occurred after the effective date of the Child Abuse Amendments.

⁵¹ Fleischman, *Bioethical Review Committees in Perinatology*, 14 *Clinics in Perinatology* 379 (1987); Fleischman, *An Infant Bioethical Review Committee in an Urban Medical Center*, *Hastings Ctr. Rep.*, June 1986, at 16. See also Fleischman & Murray, *Ethics Committees for Infants Doe?* *Hastings Ctr. Rep.*, December 1983, at 5 (describes "Neonatal Ethics Rounds" at Montefiore Medical Center that preceded formation of bioethical review committees and sets forth Fleischman's view of the purpose of such committees).

⁵² Office of Inspector General, U.S. Department of Health and Human Services, *Infant Care Review Committees Under the Baby Doe Program 11* (1987) [hereinafter *Committees OIG Report*]. Commenting on an earlier draft of this report, Montefiore Medical Center noted that personnel from the Office of Inspector General (OIG) "spent a full-day on-site. . . [at] Montefiore, in which OIG staff conducted case reviews and interviewed Committee members to get an in-depth understanding of the Committee's work." Letter from Nadia C. Adler, Vice President—Legal Affairs and General Counsel, Montefiore Medical

Center, to William J. Howard, General Counsel, United States Commission on Civil Rights, at 5 (Nov. 11, 1988) (*reprinted* in app. D). Montefiore pointed out that the Inspector General's report stated that the Inspector General's report described the Einstein-Montefiore Committees as "generally structured and functioning in conformance with the HHS model guidelines." *Id.*, quoting Committee's OIG Report at 11.

In a letter commenting on the portion of chap. 12 critical of the Office of Inspector General for, among other things, praising the Einstein-Montefiore Committees in its report, the Inspector General wrote, "[Y]ou state that the OIG failed to review the facts in unreported cases considered by hospital infant care review committees. The purpose of our hospital visits was to determine how hospital committees are structured and functioning to deal with potential baby doe situations. It was never our intent to review actual case files." Letter from Richard Kusserow, Inspector General, to William Howard, General Counsel, U.S. Commission on Civil Rights 1-2 (Oct. 12, 1988). Referring to the draft's criticism of the Inspector General's report for describing the principles used by the Einstein-Montefiore Committees without pointing out their divergence from the standards required by the Child Abuse Amendments, the Inspector General wrote, "The purpose of this portion of the report was simply to serve as a reference to other hospitals considering the establishment of similar committees." *Id.*

⁵³ Fleischman, *Bioethical Review Committees in Perinatology*, 14 *Clinics in Perinatology* 379, 383 (1987).

⁵⁴ *Id.* at 387-88.

have found these principles to be helpful in deliberations and discussions at our infant bioethical review committee meetings.”⁵⁵ Among those principles is: “Withholding or withdrawing treatment may be considered when such treatments are reasonably deemed futile and merely prolonging the dying process or when the medical treatment imposes a burden that lacks compensating benefits for the infant.”⁵⁶

Commenting on an earlier draft of this report, Montefiore Medical Center asserted that these “principles are intended to assist the Committee members in applying the Child Abuse Amendments to the cases under review.”⁵⁷ Emphasizing that the “Child Abuse Amendments and the regulations thereunder expressly defer to the ‘treating physician’s (or physicians’) reasonable medical judgement,” the center stated:

In other words, Congress and HHS have made clear that the determination as to what, if any, treatment is medically indicated, is to be left to the professional judgment of the treating physician(s). Given that medical judgments are key to decision-making under the Child Abuse Amendments, it cannot responsibly be suggested that the Committee has violated the Child Abuse Amendments, simply on the superficial observation that medical treatment has been withheld.⁵⁸

The center relied in particular on the HHS interpretation of the exception to a general requirement of treatment the Child Abuse Amendments create 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.”⁵⁹ As the quoted passage makes clear, however, such benefits-burden balancing is legal only when the child is

“highly unlikely to survive.” The statutory language itself requires that “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.”⁶⁰ Although the law is phrased in the conjunctive, the principle Fleischman says the Einstein-Montefiore committees employ is phrased in the disjunctive: unlike the law, it allows treatment denial in cases of futility *or* under benefit-burden analysis.

From February 1984 through August 1986 (during the last 11 months of which the Child Abuse Amendments were applicable), eight cases involving withholding of life-preserving surgery from children “in the first days of life” were reviewed by the affiliated committees. (A total of 30 neonatal cases were reviewed; the article is not clear about the treatment/nontreatment outcome in the other 22 cases.) In one case in which the attending physician believed treatment should be provided and the parents disagreed, the committee referred the matter to the child protective services agency.⁶¹ In a second case in which the treating physicians and parents believed treatment should be withheld, the committee considered that it should be provided, and both the physicians and parents were then convinced to agree to continued treatment.

In a third case the treating physicians wanted to deny treatment while the parents desired it to be provided; although the child died (presumably without receiving the life-saving surgery), the committee retrospectively concluded that “the parents’ request was imposing undue pain and suffering on the infant for no potential benefit.” In all the other cases the committee agreed with the desire of physicians and parents to withhold treatment.⁶²

⁵⁵ *Id.* at 384.

⁵⁶ *Id.* at 384–85. *But cf.* 45 C.F.R. §1340.15(b)(2) (1987) (definition of the Federal medical treatment standard of care barring “withholding of medically indicated treatment”) (discussed in chap. 7).

⁵⁷ Letter from Nadia C. Adler, *supra* note 52, at 3.

⁵⁸ *Id.* at 7–8.

⁵⁹ *Id.* at 7, quoting 45 C.F.R. §1340.15 app. (1987). See chap. 7.

⁶⁰ 42 U.S.C.A. §5102(2)(B)(3) (West Supp. 1988).

⁶¹ Montefiore Medical Center, commenting on this statement in an earlier draft, expressed concern that it implied the view “that the Einstein-Montefiore Committee took a neutral stance and was attempting to evade responsibility” when in fact the committee made the referral in order to override the parental refusal to consent to treatment. Letter from Nadia C. Adler, *supra* note 52, at 11. The Commission does not mean to suggest that the committee’s action in this case implied neutrality; rather, in this

case it is clear that the committee acted properly and fulfilled the responsibility to report imposed upon it by the law.

⁶² Fleischman, *supra* n. 53, at 388–89. In its letter of comment, Montefiore says, concerning the third case: “As Dr. Fleischman’s article plainly states, a retrospective review of the case (the infant was imminently dying and indeed died before the Committee could be convened for prospective review) indicated that the parents’ wish to provide treatment would have imposed ‘undue pain and suffering on an infant for no potential benefit.’ (Fleischman, p. 389) The Report, once again, omits this detail.” Letter from Nadia C. Adler, *supra* note 52, at 12. In fact, the Fleischman article at no point states that the child was imminently dying. If Montefiore is making this assertion based on its review of the medical records of the case, rather than on the article, then the denial of treatment would in fact not have violated the Child Abuse Amendments. However, what is striking about the description of the case in Fleischman’s article, like that of all the other

Reviewing the first 30 months of the committees' operations, Dr. Fleischman concluded that "its existence had reversed the treatment decision for only one patient."⁶³ This did not lead him to consider, however, that the committees were not serving their function. Rather, he wrote:

Since withholding or withdrawing of medical treatments is often carried out by the nurses with the consent and involvement of the families, review and confirmation of the appropriateness of this course of action by the ethics committee has made both nurses and parents far more comfortable with this aspect of the care of infants. . . . The psychological trauma of making a decision that results in the death of one's own child, we believe, may be greatly relieved by this decisional review process.⁶⁴

The Commission emphasizes that in the absence of more detailed facts about the cases reviewed by the Montefiore committees from October 1985 onward, it is impossible to determine whether any of the treatment denials violated the standards established by the Child Abuse Amendments. However, Fleischman's article describes a set of committees that has been employing a balancing of "burden" and "benefit" standard that takes into account quality of life factors, rather than directly and explicitly applying the standards created by the amendments. Therefore, it seems a fair conclusion that the Einstein-Montefiore committees adhere more closely to the President's Commission/AAP model than to the HHS model.

The committee at University Hospitals of Cleveland has also been the subject of a published report.⁶⁵

The authors, who are associated with the committee, are quite open about their rejection of the HHS model:

Although federal regulations have stimulated creation of ethics review committees their essential function is not adherence to government regulations but fulfillment of important needs within the hospital.

. . . .

cases he details, is that the committee's reasoning is never described in terms of whether the cases fit within the categories established by the Child Abuse Amendments, but always in such ambiguous and amorphous terms as whether treatment or nontreatment would be "beneficial," or "appropriate," or in "the best interests of the infant," language largely popularized by the President's Commission's Report.

⁶³ Fleischman, *supra* n. 53, at 389. Fleischman believed that in the case referred to the child protective services agency, "it is highly likely that the same outcome. . . would have occurred prior to the existence of our infant bioethical review committee." *Id.*

Our approach differs. . . with the optional model [proposed by HHS]. . . . We prefer not to specify exceptions to the requirement to provide lifesaving treatment, because of concern that this might lead to oversimplification, neglecting unique aspects of individual cases. . . . We specify that the best interests of the patient are our primary concern in dealing with infant (or other incompetent) patients.⁶⁶

The authors are frank in acknowledging that their criteria for treatment decisionmaking differ from those required by the law, but they claim they do not violate the "spirit" of the law when they conclude a child should be denied legally mandated lifesaving treatment as long as they consider death to be in the child's "best interests":

Committee recommendations are based on moral rather than legal. . . considerations. . . .

. . . .

. . . If the committee, family, and physician recommendations are in agreement but the proposed medical action appears contrary to government regulations, the potential conflict should be communicated to the medical director or chairman of the pediatric department. Some may regard an action (or inaction) that runs counter to specific statutes as civil disobedience. Although civil disobedience is morally justified if a law is unjust, we do not claim that the new federal regulations are unjust. Rather, the regulations are open to alternative interpretations of what constitutes the best treatment for individual patients. . . . In other words, the spirit of the law supports the practitioners' obligation to promote the patient's interests in situations where literal observance may oppose it.⁶⁷

It is evident from the article that the authors think one of the good effects of a functioning committee system is a decreased risk of government intervention. They report that on two occasions the committee was contacted by the Department of Health and Human Services because Baby Doe complaints had been received. "When the results of [committee deliberations] were reported to the Department. . . , no further investigation was judged necessary."⁶⁸ The authors suggest that "proceedings might have

⁶⁴ *Id.* at 389-90.

⁶⁵ Kliegman, Mahowald & Youngner, *In Our Best Interests: Experience and Workings of an Ethics Review Committee*, 108 J. of Pediatrics 178 (1986).

⁶⁶ *Id.* at 178-79.

⁶⁷ *Id.* at 180, 185 (emphasis in original). The idea of having hospital legal counsel on the committee was rejected because of "the desire to focus on ethical rather than legal matters, and concern that an attorney's presence might impede that purpose." *Id.* at 186.

⁶⁸ *Id.* at 183.

been initiated in at least the two cases reported anonymously to the federal government, had our committee not been in place.”⁶⁹

Public information about a fourth hospital committee places it in the pattern of the President’s Commission/AAP model rather than the HHS model as well. St. Joseph’s Hospital in Denver, Colorado, made a point of calling its committee an “Infant Bioethics Committee” rather than an “Infant Care Review Committee” in order “to stress that ours is a *human value*—not a legal—emphasis.”⁷⁰ It also “decided early on not to include a lawyer, believing his/her presence could alter the human value course set by the IBC.”⁷¹

What evidence is available from surveys suggests these four committees are not atypical. In September 1987, the HHS Inspector General published a report based on visits to ethics committees in 10 hospitals in eight major cities.⁷² Although the HHS guidelines recommend that committee meetings be called whenever a preliminary decision has been made to withhold or withdraw life sustaining treatment from an infant with a disability in relevant categories,⁷³ 8 of the 10 committees visited had no such requirement.

In contrast, “All committees indicated they review cases involving disagreement between principal parties in the case (treating physician, parents, other hospital staff).”⁷⁴ The 1986 AAP/University of Connecticut survey found that of the ethics committees with prospective review, only 23.2 percent made it mandatory in certain cases—and only 61.7 percent of that 23.2 percent, or 14.3 percent of all committees with prospective review, required review in all cases in which treatment might be withheld or withdrawn from any infant.⁷⁵

These are significant findings. It appears 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.⁷⁶

Infant Care Review Committees and Reporting

Even before the passage of the 1984 amendments, the Federal regulations implementing the Child Abuse Prevention and Treatment Act required States receiving Federal funding for their child protective services programs to “provide by statute that specified persons must report and by statute or administrative procedure that all other persons are permitted to report known *and suspected* instances of child abuse and neglect to a child protective agency or other properly constituted authority.”⁷⁷ The implementing regulations for the Child Abuse Amendments of 1984 establish that States receiving Federal funds must ensure that health care facilities designate individuals with the duty promptly to notify the State child protective services agency of all “cases of suspected medical neglect (including instances of the withholding of medically indicated treatment from disabled infants with life-threatening conditions).”⁷⁸

Because not merely known but also “suspected” instances must be reported, the health care facility’s obligation to notify the State agency is not limited to cases in which, for example, the infant care review committee or the responsible hospital official makes a final determination that illegal withholding of treatment is occurring or about to occur. Nor is it limited to cases in which the infant care review committee or the responsible hospital official has attempted to convince a parent or guardian to consent to legally required treatment but has failed and is turning to the civil authorities as a last resort.

⁶⁹ *Id.* at 187.

⁷⁰ Infant Bioethics Committee, *A Demonstration by the St. Joseph Hospital IBC*, in The Center for Applied Biomedical Ethics at Rose Medical Center, *Medical Neglect and the Disabled Infant: The Impact of the Baby Doe Regulation 25, 25-26* (rev. ed. 1987) (quoting Dr. Donald W. Parsons, chair of the Infant Bioethics Committee).

⁷¹ *Id.*

⁷² Committees OIG Report, *supra* note 52, at ii.

⁷³ HHS Model ICRC Guidelines, *supra* note 30, at 14895.

⁷⁴ Committees OIG Report, *supra* note 52, at 7.

⁷⁵ 65.8 percent of the 23.2 percent, or 15.3 percent of all committees with prospective review, required review in instances of withholding or withdrawing treatment from noncomatose infants. The rest of those who did make review mandatory did so in cases of disagreement among medical staff, or among medical staff and parents. National Collaborative Survey, *supra* note 3, at 44 (1987) (table 22).

⁷⁶ *Cf.* the rationale for such committees given by Dr. Norman Foster, *supra* note 18 & accompanying text.

⁷⁷ 45 C.F.R. §1340.14(c) (1987) (emphasis added).

⁷⁸ 45 C.F.R. §1340.15(c)(2)(ii) (1987).

Webster's defines "suspected" as "that one suspects or has a suspicion of. . . ." ⁷⁹ "Suspicion" is defined as "imagination or apprehension of something wrong or hurtful without proof or on slight evidence."⁸⁰ By contrast, "known" is defined as something "that has become a part of knowledge <a truth that no one denies>."⁸¹ Clearly, when there is enough question about an ongoing or contemplated withholding of treatment that an infant care review committee is convened to discuss it, there must be at least a "suspicion" that withholding of medically indicated treatment may be in prospect. The plain language of the applicable law would require a report.

Yet, it is evident that this is not the practice of most infant care review committees. The HHS Inspector General's report noted that of the "between 20 and 36 baby doe cases" considered by ethics committees at the 10 hospitals studied "since the regulations went into effect in October 1985," only 3 were reported to State child protective service agencies.⁸² "Committee members pointed out that differences of opinion between treating physicians, parents and the committee can usually be resolved through an informal discussion process. *If this is not possible*, the hospital refers the case to CPS for investigation and possible legal action."⁸³

These widespread failures to report are especially serious in light of the adoption by many hospital ethics committees of an approach that in general bypasses the Child Abuse Amendments standard of care in favor of the nebulous and subjective tripartite division of cases promoted by the President's Commission and the AAP. It means that there has usually been no independent review or investigation of what may have been—if the figures from the 10 hospitals contacted by the HHS Inspector General may be projected to the Nation at large—hundreds

of potential Infant Doe cases since the Child Abuse Amendments went into effect in October 1985.

Limitations of Hospital Self-policing

It is questionable whether most committees are constructed in a manner that suits them to searching scrutiny of proposed denials of treatment. Infant care review committees, although they upon occasion have "outside" members, represent an approach to the "Baby Doe" problem that relies essentially upon the internal self-regulation of the health care community. Not only the Department of Health and Human Services,⁸⁴ but also the American Academy of Pediatrics,⁸⁵ recommended that committees include representatives of disability groups. But, as Adrienne Asch testified, in practice, a disability perspective is often unrepresented on the committees.⁸⁶ The 1986 survey found that of the responding hospitals, less than a quarter of their ethics committees—23.9 percent—had a representative of a disability group.⁸⁷ Instead, the committees are dominated by health care personnel from the institutions themselves. A practicing pediatrician serves on 86.6 percent of the committees, a practicing neonatologist on 75 percent, a practicing physician of another specialty on 80.2 percent, a practicing registered nurse on 88.4 percent, and a hospital administrator on 78.3 percent.⁸⁸

Yet, a preponderance of medical personnel on committees does not necessarily mean that they are especially well equipped to serve as prognosis committees. As Dr. Mildred Stahlman testified, "[M]ost committees are not committees of experts in the medical field that the patient's problem lies."⁸⁹ In the words of George Annas, chief of the Health Law Section at the Boston University School of Public Health, "If consultation concerning the patient's prognosis is indicated, . . . a medical expert in the particular condition from which the patient is

representation of disability groups, it is doubtful that such organizations have enough resources to provide adequate input into every individual hospital's ethics committee. It would be difficult to find an adequate number of disability rights advocates with up to date and accurate information on the treatment of every disability to cover every hospital in the Nation.

⁸⁸ *Id.*

⁸⁹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 9 (vol. I) (1985) (testimony of Mildred T. Stahlman, M.D., Director, Division of Neonatology, Vanderbilt University). Dr. Stahlman opposed resort to committees not because she believed they are disposed to approve illegal denial of treatment but because she believed decisions about provision or denial of treatment should be left to "neonatologists [who are] their patients' best advocates." *Id.* at 5.

⁷⁹ Webster's Third New International Dictionary of the English Language 2303 (P. Grove ed. 3rd ed. 1981).

⁸⁰ *Id.* at 2304.

⁸¹ *Id.* at 1253.

⁸² Committees OIG Report, *supra* note 52, at iii.

⁸³ *Id.* at 5 (emphasis added).

⁸⁴ HHS Model ICRC Guidelines, *supra* note 30, at 14894.

⁸⁵ Infant Bioethics Task Force and Consultants, *supra* note 22 at 307.

⁸⁶ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 144 (vol. II) (1986) (testimony of Adrienne Asch, Adjunct Lecturer in Social Psychology, City College of New York).

⁸⁷ National Collaborative Survey, *supra* note 3, at 35 (1987) (table 13). Even if local hospitals were to seek to broaden

suffering should be consulted, not a committee of generalists.”⁹⁰

Many hospital ethics committees are largely insular bodies, sharing the mores and limitations of knowledge and viewpoint of the local hospital. A reluctance to criticize one’s colleagues, let alone report their decisions to a State agency, is only natural in such a setting.

As Carlton Sherwood testified:

Physicians and spokesmen from medical organizations frequently render offhand criticism of nontreatment incidents. Yet you’ll note that not one physician or medical organization has ever formally or informally filed a complaint against any of the physicians who conducted these experiments, including Bloomington, Indiana.

Indeed, rather than being censured, several of the physicians went on to more prestigious hospitals where they continue to practice medicine, and some even teach, presumably, the same methods that they were practicing when they authored these articles.⁹¹

Resort to infant care review committees, in short, presents the same problem generally applicable to the creation of an internal body as a means of showing the public that the institution is serious about correcting abuses: an institution rarely does a good job of policing itself. “Institutions and their staffs,” Annas has written, “often see the primary function of ethics committees as protecting them against potential legal liability for treating or not

treating particular patients. . . . Ultimately, it will be seen as unjust to have fundamentally different policies regarding the treatment of handicapped newborns at different hospitals. Policy in this area will have to be nationally based and thus consistent from one hospital to another. . . . [A]s soon as a national consensus does develop, it will not be fair or feasible for individual hospitals to ignore it and set their own idiosyncratic policies.”⁹² Outside oversight is needed.

Conclusion

Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments,⁹³ and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

At the same time, it is clear that such committees are here to stay. Therefore, the Commission believes there is a need to ensure 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.⁹⁴

⁹⁰ Annas, *Ethics Committees in Neonatal Care: Substantive Protection or Procedural Diversion?*, 74 Am. J. Pub. Health 843, 844 (1984). After the New Jersey Supreme Court, in the Karen Ann Quinlan case, called for the use of hospital ethics committees to determine when life support systems should be withdrawn: “This was soon seen as an improper use of such a committee: the court found medical prognosis the determining factor, and only qualified physicians can make this determination. Thus New Jersey ‘ethics committees’ have been replaced by ‘prognosis committees’ made up entirely of consulting physicians.” *Id.* at 843.

⁹¹ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 47–48 (vol. II) (1986) (testimony of Carlton Sherwood).

⁹² Annas, *supra* note 90, at 843, 845. Annas wrote before the passage of the Child Abuse Amendments of 1984, which established the national standards. Annas pointed out that, in contrast to the HHS model set forth in its section 504 Final Rule, the AAP model “tilts more in the direction of protecting the institution by keeping difficult cases out of court than of protecting the infant. . . . [U]nlike the Administration’s proposal, the AAP proposal contains no substantive rules for the ethics committee to apply. . . .” *Id.* at 844.

⁹³ See chap. 9.

⁹⁴ See chap. 13.

The Performance of the Federal Government

How well has the Federal Government fulfilled its responsibilities to ensure adequate enforcement of Federal laws that protect children with disabilities from discriminatory denial of medical treatment for life-threatening conditions? The two principal sources for Federal involvement have been enforcement of regulations issued under section 504 of the Rehabilitation Act of 1973¹ until they were struck down, and enforcement of the Child Abuse Amendments of 1984.²

Section 504

Responsibility for enforcing section 504 in this context rested with the Office for Civil Rights (OCR) in the Department of Health and Human Services until a final judgment and order was entered by the New York Federal District Court enjoining the final version of the "Baby Doe" regulations on June 11, 1984.³

In none of the cases OCR investigated—even the Bloomington Infant Doe case—did it officially determine that a violation of section 504 had occurred.⁴ Standing alone, however, that observation is misleading. When it found a discriminatory denial of treatment, OCR asked for assurances that practices would be changed to achieve compliance with section 504 in the future. If it got them, it did not make a public "finding of discriminatory with-

holding of medical care."⁵ Thus, in theory OCR might detect noncompliance in fact and secure remedial action by the discriminating party, thus fulfilling its role, without officially reporting a finding of noncompliance.

However, OCR has been criticized for failure to conduct prompt and effective investigations.⁶ Of 150 cases OCR investigated from April 1982 through December 1983, only 31 were closed by the latter date—all with a finding of no violation or of insufficient information to investigate.⁷

It appears that members of the OCR staff assigned to Baby Doe investigations were unsympathetic to their enforcement duties:

[C]ritics. . . within the department. . . say the government's policy violates family privacy and intimidates hospitals and their staffs.

One department employee, who has been sent to investigate Baby Doe cases, called the assignment "probably the ugliest thing I've ever done," and added, "I never want to face another mother who is looking at me and saying, 'Why are you into my family business?'" . . .

Another Baby Doe team member, who has almost a decade of experience in policing civil rights for the agency, said, "We never had a Baby Doe problem before this administration. It was beyond our imagination. It just came out of the blue from someone who has a very creative mind."

¹ See chap. 6.

² See chap. 7.

³ *Am. Hosp. Ass'n v. Heckler*, 585 F. Supp. 541 (S.D.N.Y.), *aff'd* 794 F.2d 696 (2d Cir. 1984), *aff'd sub nom. Am. Hosp. Ass'n v. Bowen*, 476 U.S. 610 (1986). See chap. 6.

⁴ *Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1622 (1984).

⁵ *Id.* at 1649.

⁶ See, e.g., *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 250 (1986) (vol. II) (testimony of Thomas Nerney, President, Disability Institute).

⁷ Sherwood, *Baby Doe: The Politics of Death* 11 (1984) (Washington Times reprint).

Department employees interviewed *all* said they had serious misgivings about the Baby Doe emphasis.⁸

Under the OCR procedures for Baby Doe investigations, medical consultants not unnaturally played a significant role.⁹ Generally speaking, only an educated and experienced medical expert—not a lay investigator inexperienced in medicine or disability—can make the technical judgment concerning what medical treatment is necessary to preserve a particular patient's life. Effective investigations, therefore, necessarily depend upon the use of medical consultants who are competent and willing to make such a medical judgment in strict accordance with the nondiscrimination principles embodied in section 504.

OCR's selection of at least some medical consultants was surprising. They included Dr. Gordon B. Avery and Dr. George Little, both of whom submitted affidavits on behalf of the plaintiffs in the suit to invalidate the original regulations.¹⁰ In a medical journal article, Dr. James Strain, the president of the American Academy of Pediatrics, revealed that during an investigation of alleged denial of treatment at Rochester, New York's, Strong Memorial Hospital in March 1983, the neonatologist flown in as OCR's consultant refused to examine the children concerning whom denial of treatment was alleged on the grounds that "the investigators had failed to obtain the parents' consent to examine the children."¹¹ Since the parents had presumably at least nominally acquiesced in the suspected denial of treatment, unilaterally giving them veto power over an investigation of the allegations was not a realistic way for the consultant

⁸ Cimons and Green, *U.S. Moves in Baby Doe Cases Stir Anger*, Los Angeles Times, Nov. 12, 1983, at A1, col. 4, A6, col. 2 (emphasis added). See also *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights 250-51* (1986) (vol. II) (testimony of Thomas Nerney, President, Disability Institute) (Department of Health and Human Services probably has many physicians who "make arguments about the primacy of the medical profession").

⁹ See, e.g., Office for Civil Rights, Department of Health and Human Services, *Discrimination Against Handicapped Infants by Withholding Treatment or Nourishment: Interim Expedited Procedure 3* (March 22-25, 1983) (included as Attachment 4 to Affidavit of Betty Lou Dotson, *Am. Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983)).

¹⁰ See Office for Civil Rights' Medical Consultants, attachment to Affidavit of Nathan D. Dick, Affidavit of George A. Little, M.D., attachment to Plaintiff's complaint for Declaratory and Injunctive Relief, Statement of Points and Authorities in Support of Complaint for Declaratory and Injunctive Relief (filed Mar.

to do an unbiased investigation of whether the allegations were substantiated.

Significant delays prevented efficient enforcement in investigations of substantial and notorious denial of treatment practices in Connecticut and Oklahoma.

Perhaps the first public acknowledgement of regular denial of lifesaving treatment to children with disabilities concerned Yale-New Haven Hospital. In 1973 Yale-New Haven pediatrician Raymond S. Duff coauthored a medical journal article revealing that 14 percent of a series of 299 deaths in the hospital's Newborn Special Care Unit were caused by deliberate withholding of life-preserving treatment, and providing a defense of the practice.¹²

In June 1981, the *Hartford Courant* published a series of articles by medical reporter Diane Brozek describing the continuation of the practices that had been set forth in 1973.¹³ "Doctors at Yale-New Haven Hospital's Special Care Unit routinely offer parents the option of letting newborns with spina bifida die by withholding food and the surgery needed to close the baby's lesion to prevent infection," she concluded.¹⁴ She recounted a number of specific instances presenting prima facie violations of section 504 as it was being publicly interpreted by the Departments of Justice and Health and Human Services:

* [Michael Renfrew had brain damage resulting from a hemorrhage shortly after his birth. T]he doctors recommended more than once that Michael be allowed to die. [His father] Douglas Renfrew couldn't bring himself to make the decision. He remembered telling the medical team that multiple [sic] handicapped children deserve to live "if only because they teach us to value life."

18, 1983), and Affidavit of Gordon B. Avery, M.D., Exhibit A to Defendant's Deposition of Gordon B. Avery, M.D. (Mar. 30, 1983), *Am. Academy of Pediatrics v. Heckler*, 585 F.Supp. 541 (S.D.N.Y. 1983) (Civil Action No. 83-0774).

¹¹ Strain, *Special Report: The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 *New Eng. J. Med.* 443, 444 (1983).

¹² Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 *New Eng. J. Med.* 890 (1973).

¹³ Brozek, *Defective Newborns Are Dying By Design*, *Hartford Courant*, June 14, 1981, at 1, col. A1; Brozek, *At Issue: A Productive Life or Tragedy*, *Hartford Courant*, June 15, 1981, at A1, col. 1; Brozek, *Siamese Twins Case a Test of Infant Care Practices*, *Hartford Courant*, June 16, 1981, at A1, col. 3; Brozek, *Parents Chose Death for Baby*, *Hartford Courant*, June 17, 1981, at A1, col. 1.

¹⁴ Brozek, *At Issue: A Productive Life or Tragedy*, *Hartford Courant*, June 15, 1981, at A1, col. 1.

The baby's doctor, E. Laurence Hoder, agreed to continue care, but the infant died January 27. When the baby's heart began failing that night, Renfrew finally agreed by phone to disconnect a respirator so Michael could die. . . .¹⁵

* [When Eric Scuterud was born with spina bifida at Yale-New Haven hospital in 1980, his parents] were told they could go ahead with the lifesaving operation and then institutionalize their baby. The doctors also gave the couple the option of letting the baby die by withholding food and the surgery that would close the back lesion to prevent infection.

. . . .

Doctors offered to let Eric go home to die, with an adequate supply of morphine to sedate him. . . .

Doctors also told Honey Scuterud she would not be feeding him.¹⁶

* Dr. Richard A. Ehrenkranz, on staff at the Yale-New Haven unit, said doctors there almost always abide by parents' decisions, whether for life or death.

. . . .

. . . Ehrenkranz said the staff doesn't intervene to save a child against his parents' wishes, even when the child has a reasonable chance to survive with treatment. "Some medical institutions choose to step in, through the courts," he said. "We do not."¹⁷

* [Although o]verdose deaths at Yale-New Haven are "infrequent," . . . a doctor there said[, in some cases] he and other doctors suggested the option, assuring parents they would sign the death certificate, no questions asked.

The parents, he said, ended their infants' lives with morphine or phenobarbital prescribed by the doctors and usually dissolved in a baby bottle.¹⁸

In reaction to the *Courant* series, the Connecticut Senate Public Health Interim Study Committee on

¹⁵ Brozek, *Defective Newborns Are Dying By Design*, Hartford *Courant*, June 14, 1981, at A1, col. 4.

¹⁶ *Id.* at A25, cols. 2-3. Mrs. Scuterud felt she could not face the prospect of starving her child at home:

"That was the one thing I know I couldn't do, not in my house," she recalled. The couple ordered the surgery, hoping the doctors were right when they said Eric probably wasn't brain damaged.

Id. at A25, col. 3. In 1981 Brozek wrote, "Eric Scuterud is intellectually normal for a year-old baby. He is quick with a grin and flirts with strangers by throwing kisses with a loud smack of his lips." *Id.* at A25, col. 1.

¹⁷ *Id.* at A25, cols. 3-4.

¹⁸ *Id.* at A1, col. 3. Brozek commented:

This daring practice and its acknowledgement by a doctor signal how routine the concept of nontreatment of defective newborns has become in medical practice and how far some medical professionals have taken it.

Medical Treatment for Newborn Infants began a series of hearings, chaired by Senator Regina Smith. At those hearings, "Dr. Joseph B. Warshaw, director of newborn services at Yale-New Haven, said that 'two or three times' in the last five years, infants with Down's Syndrome. . . were not treated for intestinal blockages that prevented them from digesting food."¹⁹

Dr. Raymond S. Duff testified:

[I]n light of religious, personal, and family values and circumstances, some medical conditions are estimated to involve such a destructive impact on the family and often on the child as well that rescue seems unwise. Family and health professionals in these situations believe that tragedy will only be compounded for everyone if rescue is attempted.²⁰

However, the committee received evidence that these judgments seemed at times to be less those of the family than those of Dr. Duff. For example, concerning his son James, born with cerebral palsy at Yale-New Haven Hospital in 1975, Leo Arria wrote Senator Smith:

Even after realizing that James may not be normal we decided that as long as he was alive we wanted to do everything we possibly could do for him. It was then that we were called into conference with a Doctor Duff, who we were told was the head of Pediatrics for the hospital. Doctor Duff told us that James was going to be a great burden to us throughout our lives. He also told us that James would be a vegetable and a helpless human being. He told us to consider very seriously abandoning the child.²¹

Theodore and Cheryl Mekdeci wrote Senator Smith that their daughter Kimberly was born with spina bifida in 1975:

Ending a human life by overdose clearly moves the issue out of the long disputed area of passive euthanasia by withholding care into the outlawed territory of active euthanasia, or causing death.

Id. at A25, col. 1.

¹⁹ Cohen, *Doctor Admits Hospital Let Newborns Die*, Hartford *Courant*, Oct. 1, 1981, at A1, col. 1. *See also* DeRenzo, Summary of Hearings on the Treatment of Newborns with Disabilities 6 (Feb. 10, 1982) (on file at U.S. Commission on Civil Rights).

²⁰ Duff, *Decision Making in Extreme Situations* 5 (Testimony prepared for presentation at hearings of the Public Health Interim Study Committee on Medical Treatment for Newborn Infants, Oct. 20, 1981).

²¹ Letter from Leo F. Arria to State Sen. Regina Smith (Apr. 7, 1982) (on file at U.S. Commission on Civil Rights). Mr. Arria and his wife talked with another pediatrician and decided to authorize medical treatment. *See also* letter from Theodore and Cheryl Mekdeci to State Sen. Regina Smith (undated) (on file at the U.S. Commission on Civil Rights).

Kimberly was placed in the Newborn Special Care Unit at Yale New Haven Hospital. [We] were approached by Dr. Duff. He wanted to know if we fully understood the future life we would be faced with. Our daughter would be a burden to us and would need constant care and may never amount to anything other than to be a vegetable, is what he had told us. There was the possibility that she would cause us much pain. We asked him if he was advis[ing] us against the surgery, asking us to take the chance of our daughter dying. He told us it was something that we should consider.²²

The committee obtained a Yale-New Haven hospital policy that explicitly stated that among the factors to be considered in decisions to provide or withhold treatment were "the quality of life for the child and family" and "the risks of psychological burdens."²³

The Brozek series and the legislative hearings prompted an investigation headed by Thayer Baldwin, Jr., chief of the Bureau of Health System Regulation of the Connecticut State Department of Health Services. At the conclusion of his investigation, the report of the bureau recommended against any "attempt to define or interfere with medical practice." It said "the enormous variety of personal feelings on the subject" meant that laws preventing denial of treatment "would be ignored and ineffective."²⁴ However, the report did make factual findings about a number of cases involving 11 hospitals around the State:

Two . . . infants had multiple congenital anomalies involving one or more organs and body systems and including intestinal and neurological dysfunction in varying degrees. Although individual physical anomalies were treatable, with resultant varying prognoses, a physician/parent decision was made to withdraw/withhold treatment and active support, including intravenous fluids which provided nourishment. Alternative nourishment was then offered orally "as tolerated" to one of these infants. Although this infant died of "malnutrition," it is not known whether this was due to lack of adequate intake or to intestinal dysfunction. The second infant was provided no nourishment in any form and subsequently died of dehydration.

. . . .

²² Letter from Theodore and Cheryl Mekdecis to State Sen. Regina Smith (undated) (on file at the U.S. Commission on Civil Rights). The Mekdecis wrote:

This time [after birth] is a very trying time for the parents and being persuaded in the direction of ending the newborn child[']s life is something that might be regreted [sic] later if parents were to decide this way without feeling that there are other alternatives. . . .

[A] low birth weight, full term infant was transferred from another hospital on oxygen support. Problems noted early on included physical signs of Down's Syndrome, heart defect (probable AV canal), and probable duodenal stenosis. (The heart problem was operable, but with a high mortality rate.) The infant was prepared for duodenal surgery, however the parents chose not to perform surgery. The mother did not want the baby to suffer or to ruin the lives of their other children. . . . A physician-supported, subsequent parent decision was made to discontinue all support. A statement signed by the parents appeared in the record which stated their decision against abdominal surgery and their decision to withdraw "medical support" and their understanding of the "full meaning of this decision."

All "support" was discontinued on the fourth day of life, including oral feedings (which were not feasible) and intravenous nourishment. These activities were substantiated by doctors' orders and nurses' records. At death (at 23 days old) the infant showed a substantial weight loss from birth.

[A] severely premature infant required suctioning for resuscitation. . . . A genetic consult confirmed the probability of Down's. A surgical consult revealed probable duodenal atresia. There were several instances of bradycardia (slow heart rate) beginning on the first day of life. On the third day of life, the parents made a decision to "let nature take its course" and opted for "non-active intervention". . . . [R]ecords indicated that the IV line (which included nourishment), antibiotics and other support were withdrawn on the third day. The infant died on the fourth day, following increased episodes of bradycardia.

. . . .

[F]our infants had multiple congenital anomalies and physiological and medical problems including varying degrees of cardiorespiratory and/or neurological deficiencies. (An infant with Down's Syndrome was included in this group.) Physician/parent decisions were made to withhold or withdraw artificial means of respiration from these infants apparently based on prognoses of poor quality lives from complications requiring continuing extensive support.

. . . .

. . . Notes such as "Plan is to not ventilate the infant. . . . The parents accept this plan," "little chance of even a remotely normal life," "multiple surgery and maximal family support and medical care will be required

Kimberly today is mainstreamed into a regular classroom at school. She is socially and emotionally well adjusted and is a beautifully bright individual. She also shows much love.

²³ Guidelines for Deciding Care of Critically Ill or Dying Patients[:] A Summary of the Yale-New Haven Hospital Policy 5 (undated) (on file at the U.S. Commission on Civil Rights).

²⁴ Baldwin, Infant Death[:] Life and Death in Newborn Special Care Units 11 (1982) (on file at U.S. Commission on Civil Rights). See chap. 10 and text accompanying notes 38-40.

to achieve a reasonable life". . . were observed in the medical records. . . .

Articles in the Hartford Courant which precipitated this investigation by the Department of Health Services referred to cases in which infants were starved or overdosed at home. In three of the eighteen cases reviewed, the infant died at home. Our review of hospital records did not provide enough information to either prove or rule out any malfeasance after discharge from the hospital. However, there appears to be a high possibility that active euthanasia was involved in at least one of these cases.

. . . .

. . . From our review, it would appear that in every hospital in which we reviewed records, selective life/death decisions, involving withdrawal or withholding of treatment, were being made by physicians and parents on a case by case basis.

. . . Some records at one institution included signed statements by parents that it was their decision to withdraw treatment even though death would necessarily follow.²⁵

On June 17, 1982, State Senator Smith filed a formal complaint with the U.S. Department of Justice, to which she attached the Brozek articles, the Baldwin report, and information from testimony given at the hearings before her committee (including the two parental letters concerning Dr. Duff quoted earlier).²⁶ She requested an investigation "to determine whether or not Section 504 of the Rehabilitation Act or any other federal criminal or civil statute is being ignored and violated."²⁷ The Justice Department did not itself initiate an investigation and did not refer the complaint to the HHS Office

²⁵ *Id.* at 14-17. In another case involving a child with "perinatal and neonatal asphyxia resulting in serious brain damage and related complications," who was "able to breathe room air and to be fed by mouth," a "parent/physician decision had been made. . . to discontinue tube feedings and feed only by mouth on demand with the expectation that this course would result in death." The infant was "discharged home. . . and subsequently died at home of cardiorespiratory arrest." *Id.* at 16.

²⁶ Letter from State Sen. Regina Smith to William Bradford Reynolds, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, and Arthur Peabody, Special Litigation Section, U.S. Department of Justice (June 17, 1982) (on file at U.S. Commission on Civil Rights).

²⁷ *Id.* at 1.

²⁸ Memorandum from Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, to Thomas Donnelly, Acting Secretary, U.S. Department of Health and Human Services 1 (Mar. 1, 1983). According to Ms. Dotson, "OCR had already initiated a compliance review of the Yale-New Haven Hospital in August 1982, which covered the same issues involved in the Regina Smith complaint." *Id.* According to Yale-New Haven Hospital, it received a letter announcing a civil rights

for Civil Rights until October 1982.²⁸ It was not until February 10, 1983, that any response was sent to Senator Smith on her complaint. On that date Caroline Chang, Region I Director of the Office for Civil Rights, wrote her to inform her that on February 1, 1983 (3 months after the complaint had been referred to OCR by the Justice Department), her complaint had been referred to the Region I office for investigation. The Chang letter continued:

You have provided OCR with complete information sufficient to initiate our processing of your complaint. OCR has jurisdiction over the subject matter of the complaint pursuant to Section 504 of the Rehabilitation Act of 1973. . . .

We have determined that Yale-New Haven Hospital is a recipient of Federal financial assistance from the Department of Health and Human Services. . . .

In approximately ninety days, OCR will complete its investigation to determine if there has been a violation of Section 504 and its regulation. If no violation is identified, OCR will inform you and Yale-New Haven hospital in writing. If there is a determination that a violation has occurred, Yale-New Haven Hospital will be notified and requested to take corrective action within the next ninety days.²⁹

However, Peter Chan of the Region I office telephoned Senator Smith some months later to tell her that the investigation would take longer than expected. Finally, approximately a year later, he informed her that the investigation had been concluded at the regional level.³⁰ The investigative findings were cleared at the regional level on March 2, 1984, and the national office cleared a letter of

compliance review on July 27, 1982, and Federal investigators arrived on Sept. 14, 1982.

During the fall of 1982, HHS personnel reviewed over one hundred charts of deaths between January and June, 1981, and March through August, of 1982. They subsequently reviewed 110 charts of babies with specified conditions admitted between October 1979 and December 1982. They also conducted extensive reviews with Hospital physicians, nurses, social workers, administrators and others. . . . In March, 1983, OCR Investigator Peter Chan returned to the Hospital for additional interviews with physicians. On July 21, 1983, Investigator Chan again met with representatives of the Hospital requesting additional information.

Letter from John E. Fenn, Chief of Staff, Yale-New Haven Hospital to William J. Howard, General Counsel, U.S. Commission on Civil Rights 1-2 (Oct. 6, 1988) (printed in app. D of this report).

²⁹ Letter from Caroline Chang, Region I Director, Office for Civil Rights, U.S. Department of Health and Human Services, to State Sen. Regina Smith (Feb. 10, 1983) (on file at U.S. Commission on Civil Rights).

³⁰ Telephone interview with State Sen. Regina Smith (Sept. 16, 1988).

finding on May 18, 1984.³¹ In the meantime, however, enforcement was suspended in March 1984 as a consequence of the suit challenging the final rules.³² As a result, the letter of finding was never issued.³³

In short, in a matter that by its nature was a matter of life and death, it took nearly 2 years from the time the complaint was filed to bring an investigation to conclusion, at least 10 months of which was used after the investigators' medical chart review and interviews of hospital personnel had already occurred. By the time HHS was finally ready to act, it was too late.

This pattern was to continue. In October 1983, an article entitled "Early Management and Decision Making for the Treatment of Myelomeningocele" was published in *Pediatrics*,³⁴ the journal of the American Academy of Pediatrics. The authors were Richard H. Gross, MD, Alan Cox, MD, Ruth Tatyrek, MSW, Michael Pollay, MD, and William A. Barnes, MD. They were from the departments of Orthopaedic Surgery, Pediatrics, Neurosurgery, and Urology of the University of Oklahoma Health Sciences Center, and Department of Social Service, Oklahoma Children's Hospital, Oklahoma City.³⁵

The article described a selective treatment program carried out at Oklahoma Children's Hospital. The article tracked the "treatment" regimen for 69 infants born with spina bifida between July 1, 1977, and June 30, 1982.³⁶ According to the article, a hospital team assessed each infant within 48 hours of birth. For those infants born with high lesions who were suspected of having hydrocephalus or other anomalies, a meeting was convened to decide upon a treatment recommendation to the family. The recommendation could be for "vigorous" treatment or for "supportive care."³⁷ "Supportive care" meant that lifesaving surgery to close the lesion would not be performed and "active treatment" would not be given "for infection and other acute illnesses."³⁸ In addition, the criteria used by the team included an assessment of "contribution from home and family"

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.³⁹

Of the 69 infants in the experiment, 36, or 52 percent, were recommended for treatment. Thirty-three, or 48 percent, were recommended for "supportive care." Of those recommended for treatment, all survived with the exception of one who died as a result of a car accident. Twenty-eight of the families receiving the recommendation for nontreatment (supportive care) accepted the recommendation. The families of five children demanded treatment, and of those five children, three, according to the authors, "are alive and well."⁴⁰ The majority of infants for whom no treatment was planned were sent to a facility called the Children's Shelter.⁴¹ At the end of the experiment, 24 families had finally agreed to the nontreatment regimen, and all 24 children died. The experiment was called a success by the authors: "[T]his approach seems to us the best alternative available at this time."⁴²

The *Pediatrics* article came to the attention of Carlton Sherwood, one of only two investigative reporters to have won both the Pulitzer and the Peabody awards for investigative reporting. He was then working for Cable News Network and took a television crew with him to Oklahoma. Initially, he was denied interviews by both the hospital and the Children's Shelter, a facility to which, according to the article, children being provided only "supportive care" were frequently sent. One snowy Sunday, however, a nurse named George McCormack decided not only to allow the reporter and camera crew inside the shelter, but also to tell the story of his unsuccessful attempts to obtain lifesaving surgery for a baby born with spina bifida who had not been treated.⁴³

Sherwood's camera captured the picture of Carlton Johnson, a black baby born with spina bifida to

³¹ Telephone interview with Patricia Mackey, Office for Civil Rights, U.S. Department of Health and Human Services (Sept. 20, 1988).

³² Telephone interview with Peter Chan, Region I Office, Office of Civil Rights, U.S. Department of Health and Human Services (Sept. 19, 1988).

³³ Telephone interview with Patricia Mackey, Office for Civil Rights, U.S. Department of Health and Human Services (Sept. 20, 1988).

³⁴ Gross, Cox, Tatyrek, Pollay & Barnes, *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 *Pediatrics* 450 (1983).

³⁵ *Id.* at 450.

³⁶ *Id.* at 452.

³⁷ *Id.*

³⁸ *Id.* at 452, 453.

³⁹ *Id.* at 456.

⁴⁰ *Id.* at 451.

⁴¹ *Id.* at 452.

⁴² *Id.* at 457.

⁴³ Interviews with Carlton Sherwood (February 1984).

an unmarried mother receiving welfare.⁴⁴ A large sac was visible on Carlton Johnson's back, according to McCormack the result of the refusal of Oklahoma Memorial Hospital-associated physicians to treat him. McCormack told the reporter that he had requested an operation for Carlton Johnson on more than one occasion.⁴⁵

Sherwood's discoveries and interview with McCormack were aired in February 1984, as part of a three-part series on Cable News Network which provided graphic evidence that the Oklahoma Children's Hospital not only had conducted the selective treatment experiment but also was apparently still refusing to provide necessary medical treatment to children born with surgically correctable problems, especially if the child came from a poor family.

Of particular importance for the future legal status of calls for Federal investigation of the selection process was an interview with Carlton Johnson's mother. Sharon Johnson stated that the doctors had told her that her child could not live. She had no idea that with an operation her son would be able to move into a family home and live as normal a life as his disability would allow.⁴⁶ This evidence suggested that the physicians were not simply deferring to parental decisions, but rather securing parental consent to nontreatment by providing unwarrantably pessimistic prognoses. It raised the question of whether parents were in fact giving legally effective informed consent.

Attention within the disability rights movement was drawn to the *Pediatrics* article soon after it was published. Michael Lottman, a disability rights attorney and former Justice Department official, drafted a letter alleging that the Oklahoma proce-

dures entailed various constitutional and statutory violations.⁴⁷ His draft was brought to Martin Gerry, former director of the Office for Civil Rights in the Department of Health, Education, and Welfare.⁴⁸ Gerry agreed with the basic findings in the Lottman draft and circulated a revised letter of complaint to various disability rights groups. The Association for Persons with Severe Handicaps, the Association for Retarded Citizens/United States, the National Down Syndrome Congress, the Spina Bifida Association of America, Martin Gerry, and Nat Hentoff, a civil libertarian columnist for the New York City weekly *The Village Voice*, joined in the formal complaint.⁴⁹

On February 24, 1984, the written complaint was submitted to both Attorney General William French Smith and Margaret Heckler, Secretary of the Department of Health and Human Services.⁵⁰ The complaint alleged violations of three Federal statutes and the HHS regulations involving human experimentation.⁵¹ It emphasized the urgency of government action in response to the complaint. "It is imperative that the Federal Government act decisively to put an end to these multiple and long-standing illegalities, and that intervention be effected immediately before more lives are lost. If existing administrative procedures . . . cannot move quickly enough in this desperate situation, then the government must go to court to put an end to these deaths pending a final administrative or judicial determination."⁵²

The Department of Health and Human Services is required to investigate complaints "promptly."⁵³ Despite the life-threatening urgency of the allegations in the complaint, 96 days passed before the

⁴⁴ Interviews with Carlton Sherwood (February 1984).

⁴⁵ Cable News Network Transcript, *Who Lives, Who Dies?* 3 (Feb. 21, 22, & 24, 1984) (on file at U.S. Commission on Civil Rights).

⁴⁶ *Id.*

⁴⁷ Telephone interview with Michael Lottman (Aug. 24, 1988).

⁴⁸ The Department of Health, Education, and Welfare was subsequently divided into HHS and the Department of Education. HHS now has responsibility for these issues.

⁴⁹ Interview with Martin Gerry (Sept. 13, 1988).

⁵⁰ Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

⁵¹ The alleged violations were of section 504 of the Rehabilitation Act, 29 U.S.C.A. § 794 (1985); of the Medicaid requirements that services not be denied to eligible recipients without a fair hearing, 42 U.S.C.A. § 1396a(a)(3) (West Supp. 1988); that medical assistance to eligible recipients be of the same amount,

duration, and scope as that provided to others, 42 U.S.C.A. § 1396a(a)(10)(B) (West Supp. 1988); and that care and services be provided in a manner consistent with the best interests of the recipient, 42 U.S.C.A. § 1396a(a)(19) (West Supp. 1988); of regulations governing experimentation on human subjects, forbidding such experimentation without informed consent, 45 C.F.R. §§ 46.116, 46.406 & 46.408 (1987); and of the Federal criminal code, 18 U.S.C.A. §§ 241 & 242 (1969). Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services 5, 6 (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

⁵² The letter invoked *United States v. Frazer*, 297 F. Supp. 319 (M.D. Ala. 1968) as precedent for such a suit. Letter to William French Smith, Attorney General, U.S. Department of Justice, and Margaret Heckler, Secretary, U.S. Department of Health and Human Services 6 (Feb. 24, 1984) (on file at U.S. Commission on Civil Rights).

⁵³ 45 C.F.R. §§ 84.61 & 80.7(c) (1987).

Office for Civil Rights (OCR) took measurable action on the complaint. On May 30, 1984, a meeting was convened in Washington, D.C., attended by Betty Lou Dotson, OCR director; Surgeon General C. Everett Koop; Kent Smith, executive director of the Spina Bifida Association of America; and two private physicians who had been critical of the practices reported at Oklahoma Children's Hospital, Dr. David McClone of Chicago Children's Hospital and Dr. John Freeman of Johns Hopkins Hospital in Baltimore. Dr. Freeman later wrote that to "defus[e] the adversarial approach" and "prevent the necessity for and the problems inherent in litigation," it was the "consensus of the meeting. . .to use a more indirect approach to the University of Oklahoma through Dr. Koop and the Spina Bifida Association to see what current practices are being utilized by the University of Oklahoma in their determinations of who should be treated."⁵⁴ Physicians at the hospital refused to give the Surgeon General assurances that the practices had ceased.⁵⁵

Disturbed by the reports of this meeting and wanting to make clear that the presence of a representative of one of the complainant groups at the meeting could not be interpreted as adequate justification for a failure to undertake a formal investigation and appropriate legal action,⁵⁶ Martin Gerry on June 4, 1984, wrote identical letters to the Attorney General and the Secretary of Health and Human Services "to advise. . .formally that I represent each of the organizations and individuals listed on the signature page of the February 24, 1984, letter in connection with matters raised in the Complaint." The letter emphasized that the February letter "represents a true and complete complaint" with regard to which 45 C.F.R. §80.7 required "that the Department of Health and Human Services initiate a prompt investigation 'whenever a compliance review, report, *complaint*, or *any other information* indicates a possible failure to comply' with the law," and to ask the Department to "designat[e] a liai-

son. . .for us to contact in order to avoid any future confusion."⁵⁷

On July 2, 1984, Betty Lou Dotson, Director of the Office for Civil Rights in the Department of Health and Human Services, responded to the June 4 letter to Secretary Heckler. She stated:

When this matter came to our attention in February, we initiated efforts to develop a comprehensive and legally viable investigative plan. These efforts included a May 30, 1984, meeting with the Surgeon General, two nationally recognized medical experts on spina bifida, the Executive Director of the Spina Bifida Association of America (a cosigner of your earlier letter on this subject), and others. That meeting produced a consensus on the initial steps to be taken to most effectively deal with this serious matter. Also during the course of these preliminary efforts, we received information, seemingly reliable but not independently verified, that the treatment procedures followed during the 1977-82 time period are no longer in effect at the University of Oklahoma Health Sciences Center.⁵⁸

The letter also stated that after the March 12, 1984, filing of a suit to enjoin the section 504 "Baby Doe" regulations, HHS, in order to avert a preliminary injunction, had agreed "to delay, until resolution of the litigation, direct investigation of complaints not involving live infants at risk." It pointed out that on June 11 the district court had issued an injunction barring HHS from investigating treatment decisions concerning newborn infants under section 504.

The letter recognized that the complainants "also asked that this issue be reviewed from the context of HHS regulations regarding the Medicaid program and human experimentation." It justified not having considered these issues because "HHS has concentrated its efforts to assure appropriate treatment for handicapped infants on enforcement of section 504, the approach we believed to have the strongest legal basis." In light of the court order precluding use of this basis, Ms. Dotson wrote, "I have forwarded your complaint to the appropriate HHS offices for review pursuant to these other authorities. . . .You

⁵⁴ Letter from John Freeman to Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, and C. Everett Koop, Surgeon General of the United States (May 30, 1984) (on file at U.S. Commission on Civil Rights).

⁵⁵ Gerry, *The Civil Rights of Handicapped Infants: An Oklahoma Experiment*, 1 Issues in L. & Med. 15, 56 (1985), citing telephone interview with C. Everett Koop, Surgeon General of the United States (Nov. 16, 1984).

⁵⁶ Interview with Martin Gerry (Sept. 13, 1988).

⁵⁷ Letter from Martin Gerry to William French Smith, Attorney General, U.S. Department of Justice (June 4, 1984) (emphasis in original); letter from Martin Gerry to Margaret Heckler, Secretary, U.S. Department of Health and Human Services (June 4, 1984) (emphasis in original) (on file at U.S. Commission on Civil Rights).

⁵⁸ Letter from Betty Lou Dotson, Director, Office for Civil Rights, U.S. Department of Health and Human Services, to Martin Gerry (July 2, 1984) (date of June 29, 1984, also appears on letter) (on file at U.S. Commission on Civil Rights).

can be sure all appropriate actions within our legal authority will be taken.”⁵⁹

On July 3, 1984, William Bradford Reynolds, Assistant Attorney General of the Civil Rights Division of the Justice Department, responded to Mr. Gerry’s June 4 letter to Attorney General Smith. The Justice Department letter stated that “(u)nder federal regulations, this Department’s role in enforcing section 504 does not ordinarily commence until the Department of Health and Human Services or other authorized agency has referred a matter of violation of section 504 to us for appropriate action.” Presumably referring to the May 30 meeting, Reynolds said: “In response to my recent inquiry on the status of such an investigation, the Department of Health and Human Services advised that it was in the process of convening a group of experts to develop an investigative plan and that the activities of the Center were in the interim being appropriately monitored.” However, he wrote, in light of the district court injunction, “recent judicial action prevents further HHS action in this area at this time.”

You also suggest that we consider criminal prosecutions under 18 U.S.C. [§§]241 and 242. Those statutes create no independent rights, but depend on proof of violation of existing federal rights. As of now, the court decisions on the treatment of handicapped infants under Section 504 negate any federal right in that area. Even if we prevail in our position that Section 504 protects newborn infants against discrimination based on handicap, we believe that addressing the issue under Section 504 would be more satisfactory than criminal proceedings.⁶⁰

On July 13, 1984, Martin Gerry again wrote Secretary Heckler on behalf of the complainants, charging that “at least twelve additional disabled infants [had] been unlawfully denied treatment by the same facilities” in the preceding 3 months. He challenged the conclusion that action by the Department under section 504 was precluded, maintaining that the New York court’s injunction need not be interpreted to preclude investigation of a complaint

⁵⁹ *Id.* As of September 1988, HHS had not informed the complainants of any investigations conducted, action taken, or determinations made with regard to the Oklahoma complaint under these other authorities. Interview with Martin Gerry (Sept. 13, 1988).

⁶⁰ Letter from William Bradford Reynolds, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, to Martin Gerry (July 3, 1984) (on file at U.S. Commission on Civil Rights).

⁶¹ Letter from Martin Gerry to Margaret Heckler, Secretary, U.S. Department of Health and Human Services (July 13, 1984) (on file at U.S. Commission on Civil Rights).

related to Oklahoma.⁶¹ Secretary Heckler replied on October 11, 1984, reaffirming the conclusion of the HHS and Justice Departments that the New York court’s injunction had nationwide effect and precluded further HHS action.⁶²

In October 1985, the American Civil Liberties Union and the National Center for the Medically Dependent and Disabled (a Legal Services Corporation-funded national support center) filed suit against a number of physicians at Oklahoma Children’s Hospital. The suit was filed on behalf of Sharon Johnson (Carlton Johnson’s mother), Carlton Johnson himself, the parents of another child with disabilities who had died after allegedly being denied lifesaving treatment at Oklahoma Children’s Hospital, the Spina Bifida Association of America, and the Association for Persons with Severe Handicaps.⁶³

On February 12, 1987, several Members of Congress wrote HHS Secretary Otis Bowen to solicit involvement of the Department in the case, which would include an HHS request for Justice Department intervention.⁶⁴ Central to the letter was an argument based on the Supreme Court’s decision in *Bowen v. American Hospital Association*.⁶⁵ *Bowen* had narrowed the injunction that, as entered by the lower courts, had forbidden HHS to investigate any cases involving denial of treatment to newborn children under the aegis of section 504. *Bowen* prohibited only investigation of such cases where there had been parental consent to the treatment withholding. In the *Johnson* case, the plaintiffs alleged that decisions to deny treatment were made by hospital personnel without legally valid parental consent. However, HHS never agreed to be involved or to request the intervention of the Justice Department.

The pattern is clear. The disability rights organizations and Members of Congress ultimately fared no better with regard to Oklahoma Children’s Hospital than did the Public Health Committee of the Connecticut State Legislature with regard to

⁶² Letter from Margaret Heckler, Secretary, U.S. Department of Health and Human Services, to Martin Gerry (Oct. 11, 1984) (on file at U.S. Commission on Civil Rights).

⁶³ *Johnson v. Sullivan*, No. CIV-85-2434A (W.D. Okla. filed Oct. 3, 1985).

⁶⁴ Letter from U.S. Reps. Beau Boulter, Thomas Bliley, Bob Dornan, Chris Smith, Jack Kemp, Harold Volkmer, and Henry Hyde to Otis Bowen, Secretary, U.S. Department of Health and Human Services (Feb. 12, 1987).

⁶⁵ 476 U.S. 610 (1986). For further discussion of this case, see chap. 6 and text accompanying notes 108-135.

Yale-New Haven Hospital. No legal action was taken to stop the well-documented denials of treatment.

In both instances, official complaints were documented by credible and detailed information strongly suggesting violations of section 504. In both instances, the complaints detailed an ongoing pattern or practice that suggested that lives continued to be at risk. In both instances, prompt action would have allowed investigations and compliance action to be taken before there was any judicial bar.⁶⁶ It took the Justice Department more than 3 months to refer the Connecticut complaint to OCR; it took OCR more than 3 months to refer it to its regional office for investigation; and despite a pledge to complete the investigation in approximately 3 months, it took 15 months—by which time it was too late. It took OCR more than 3 months to take any significant action on the Oklahoma complaint—and when it did, the action was to substitute informal inquiries for the legally required investigation. In short, confronted 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.

The Child Abuse Amendments of 1984

The second major Federal role in enforcing the rights of children with disabilities to be free from medical discrimination came with the effective date of the Child Abuse Amendments of 1984. Beginning on October 9, 1985, and continuing through the

present, the National Center for Child Abuse and Neglect in the Office of Human Development Services at HHS has had the responsibility for enforcing the requirements these grants impose upon the States.

This report has already detailed the failure of a number of State Child Protective Services agency standards and procedures to meet the prerequisites for Federal funding embodied in the Child Abuse Amendments and their implementing regulations. Nevertheless, these States have all been certified by HHS for receipt of Federal funds under the Child Abuse Prevention and Treatment Act, without being advised that they are out of compliance or being given any deadline to bring their standards and procedures into compliance.⁶⁷ The Commission considers this a significant failing on the part of HHS.

In 1987 the Office of Analysis and Inspections of the HHS Office of Inspector General did two studies in response to the requirement of the Child Abuse Amendments that “[n]ot later than October 1, 1987, the Secretary shall submit to the appropriate Committees of the Congress a detailed report on the implementation and the effects of the provisions of this part and the amendments made by it.”⁶⁸ One study focused on State Child Protection Services’ implementation of the Child Abuse Amendments,⁶⁹ while the other dealt with hospital review committees.⁷⁰ Certain portions of those reports evince a disturbing failure on the part of the Inspector General personnel involved in writing them either fully to understand the requirements of the Child Abuse Amendments or to make the appropriate

⁶⁶ Courts are often influenced by the circumstances of precedent-setting cases. Both the *Bowen* Supreme Court decision and the Second Circuit decision in *University Hospital* were issued by a closely divided court. Given the compelling and sympathetic nature of the facts, if litigation had been initiated in either the Connecticut or the Oklahoma cases, it is at least possible that the decisions ultimately rendered concerning the applicability of 504 rendered by the courts might have been different.

⁶⁷ See chap. 10.

⁶⁸ 42 U.S.C.A. § 5103 note (West Supp. 1988). In comments submitted on a draft of this report, reprinted in app. E, the HHS Inspector General stated that it was “incorrect” to characterize the two studies as made in response to the requirement of the Child Abuse Amendments. Letter from Richard Kusserow, Inspector General, to William J. Howard, General Counsel, U.S. Commission on Civil Rights 1 (Oct. 12, 1988). However, on June 8, 1988, HHS Secretary Otis Bowen submitted them to Congress with a document entitled “Report to the Congress: Implementation of the Child Abuse Amendments of 1984 Relating to the

Protection and Care of Disabled Infants With Life-Threatening Conditions” (on file at U.S. Commission on Civil Rights). That document described its purpose as “to provide to the Congress, as required by Section 126 of Public Law 98-457 (the Child Abuse Amendments of 1984), a detailed report on the implementation and the effects of the provisions of this legislation for disabled infants with life-threatening conditions.” *Id.* at i. It stated: “[T]he Department. . . requested an inspection by the Office of Inspector General (OIG) to (a) determine state compliance with these new requirements, and (b) review hospitals’ use of the Model Guidelines for Infant Care Review Committees. This study, conducted in FY 1987, found that the States and the hospitals are complying with the legislation.” *Id.* at ii.

⁶⁹ Office of Inspector General, Department of Health and Human Services, Survey of State Baby Doe Programs (1987) [hereinafter State Agencies OIG Report].

⁷⁰ Office of Inspector General, Department of Health and Human Services, Infant Care Review Committees Under the Baby Doe Program (1987) [hereinafter Committees OIG Report].

inquiries to determine whether they are being carried out.

In the report on infant care review committees, for example, the Office of the Inspector General noted that of the "between 20 and 36 potential Baby Doe cases since the Federal regulations went into effect in October 1985" considered by the 10 committees whose activities were monitored, only 3 were reported to state CPS agencies.⁷¹ The Office of Inspector General did not review the facts in these unreported cases to determine whether or not they met the standards established in the Child Abuse Amendments. It is hard to see how, without doing this, the Department could accomplish its task of ascertaining whether the committees are fulfilling what HHS has described as "the role of the ICRC [infant care review committee] to review the case. . . and recommend that the hospital seek CPS agency involvement when necessary to assure protection for the infant and compliance with applicable legal standards."⁷²

It is equally disturbing that, apparently as a typical exemplar of such committees generally, the OIG report provides a detailed description of the "interlocking Infant Bioethical Review Committees. . . in

four affiliated hospitals which make up the Albert Einstein College of Medicine and the Montefiore Medical Center in Bronx, New York," including an account of the "set of principles which serve as the basis for making decisions involving critically ill infants," without pointing out that those principles differ from the treatment standards required by the Child Abuse Amendments.⁷³

The OIG report does make clear that, as discussed in some detail above, most of the committees surveyed review only cases in which there is disagreement among health care personnel or between them and family members, and do not report to CPS agencies if the disagreement can be resolved—regardless, for all the OIG report shows, of whether the agreed resolution abides by or violates the treatment principles embodied in the Child Abuse Amendments.⁷⁴ In light of these significant indications of lack of compliance,⁷⁵ it is disconcerting that the official reaction of the then Acting Assistant Secretary for Human Development Services was that, "Overall, we are encouraged by the findings, observations, and data contained in these reports. . . . The findings and data reported do not raise serious questions or issues for our attention."⁷⁶

⁷¹ *Id.* at 9. See chap. 11, text accompanying notes 73–77, for a discussion of the provisions of the Child Abuse Prevention and Treatment Act that require all "suspected" cases of withholding of medically indicated treatment be reported, not merely those in which a hospital committee finally decides that such has in fact occurred or is about to occur. The Inspector General's report fails to comment on this apparently widespread noncompliance, and HHS has neglected to take any action to inform States that toleration of such illegal failure to report does not meet their responsibilities under the relevant law.

⁷² Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878, 14880–81 (1985).

⁷³ Committees OIG Report, *supra*, note 70, at 11–12. The Committees OIG Report describes the principles as recognizing that "[w]ithholding or withdrawing treatment may be considered when it is deemed futile and would merely prolong the dying process or when the medical treatment imposes a burden which lacks compensating benefits for the infant. If such a decision is made, the infant and the family are cared for in a supportive and dignified manner." *Id.* at 11. Cf. 45 C.F.R. § 1340.15(b)(2) (1987). In his letter commenting upon a draft of this report, the Inspector General described this passage as "misleading" because "[t]he purpose of this portion of the report was simply to serve as a reference to other hospitals considering the establishment of similar committees." Letter from Richard Kusserow, Inspector General, to William J. Howard, General Counsel, U.S. Commission on Civil Rights 2 (Oct. 12, 1988). But that is precisely what the Commission criticizes: a government agency suggesting that a committee employing principles out of compliance with the law is a fit reference for other hospitals that might establish such committees.

⁷⁴ See chap. 11.

⁷⁵ Facts indicating other instances of incomplete compliance are included in the report on State agencies. 45 C.F.R. § 1340.15(c)(3) (1986) requires:

The programs and/or procedures must specify that the child protective services system will promptly contact each health care facility to obtain the name, title, and telephone number of the individual(s) designated by such facility for the purpose of the coordination, consultation, and notification activities. . . , and will at least annually recontact each health care facility to obtain any changes in the designations.

The Agencies OIG report discloses that as of March 1987, five States admitted that more than one-third of their hospitals with neonatal intensive care units or obstetrical units had not designated such liaisons, 13 States admitted that some number of such hospitals (less than one-third) had not done so, and 3 States admitted that they did not know how many had done so. State agencies OIG Report at 4, *supra*, note 69. Furthermore, only 28 States stated that they updated their lists of liaisons annually, as required; 5 stated they update "periodically or as needed," while the others apparently failed to reply. (The Agencies OIG Report leaves unclear whether some of the 28 States did not receive Federal funds, and thus were not required to comply with the Child Abuse Amendments.) *Id.*

⁷⁶ Memorandum from Phillip N. Hawkes, Acting Assistant Secretary for Human Development Service, HHS, to Richard P. Kusserow, Inspector General, HHS (Sept. 11, 1987) *reprinted in* Committees OIG Report, *supra*, note 70 at app. E at 1–2. The Acting Assistant Secretary did not express concern that 22 percent of the State agencies "responded that, because of the medical and ethical issues involved, CPS responsibility for Baby Doe cases is not appropriate. We will consider what appropriate action HDS [Office of Human Development Services] might take

However, after reviewing a draft of relevant portions of this report, Assistant Secretary Sydney Olson commented:

We are extremely concerned about your findings which indicate that a number of State Child Protective Service (CPS) agencies may fail to meet the requirements for federal funding as provided for in 45 C.F.R. 1340.15, and your statement that the Department of Health and Human Services has incorrectly certified them as eligible. The issues you raise are indeed serious.⁷⁷

The letter stated that “[b]ecause of the information compiled in the [Civil Rights Commission draft] report,” the HHS Office of Human Development Services will convene a staff work group “to review our current policies and instructions to determine if there are ways in which we can improve the administration of the Federal program and the use of Federal funds to accomplish its purposes” and “will review the eligibility of each State cited in your report, paying special attention to those areas of concern that you have identified.”⁷⁸

to further clarify and reinforce CPS agency responsibilities.” *Id.* at app. E at 2.

⁷⁷ Letter from Sydney Olson, Assistant Secretary, Office of Human Development Services, to William J. Howard, General

Conclusion

The Commission is dismayed at the extremely poor performance of the Department of Health and Human Services in fulfilling its responsibilities to protect children with disabilities from medical discrimination, first under section 504 of the Rehabilitation Act in the time period before its use was enjoined, and currently under the Child Abuse Amendments of 1984. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State child protective services agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

Counsel, U.S. Commission on Civil Rights 1 (Oct. 31, 1988) (reprinted in app. E of this report).

⁷⁸ *Id.* at 2.

The Protection and Advocacy System: A Resource for Enforcement

In 1975 Congress established structures called Protection and Advocacy Systems (P&A), originally attuned specifically to the need to ensure vigorous advocacy of the rights of persons with developmental disabilities.¹ The Developmentally Disabled Assistance and Bill of Rights Act required that each State or similar jurisdiction receiving Federal funding for persons with developmental disabilities establish an independent system with "authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of [persons with developmental disabilities]."²

In 1984, in substantially expanding funding for the P&A systems, Congress recognized both their importance and their impressive track record. The Senate Committee on Labor and Human Resources Report noted:

The Committee views State Protection and Advocacy Systems (P&A's) to be of critical importance in an expanding effort by the Congress to assure disabled persons. . . protection of their rights under law. . . [T]he P&A's provide an invaluable local and thus available resource to developmentally disabled people which is independent, yet knowledgeable of service providers. The

Committee notes favorably the testimony provided by Dr. Jean Elder, Commissioner of the Administration on Developmental Disabilities that "[i]n FY 1982, 41 State P&A systems served more than 41,000 persons."³

In 1986, "[b]ecause of the past accomplishments of the Developmentally Disabled Protection and Advocacy System [DD P&A]," Congress chose "to build on the experience of the existing DD P&A System in investigating and resolving situations involving abuse and neglect"⁴ of persons with mental illness by adding responsibility for advocacy for this population to the P&As.⁵ In fiscal year 1987, the P&A systems were appropriated \$15.5 million for advocacy on behalf of persons with developmental disabilities and \$10.5 million for advocacy on behalf of persons with mental illness.⁶ With these funds, the P&As provided advocacy for 70,501 persons with developmental disabilities (of whom 2,823 were represented in the context of medical and/or mental health services) and for 9,758 persons with mental illness (of whom 1,254 were represented in the context of alleged neglect in the provision of medical/mental health treatment).⁷ These figures do

¹ The law currently defines "developmental disability" to mean: a severe, chronic disability of a person which—

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is manifested before the person attains age twenty-two;

(C) is likely to continue indefinitely;

(D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or

extended duration and are individually planned and coordinated.

42 U.S.C.A. § 6001(5) (West Supp. 1988).

² Pub. L. No. 94-103, sec. 203, § 113, 89 Stat. 486, 504 (1975) (current version at 42 U.S.C.A. § 6042 (West Supp. 1988)).

³ S. Rep. No. 493, 98th Cong., 2d Sess. 28, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4361.

⁴ S. Rep. No. 109, 99th Cong., 1st Sess. 3, 8, reprinted in 1986 U.S. Code Cong. & Admin. News 1361, 1363, 1368.

⁵ Protection and Advocacy for Mentally Ill Individuals Act of 1986, Pub. L. No. 99-319, 100 Stat. 478 (codified at 42 U.S.C.A. §§ 10801 to 10851 (West Supp. 1988)).

⁶ National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 2, 3 (1988).

⁷ *Id.* at 5, 7, 13, 15.

not include the more than 160,000 individuals represented in class action suits in which the number is known, or those represented in class action suits in which the number is not known.⁸

P&A staff consist of attorneys, social workers and other advocates who are capable of providing a full range of advocacy services including the ability to pursue legal, administrative and other appropriate remedies to protect the rights of clients. . . .

P&A activities include: (1) investigating, negotiating or mediating solutions to problems expressed by persons with developmental disabilities, persons with mental illness or clients of DVRs [departments of vocational rehabilitation], their families or agency representatives; (2) providing technical assistance to attorneys, governmental agencies and service providers; (3) providing legal counsel and litigation services to persons in this population and groups who are unable to attain adequate or appropriate legal services in their communities; and (4) training advocates, consumers, volunteers, professionals, and other parties.⁹

The United States Commission on Civil Rights thinks that the P&A system affords an experienced and appropriate resource to remedy discriminatory denial of medical treatment, food, and fluids to people with disabilities. It is clear that P&As currently have a general jurisdiction that encompasses such instances.¹⁰ Indeed, P&As have handled some such cases in the past. In 1983 the Idaho agency, Coalition of Advocates for the Disabled, was involved in the highly publicized "Baby Ashley" case, defending the right of a child born with hydranencephaly to receive treatment.¹¹ In 1986 the Minnesota agency, the Minnesota Mental Health Law Project, represented hospital residents with treatment-related concerns.¹² In 1987 the Mississippi agency, Mississippi P&A System for DD, Inc., was involved in a case concerning refusal by a medicare-medicaid recipient State hospital to provide life-preserving dialysis treatment to an individual dually diagnosed with developmental disabilities and mental illness.¹³ But the P&A system has not been called upon for the bulk of enforcement in this area. In dealing with denial of treatment to children with disabilities in 1984, for example, Congress relied upon the State child protective services (CPS) agencies.

⁸ *Id.* at 5, 13.

⁹ National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 3 (1988).

¹⁰ See 42 U.S.C.A. § 6042(a)(2)(A)&(B) (West Supp. 1988).

¹¹ Telephone interview with Jim Baugh, Managing Attorney, Coalition of Advocates for the Disabled (Dec. 1, 1988).

For reasons detailed below, the Commission believes that the P&A system should be brought into active involvement in efforts to prevent illegal denial of treatment to children with disabilities. In summary, the Commission envisions the following new approach:

- Prompt reports of suspected or actual cases of withholding of medically indicated treatment would still be required to go to CPS agencies, and CPS agencies would retain the authority and responsibility to investigate them. However, the State P&A agency would be notified by the CPS agency as soon as the CPS agency received any such report. The P&A would have access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency would have independent authority, similar to that now held by the CPS agency, to obtain medical records and to obtain a court order for an independent medical examination. Further, the P&A agency would have independent standing to initiate a court proceeding to authorize medical treatment for the child, in addition to possessing standing to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency.

- To catch cases that are not being reported to the CPS agency, any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability would be required to notify the State P&A agency of meetings held to discuss the case. The P&A would then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. If the P&A deemed it necessary, it could obtain a court order for an independent medical examination. If the P&A concluded that medically indicated treatment would be withheld illegally, it would have the standing to institute a court proceeding to require that it be provided.

- To provide a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A would have

¹² National Association of Protection and Advocacy Systems, 1986 Annual Statistical Report, App. III at 4 (1988).

¹³ National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 18 (1988).

authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment were detected, the P&A could seek appropriate action by licensing boards or Federal funding sources; in extreme circumstances, it could institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

The Commission sees several advantages to involving the P&A systems more directly in the enforcement of the Child Abuse Amendments of 1984.

First, and perhaps most important, the P&A system has far more specialized experience in safeguarding the rights of persons with disabilities than does the CPS system. Although the CPS system deals with the abuse and neglect of all children, most of whom are not disabled, the P&A system since its inception has concentrated on protecting the rights of persons with disabilities. As chapter 10 documents, there is a disturbing tendency among CPS workers to evince many of the negative attitudes and pessimistic views concerning people with disabilities that are prevalent in the society as a whole. Because of their greater experience with persons with disabilities, and the knowledge and sensitivity they have thereby acquired, it is only natural that P&A workers are on the average more likely than CPS workers to be vigorous, effective, and reliable advocates for the treatment rights of those with disabilities.

Second, the P&A system is less likely to be affected by conflicts of interest than the CPS system. CPS agencies are integral parts of the State bureaucracy, compromising their willingness or ability to take action against other State agencies, such as State hospitals, that may be alleged to be involved in treatment denial.¹⁴ By contrast, the P&A system is statutorily independent of State agencies. The Governor of each State has the authority to designate the P&A agency for each State.¹⁵ However, the 1984 Developmental Disabilities Amendments sought to ensure the independence of the system by requiring "assurances. . .that the agency implementing the

system will not be redesignated unless there is good cause for the redesignation and unless notice has been given of the intention to make such redesignation to persons with developmental disabilities or their representatives."¹⁶ The Senate Labor and Human Resources Committee Report emphasized:

The Committee is . . .concerned that any change in P&A designation within any jurisdiction be only for good cause. Such good cause does not, in the Committee's view, mean aggressiveness—specifically litigation against any agency of state or local government—in the pursuit of the designee's mandate to protect persons with developmental disabilities. . . .The Committee urges the Administration on Developmental Disabilities [the HHS unit in charge of supervising the developmental disabilities aspect of the P&As] to promulgate regulations and to carefully evaluate any redesignation request to assure that there is both good cause for any redesignation request and that notice of such request has been provided to clients and client groups within the jurisdictions of the appointing authority prior to the request being submitted to the Administration on Developmental Disabilities.¹⁷

Third, since CPS agencies rely heavily on the medical profession as the major source of reports of "traditional" child abuse and neglect with which they are primarily concerned, they are often reluctant to jeopardize that working relationship by appearing in an adversarial relationship in the context of alleged medical neglect.¹⁸ Unlike the CPS agencies, the P&A agencies have no special relationship with the medical profession that would impair their ability to be vigorous advocates.

Fourth, P&A agencies are accountable to the populations they serve. They must provide an annual opportunity to the public to comment on their priorities and must have a grievance procedure "to assure that persons with developmental disabilities have full access to services of the system."¹⁹ This provision for oversight, not present in most CPS agencies, is an important check on the danger of relaxing the vigilance and vigor essential to effective advocacy. The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987,²⁰ in the words of the Senate Labor and Human Resources Committee Report, added:

¹⁴ See chap. 10.

¹⁵ National Association of Protection and Advocacy Systems, 1987 Annual Statistical Report 1 (1988).

¹⁶ Developmental Disabilities Act of 1984, Pub. L. No. 98-527, sec. 2, §142(a)(5), 98 Stat. 2662, 2680 (codified at 42 U.S.C.A. §6042(a)(5) (West Supp. 1988)).

¹⁷ S. Rep. No. 493, 98th Cong., 2d Sess. 29, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4362.

¹⁸ See chap. 10.

¹⁹ 42 U.S.C.A. §6042(a)(2)(C)&(D) (West Supp. 1988).

²⁰ Pub. L. No. 100-146, 101 Stat. 840 (codified at 42 U.S.C.A. §§6000-6083 (West Supp. 1988)).

several provisions designed to enhance the accountability of the protection and advocacy systems by: ensuring particular attention be paid to the needs of Indians and members of racial and ethnic minorities who are developmentally disabled; requiring the establishment of grievance procedures; and by providing the public with an opportunity to make public comment on the priorities established by the System.²¹

— In the view of the Commission, therefore, it is desirable to make better use of the P&A systems to enforce the Child Abuse Amendments of 1984 and section 504, as well as other constitutional, statutory, and regulatory provisions protecting the medical treatment rights of persons with disabilities. To do so, certain tools are essential.

First, when a State CPS agency receives a report alleging the withholding of medically indicated treatment from someone with a disability, the State P&A should immediately be notified. At present, there is no provision for notification of the P&A. To enable it to make an independent assessment and, if deemed necessary, to take independent action to protect the medical treatment rights of the child, the P&A should have access to any information received or developed by the CPS agency. For the same reason, it should be given the authority to investigate the allegation, to designate medical professionals to review the medical records, and if need be, to secure a court order permitting these medical professionals to conduct a medical examination. It should have the authority to represent the interests of the child in any court proceeding, as well as independent standing to bring a court action to enforce the child's rights.

— Second, access to medical records is essential not only when a CPS agency has received a report of denial of treatment, but also when the P&A independently receives a report. Medical records are the key source in evaluating the validity of allegations of illegal denial of treatment. As the American Bar Association's Model Procedures note:

²¹ S. Rep. No. 113, 100th Cong., 1st Sess. 24, reprinted in 1987 U.S. Code Cong. & Admin. News 781, 803.

²² 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, 239 (1986) (footnotes omitted).

²³ Developmental Disabilities Act of 1984, Pub. L. No. 98-527, sec. 2, §142(a)(2)(D), 98 Stat. 2662, 2679 (codified as amended at 42 U.S.C.A. §6042(a)(2)(G) (West Supp. 1988)). See also S. Rep.

Records, if properly maintained, are the most objective data available. Interviews by themselves may be misleading, if persons alter, omit, or embellish facts. Also, records may reveal contrary views expressed by nurses, doctors and others. The medical records should provide documentary evidence of the course of the patient's medical evaluation, treatment, and change in condition, and of communication between the responsible physician and any other health professional contributing to the patient's care. The infant's medical record should specifically contain: (1) identification information; (2) evidence of appropriate informed consent or indication of why it is absent and what is being done to obtain the necessary consent; (3) patient's medical history; (4) report of patient's physical examination; (5) diagnostic and therapeutic orders; (6) observations of patient condition, including progress notes and nursing notes; (7) report of all procedures, tests, and their results; and (8) conclusions, including the provisional diagnosis, associated diagnoses, clinical resume, and necropsy reports.²²

In 1984 Congress amended the law to ensure P&A agencies access to the records of institutionalized persons with developmental disabilities when complaints from or on their behalf had been received by the P&A and they had no legal guardian other than a blanket public guardian.²³ The 1986 legislation provided for access to the records of persons with mental illness under a more detailed but essentially similar standard,²⁴ and a correlative provision was inserted into the developmental disabilities law in 1987.²⁵ In circumstances in which denial of treatment to children (and often older people) with disabilities is in contemplation, however, the parents or other guardians have, typically, nominally consented to the treatment denial. It is essential, therefore, that in such cases the P&As have authority to obtain access to the records, with appropriate assurances of confidentiality, without requiring the consent of the guardian.

Third, to circumvent the documented failure of many hospitals to report suspected instances of withholding of medically indicated treatment that come before their infant care review committees,²⁶ new mechanisms are needed. Any health care

No. 493, 98th Cong., 2d Sess. 30, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4363.

²⁴ Protection and Advocacy for Mentally Ill Individuals Act of 1986, Pub. L. No. 99-319, sec. 105(a)(4) 100 Stat. 478, 480 (codified at 42 U.S.C.A. §10805(a)(4) (West Supp. 1988)).

²⁵ Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, §301(a)(3), Pub. L. No. 100-146, 101 Stat. 840, 852 (codified at 42 U.S.C.A. §6042(a)(2)(G) (West Supp. 1988)).

²⁶ See chaps. 10 and 11.

facility that uses such a committee (or any other standing or ad hoc committee)²⁷ to review any prospective instance of withholding of treatment from a person with a disability should be required to notify the State P&A of any committee meeting to consider such a case. The P&A should be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee.

Fears that such a notification requirement would lead to frequent adversarial confrontations and vexatious litigation are not warranted by the track record of the P&As. P&As have developed a tradition of resolving potential violations of the rights of persons with disabilities or mental illness without litigation. "These Protection and Advocacy Systems (P&As) served approximately 85,000 people in 1986, and have been successful in negotiating 97 percent of their cases without resort to litigation."²⁸ Vigorous rights advocacy does not invariably require adversary courtroom proceedings, and it may well be that the rapid involvement of the P&A advocates on a local level while decisionmaking is still in process and positions have not hardened will avert the need for confrontation in many instances.

Unlike most CPS agency workers, most P&A workers should be familiar with local and specialized parent support groups, sources of financial and inkind support and counseling, which can be shared with the parents, health care personnel, and internal hospital committee. (P&As are responsible for significant information and referral for persons with developmental disabilities.²⁹) This may well lead to agreement on the part of all to follow a course of treatment in full compliance with the law. In this context, the language of the 1984 Senate Committee report is particularly appropriate: "The Committee commends the emphasis by P&A's on mediation and/or administrative remedies while at the same

time recognizes that there will undoubtedly be future instances where litigation is the necessary alternative to protect disabled persons' rights."³⁰

Fourth, to provide both a mechanism for evaluating compliance and a deterrent to violations, each State P&A should have retrospective access to the medical records of all children with disabilities who die. Presumably, in most States only a random selection would be routinely reviewed most years. However, authority should exist to review confidentially as many as the P&A deems necessary.

To ensure protection of the rights of institutionalized persons with developmental disabilities, Congress has already required that P&As automatically be provided annual survey reports on every intermediate care facility for people with mental retardation in their States.³¹ The Commission considers this proposal to be a reasonable extension of that precedent. Requiring notification to the P&A whenever an infant care review committee convenes to consider a "live" case, standing alone, will probably ameliorate the widespread failure to report by health care facilities, but it is unlikely to cure it. Since the establishment of such committees is voluntary with each hospital, it will have no effect on those facilities without them. Beyond this, the effect of the notification requirement, if there were no retrospective access, might be to drive underground contemplated withholding of treatment, as physicians seeking to avoid outside review might simply cease to use the formal hospital committees. A knowledge that all deaths of children with disabilities will at least potentially be subject to retrospective review will significantly reduce that incentive.

Fifth and finally, the Commission agrees with what the Senate Committee wrote in a slightly different context: "Providing the resources necessary to match the mandate of the P&A systems is essential if the job is to be done."³² Appropriate

²⁷ A 1985-1986 survey of hospitals with 1,500 or more births annually or a neonatal intensive care unit found that even when no official committee is designated:

In many hospitals an informal group structure is used. In 6.7 percent of hospitals, this includes physicians, specialists, and parents; in 5.7 percent, it includes a group of professionals in the hospital; [and] in another 2.5 percent of the cases it includes a group of physicians. . . .

R. Greenstein, S. Hudd & G. Fleming, National Collaborative Survey of Infant Care Review Committees in United States Hospitals 6 (1987). See also University of Connecticut Medical School/American Academy of Pediatrics, Project Summary[,] Infant Care Review Committees in United States Hospitals: A National Survey 2 (1987).

²⁸ S. Rep. No. 113, 100th Cong., 1st Sess. 10, reprinted in 1987 U.S. Code Cong. & Admin. News 781, 790. See also S. Rep. No. 493, 98th Cong., 2d Sess. 28, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4361 (98 percent of FY 1982 cases resolved without litigation).

²⁹ 42 U.S.C.A. § 6042(a)(2)(A)(ii) (West Supp. 1988).

³⁰ S. Rep. No. 493, 98th Cong., 2d Sess. 28, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4361. See also S. Rep. No. 113, 100th Cong., 1st Sess. 10, reprinted in 1987 U.S. Code Cong. & Admin. News 781, 790.

³¹ 42 U.S.C.A. § 6042(a)(4) (West Supp. 1988).

³² S. Rep. No. 493, 98th Cong., 2d Sess. 29, reprinted in 1984 U.S. Code Cong. & Admin. News 4334, 4362.

additional funding for the P&As will be needed to implement these new responsibilities. It should be adequate both for State-by-State implementation and for supportive training and technical assistance, including resources for the rapid evaluation of medical conditions.

With these powers and resources, the P&A system would be in a position to bring about what the Commission believes would be a significant improvement in enforcement of the medical treatment rights of persons, especially children, with disabilities.

Findings and Recommendations

The United States Commission on Civil Rights has undertaken to produce this report under its statutory mandate to “submit reports to the Congress and the President at such times as the Commission, the Congress or the President shall deem desirable.”¹

Nearly 7 years ago, the Nation’s attention was captured by news accounts of the starvation of Infant Doe in Bloomington, Indiana. Details of that case as well as of many other cases of wrongful denials of medical treatment for children born with disabilities are contained in this report. The report has examined and found serious deficiencies in the implementation of the Child Abuse Amendments of 1984 and makes recommendations to remedy these deficiencies. Furthermore, this report provides evidence that was unavailable in the administrative record and that would have been useful to the Supreme Court in its consideration and subsequent invalidation of the Infant Doe regulations at issue in *Bowen v. American Hospital Association*.

In the course of its hearings on the subject matter of this report, the Commission received testimony from a wide variety of individuals, including medical specialists, persons with disabilities, ethicists, hospital administrators, Federal officials, parents, academicians, and representatives of disability groups. These hearings have been published separately.² Of the many statements the Commission received, however, an excerpt from the testimony of Robert Williams, deputy director of the Pratt Monitoring Program of the D.C. Association for Retard-

ed Citizens, who himself has a physical disability, perhaps best sums up the essence of this report:

[T]he way to secure commitments [to improve the way people with disabilities are treated and the services they receive] is not. . . [to] suggest that care be withheld from newborn infants with severe disabilities until adequate funding is provided to help them obtain their maximum developmental potential. What benefit can result from this strategy? At best it can be seen as an extreme example of circular reasoning. At worst it can lead to the most vicious of circles. Appropriate support services necessary to assist the families of newborns with severe disabilities to love and care for their child in their own home will not be available as long as we devalue the life of a child so much that it becomes acceptable to withhold the most ordinary care.³

Based on its hearings, research, and this report, the Commission adopts the following findings and recommendations:

General Findings

1. Surveys of health care personnel, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to persuade the Commission of the likelihood of widespread and continuing denials of lifesaving treatment to children with disabilities.

2. The Commission is convinced that the evidence supports a finding that discriminatory denial of medical treatment, food, and fluids is and has been a significant civil rights problem for infants with disabilities. It is also persuaded that the available

¹ 42 U.S.C.A. §1975c(c) (West Supp. 1988).

² *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* (1985) (vol. I) & (1986) (vol. II).

³ *Protection of Handicapped Newborns: Hearing Before the United States Commission on Civil Rights* 272 (1986) (vol. II).

evidence strongly suggests that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984 on October 1, 1985.

3. The grounds typically advanced to support denial of lifesaving medical treatment or food and fluids are based on erroneous judgments concerning the quality of life of a person with a disability or on social judgments that such a person's continued existence will impose an "unacceptable" burden on his or her family or on the Nation as a whole. These judgments are often grounded in misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities.

4. Many people, including members of the medical profession, hold negative attitudes about life with disability that affect not only children but also adults with disabilities. Moreover, direct testimony was provided at the Commission hearings that these attitudes exist and that discrimination in the provision of lifesaving and other medical treatment occurs with respect to adults with disabilities as well as in cases involving infants and children. Further fact-finding is needed to determine the extent of discriminatory denial of medically indicated treatment in cases involving adults with disabilities.

5. There is evidence that in many instances in which lifesaving treatment is denied to children with disabilities, their parents are only nominally making the decision to withhold the treatment. In practice the doctors are often the prime movers in denying the treatment.

6. The question of whether children with disabilities should be denied lifesaving treatment has frequently been couched in popular debate as though the issue were the wisdom of government intrusion into matters of parental discretion. In fact, however, for decades the universally accepted law has been that when parents make treatment decisions that will undebatably lead to the death of their nondisabled children, the state will intervene to ensure the children's survival by mandating provision of lifesaving medical care. It is only when the children have disabilities that the claim of parental autonomy is given serious sympathetic consideration. Thus, the decisions upholding putative parental decisions to deny lifesaving treatment to their children with disabilities are rooted less in a respect for parental authority than in a bias against disability.

7. There are substantial economic costs associated with some forms of disability. Many costs, however, are less a function of the disability or the severity of the disability than of a policy that tends to segregate and isolate, at enormous public cost, those persons considered most severely disabled without even considering the alternative of providing social and economic support for the family. The assumptions influencing denial of treatment have often been: (1) that the level of severity of disability is the major determinant of lifetime costs; (2) consequently, that the more severely disabled a child may appear to be at birth the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency; and (3) therefore, the more expensive it will be to meet that person's basic needs. Although these assumptions rest on major fallacies, reliance on them has resulted in a self-fulfilling prophecy: a diagnosis of severe disability at birth leads to placements in residential and nonwork environments that significantly limit that person's capability and entail far more expense than necessary. The ultimate irony occurs when the expense that is the consequence of the original unfounded and stereotypical assumption becomes a basis for ending the lives of persons with severe, or what are thought to be severe, disabilities shortly after they are born.

8. The record developed during the Commission's two hearings and continuing investigation demonstrates that there is a grave danger to the constitutional rights of newborn children in cases in which food, water, and necessary medical care are denied on the basis of disability and predictions concerning future quality of life. The principle of equal protection of the law is offended when disability is the basis of a nontreatment decision. Procedural protections for the interests of both child and parents are often absent completely or are woefully inadequate to the task of sifting the facts.

General Recommendations

1. The Commission concludes that the Congress and the President should address the very real problems faced by people with disabilities and their families. The President should take the lead in fostering the development of a climate of social acceptance of persons with disabilities and their families by speaking publicly on the issue. The President should instruct the White House Council on Domestic Policy to review the adequacy, as well

as the coordination and development of, supportive services intended to assist such families. The President should order a review of the mechanisms designed for vigorous enforcement of the statutory rights of those with disabilities to accessible and integrated transportation, housing, education, health care, and employment. In addition, the appropriate committees of the Congress should schedule hearings to address these questions.

2. In considering legislation designed to prevent discrimination against persons with disabilities, Congress should take care to make clear that discrimination in the course of rendering medical treatment is precluded.

3. There is a need for factfinding activities by the Congress, the State legislatures, and Federal, State, and local agencies charged with the enforcement of civil rights laws and medical standards, to determine the extent to which adults with disabilities are subjected to discrimination in the provision of medical care and treatment, and to evaluate what remedies exist or are needed to prevent future discrimination of this kind from taking place. In particular, the new Secretary of Health and Human Services should direct the Department to undertake such a study.

Specific Findings Regarding Support for Families with Disabilities

1. The period surrounding birth is a time of considerable stress and emotion, and for nondisabled parents the birth of a child with a disability typically comes as a great shock. While beset by traumatic feelings of depression, grief, anger, and guilt, many such parents today have inadequate accurate information with which to make considered evaluations concerning the nature of life with a disability or the consequences for a family that includes a child with a disability.

2. One of the principal motivations for denial of lifesaving treatment to children with disabilities is the view that their continued existence will create too great a burden for their families. There is evidence that this concern has led to concurrence or acquiescence in the death or elimination of these children.

Specific Recommendations Regarding Support for Families with Disabilities

1. Congress should amend the Medicaid Act or other appropriate legislation to require that recipi-

ents of Federal financial assistance for medical services provide specific information on support and resources to parents of newborn children with disabilities. This should include information on adoption and, when necessary, information on other supported family placement with resources necessary to care for the child.

2. Congress should amend the Medicaid Act or other appropriate legislation to lower the adjusted gross income ceiling that a family must spend on disability-related medical expenses before the family member with a disability becomes medicaid eligible.

Specific Findings Regarding Section 504 of the Rehabilitation Act of 1973

1. The hearings and research conducted by the Commission, and the findings based on them, especially General Finding 5, supply a factual record that was absent in 1986 when the United States Supreme Court decided *Bowen v. American Hospital Association*, striking down regulations intended to assist enforcement of section 504 in the context of discriminatory denial of treatment to children with disabilities.

2. A central problem with the *Bowen* plurality opinion is that it suggests that section 504 puts no constraints on a recipient of Federal financial assistance responsible for the discriminatory denial of treatment to a person with a disability, if the denial is authorized by a nonrecipient such as a parent who, as a surrogate decisionmaker for a child with a disability, normally has the legal authority to provide or withhold consent for the child's medical treatment.

3. The Commission's findings suggest that parents who authorize denial of treatment to their children with disabilities are frequently substantially influenced in that decision by the views of their children's physicians and other health care personnel who frequently display inadequate awareness of the potential of these children.

4. In cases in which decisions nominally made by parents to deny treatment to children with disabilities are in fact generated by health care personnel, health care providers who do not provide lifesaving medical treatment to children with disabilities that would be provided were it not for the disabilities should be held to violate section 504 despite parental acquiescence in the treatment denial.

5. The logic of the *Bowen* plurality opinion applies equally to authorizations for denial of treatment by other nonrecipient surrogate decisionmakers, such as a guardian for a person with a disability who is not competent to make health care decisions.

6. The position taken by the plurality thus puts at risk not only children, but also older people with disabilities. In the view of the Commission, a recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient's involvement, would be prohibited discrimination. A recipient's substantial involvement in a nonrecipient's discriminatory practices should be held to violate section 504.

7. The Commission's reading of the legislative history and plain meaning of section 504 of the Rehabilitation Act of 1973 persuade it that the provision does cover discriminatory denial of medical treatment to people with disabilities.

8. The Commission concludes that passage of the Civil Rights Restoration Act establishes that a hospital's practice of reporting to State agencies instances in which parents withhold consent for provision of lifesaving treatment to their children is covered by section 504. The act defines section 504's coverage to include "all of the operations of . . . an entire corporation, partnership, or other private organization. . . which is principally engaged in the business of providing. . . health care. . . ." If a hospital engages in reporting cases of medical neglect to the State child protective services agency, that practice of reporting is among the operations of a corporation that principally provides health care. Therefore, if any part of the hospital receives medicaid or medicare, discrimination in reporting based on handicap (such as a practice of reporting instances in which religiously motivated parents refuse consent for lifesaving treatment for nondisabled children to the authorities, but failing to report instances in which parents refuse consent for lifesaving treatment for children with disabilities) violates section 504.

9. During the period in which enforcement of section 504 in this context was not yet enjoined, the performance of the Office for Civil Rights of the Department of Health and Human Services in implementing it was poor. Confronted with substantial evidence of significant and ongoing denial of lifesaving treatment to children with disabilities,

evidence that suggested an ongoing threat to lives in two 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.

Specific Recommendations Regarding Section 504 of the Rehabilitation Act of 1973

1. In light of the record developed by this Commission, and in light of the advantages of section 504 for addressing denials of treatment, the Commission recommends 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.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to make clear that withholding of medically indicated treatment, as defined in the Child Abuse Amendments of 1984, constitutes denial of the benefits of health care services for purposes of Title VI and section 504.

Specific Findings Regarding the Child Abuse Amendments of 1984

1. The Child Abuse Amendments of 1984, the product of considerable debate and negotiation, set out a detailed and, for the most part, unambiguous but nuanced standard of care which States that receive Federal funds for their child abuse and neglect programs must enforce among health care facilities. If adequately enforced, the law would provide strong protection for many children with disabilities against denial of lifesaving treatment.

2. Parents engaged in life and death decisions for their children are heavily dependent on the good faith of, and accurate information provided by, those advising them. Because advisors may be ignorant or prejudiced about persons with disabilities, there is a need for the establishment of a broadly based advisory process that includes members of the local protection and advocacy system (P&As) and others with expertise in disability and rehabilitation. Establishment of a structured care review process or committee will ensure that the decision made is in compliance with the standards set forth in the Child Abuse Amendments, provided that any participant

in the advisory process who is concerned with the well-being of the child has standing to invoke the remedies that are otherwise available under State law and the Child Abuse Amendments for dealing with child neglect.

3. Many State child protective services agencies rely heavily upon members of the medical profession for information and assistance concerning cases of parental child abuse. This close working relationship has also led to heavy reliance by many State child protective services agencies on the very medical care facilities and personnel whose actions, advice, or neglect are at issue in cases of suspected medical care discrimination. Taken together, such close working relationships among State child protective services agencies and members of the medical profession has resulted in the substantial failure of many such agencies to enforce effectively the Child Abuse Amendments of 1984.

4. It is questionable whether most hospital-based ethics or infant care review committees are constructed in a manner that makes them likely to conduct searching scrutiny of proposed denials of treatment. They represent an approach that relies essentially upon the internal self-regulation of the health care community. Few committees include representatives of disability rights groups; the majority convene only to deal with disagreements, rather than attempting to scrutinize most denial of treatment decisions to see whether they comply with the law. Instead of strictly applying the Child Abuse Amendment standards, many appear in practice to use more ambiguous criteria that include consideration of the projected "quality of life" of the child with a disability. Taking note of the great propensity by many in the medical profession to disagree with the treatment standards in the Child Abuse Amendments and of the available evidence concerning the functioning to date of hospital-based ethics or infant care review committees, the Commission is persuaded that they cannot be relied upon alone to ensure that children with disabilities are accorded the lifesaving treatment that is their right by law.

5. The Commission is dismayed at the poor performance of the Office of Human Development Services of the Department of Health and Human Services in fulfilling its responsibility to ensure that State child protective services agencies receiving funds under the Child Abuse Prevention and Treatment Act comply with the Child Abuse Amendments of 1984 so as to protect children with

disabilities from illegal discrimination in the provision of medical care. That performance requires substantial improvement. Although the Commission is encouraged by steps the Office of Human Development Services now states it will take in response to this report, it is too soon to determine whether they will result in the very significant increase in scrutiny of the performance of recipient State agencies that is essential if the Department is effectively to fulfill its responsibilities under the law.

Specific Recommendations Regarding the Child Abuse Amendments of 1984

1. Because funds available under the Child Abuse Prevention and Treatment Act are apparently not sufficient to induce all jurisdictions to comply with the Child Abuse Amendments in order to qualify for them, compliance with the Child Abuse Amendments should be made an additional requirement for State eligibility for participation in medicaid, so that the protections they afford will be made available to all children with disabilities in the United States.

2. Congress should amend the Child Abuse Prevention and Treatment Act or other appropriate legislation to establish a mechanism to improve reporting of cases of suspected withholding of medically indicated treatment by requiring that any hospital that uses a committee to review a prospective instance of withholding of treatment from a person with a disability is required to notify the State protection and advocacy (P&A) agency of meetings held to discuss the case. The P&A agency should then be afforded the opportunity to examine the medical records and discuss the situation with physicians, relatives, and the committee. It should have authority to obtain a court order for an independent medical examination, and if it concludes that medically indicated treatment would otherwise be withheld illegally, it should have the standing to institute a court proceeding to require that it be provided.

3. Hospitals without a specialized advisory process for dealing with the special needs of parents for information on disability and rehabilitation should be required to establish a process in accordance with the provisions of the Child Abuse Amendments and the recommendation made above.

4. Representatives of the local protection and advocacy system should be included in the advisory

process, both as advocates for the child's interests and as a resource for the information of the parents.

5. Congress should amend section 504 and the Child Abuse Amendments to require the establishment of such a care review process or committee within treatment facilities across the country.

6. Should any participant in a care review advisory process not be satisfied that the outcome of the process is in compliance with the standards set forth in the Child Abuse Amendments, that person should have standing to invoke such remedies, judicial or otherwise, that are available under State law for dealing with child neglect.

7. When a State child protective services agency (CPS) receives a report of suspected withholding of medically indicated treatment under the Child Abuse Amendments, it should be required promptly to notify the State P&A agency and to provide it access to the records obtained and information developed by the CPS agency. As a representative of the interests of the child, the P&A agency should have independent authority, similar to that now held by the CPS agency, to obtain medical records, to obtain a court order for an independent medical examination, to appear on behalf of the child in any court proceeding to authorize medical treatment initiated by the CPS agency. The P&A agency should also have independent standing to initiate a

court proceeding to authorize medical treatment for the child.

8. To create a deterrent to physicians who not only might fail to report a case of withholding to the State CPS agency but also might not submit it to a hospital committee, the P&A agency should be given authority to conduct retrospective reviews of the medical records of those with disabilities who die in the State. If instances of illegal withholding of medical treatment are detected, the P&A agency should be able to seek appropriate action by licensing boards or Federal funding sources and, in extreme cases, to institute suits for injunctive or monetary relief or refer cases for investigation by prosecuting attorneys.

9. Congress should afford P&A agencies appropriate financial and backup assistance to enable them to fulfill these roles capably.

10. The Office of Human Development Services in the Department of Health and Human Services should take corrective measures to ensure more rigorous scrutiny of State plans submitted for funding under the Child Abuse Prevention and Treatment Act to remedy the current widespread failure of State child protective services agencies to comply with the requirements of the Child Abuse Amendments of 1984.

A Dissenting View on the Report *Medical Discrimination Against Children with Disabilities*

By William B. Allen, Chairman

When the *final draft* of this report was presented (and approved) by the Commission in January of this year, it did not contain any information whatever as to the rate of incidence of medical neglect of handicapped newborns. Nor did it include even raw numbers of the total births and deaths of severely afflicted infants in the United States. When I inquired, therefore, as to the dimensions of the problem, no one who had assumed responsibility for the preparation of the report could respond to me. I found this extraordinary, to say the least, and utterly unacceptable, to be candid. For that reason, among others, I voted not to approve the report.¹

¹ That is to say, I abstained. I did not vote against the report, but neither did I vote to approve. Indeed, I spoke expressly in criticism of it. Mr. Destro finds this expression troublesome, despite the fact that the sentence, "I voted not to approve. . ." is exactly the grammatical equivalent of the sentence, "I did not vote to approve. . ." The point, of course, is that in the face of tremendous pressure, I do not palliate the significance of my vote by hiding behind technicalities. Rather, I candidly own that I voted not to approve, and would do so again on the record established here.

At his footnote 9 Mr. Destro worries not only about the grammar in my dissent but about my actual conduct in voting. To satisfy his curiosity in this regard, I now append to this dissent the full text I issued at the time I voted to abstain, entering an elision covering the material reproduced in the dissent (appendix 1). Suffice it to say that Mr. Destro's litmus, the Commission's "approach to the issue of medical care discrimination," falls wide of the mark of my observations. The question is not, or should not be a question of approach. It should be a question of actual contribution toward safeguarding vulnerable lives and rights. I indicated at the Commission debate, and now reaffirm, my belief that the Commission's "approach," far from protecting handicapped newborns, can only eventuate in making it more difficult to protect them.

The shortest path to the defense of handicapped newborns would be, not to carve out ever new exceptions to legal standards crafted over centuries, but rather to assure immediately the full range of protections to which persons are otherwise entitled. That would mean not new laws but confirmed enforcement of laws

Since the Commission's final vote on the report, an appendix A has been added, reducing statistics from the Center for Disease Control from 1983 and partially responding to my inquiry. Nevertheless, those statistics do not accomplish all that I sought. In the first place, they provide no indication of what has occurred within the medical profession *since* the period of great concern about "Baby Doe" cases and since the enactment of the Child Abuse Amendments of 1984.² That is, they say nothing about the dimensions of the problem during the very years when this report was being prepared at a cost of half a million dollars! Secondly, no comparative analysis

against homicide and entailing every ordinary gradation and distinction admitted in such cases. That is the import of my repeated—but still ignored—insistence, that handicapped newborns have the same rights all other persons enjoy—none more and none less.

² At page 208 Mr. Destro falsely characterizes my concern to know the facts as an attempt to get hard numbers on who committed what crimes. What I asked for, and I repeat, was simply a number indicating the incidence of handicapped newborns and a number of the deaths within that class. Mr. Destro finds it "incomprehensible" that anyone should seek such information. I am comforted, however, that staff was able to provide just that (*though without comment*) in the report's appendix A, and I am still more confirmed in my credulity by the fact that the Inspector General's 1987 reports from the Department of Health and Human Services make a fine effort in that direction.

What I find "incomprehensible" is that our staff and the subcommittee read and commented on the HHS reports, but nowhere attempted to come to terms with these numbers. That the reader may not suffer from the omission, I add those *brief* reports as appendices to this statement (2 and 3). Let the readers judge what the so-called "hard" evidence suggests, and I will be surprised if they come to any conclusion other than that the effort expended to "justify" a defective report could well have produced a better one if well directed—directed, that is, towards the report's own announced purpose: "to determine the nature and extent of the *practice* of withholding medical treatment or nourishment from handicapped infants." (Report, 1.1)

is provided of the various figures, and particularly those touching upon the three conditions most frequently adduced in this report. According to the 1983, and thus prereform figures, there were 3,093 live births with Down syndrome, of whom 84 died of the condition. There were 1,747 spina bifida births, of whom 95 succumbed. And there were 3,238 cases of *all* of the listed atresias, of whom 261 passed. The question remains: Are these numbers extraordinary? Of these deaths, what proportion might have been unnecessary?

In short, I remain convinced that this report reflects all too prominently a certain kind of research incontinence. The failure to make as strong a demonstration as possible reflects only one side of that methodological flaw. On the other side has been the steadfast refusal to vent the report among critics in advance. When (as an *ex officio* member) I proposed last fall that the draft be sent out to interested parties for confidential comment, the drafting subcommittee refused. That meant that we had no means to measure the sufficiency of the report's representation of the "other side." The interest of producing the strongest possible counterargument is to enhance the credibility of the final document. As a matter of practice, Commission reports should always be expected to contain the most sympathetic representation possible of the strongest counterarguments to the positions taken. Even when such an approach will not guarantee that we persuade others, it will guarantee that we will earn their respect.³

Apart from these methodological considerations, I have previously written of substantive concerns that troubled me. The editing of the "final draft" has only partially relieved those substantive concerns. I remain persuaded, however, that the interests of handicapped newborns have been sacrificed to a

³ Mr. Destro misreads my statement and compounds his error by then declaring his understanding that I "subsume the question entirely into the realm of medical ethics." (Destro, p. 208, n.3) My statement so clearly rejects this contention, in advance as it were, that I will not belabor the point. I will pause only long enough to say that, by giving space to voices that were not heard in preparing this report, I do not endorse their views of course. I add here, as an appendix, the letter I received from the American Academy of Pediatrics, stating their views (appendix 4). Further, since I have specifically disagreed with Dr. Engelhardt's interpretation of the Hippocratic Oath, there really can be no honest occasion for anyone to misconstrue this. Perhaps now is also a good place to remind the unwary that the argument *ad Hitlerum* generally betrays a want of defensible principle.

⁴ At page 211 Mr. Destro appropriates my observation, that this report does not substantiate its claims of widespread abuse, to a

political mission. I do not require in this space to repeat those arguments.⁴ I believe at this moment that the most urgent contribution I require to make is to make clear the argument to which those who would defend handicapped newborns must respond. To that end, these remarks will be followed immediately by the commentary of Dr. Tristram Engelhardt, perhaps the foremost medical ethicist in the United States. Dr. Engelhardt prepared his evaluation of the report at my request and on extremely short notice, since I was not free to send it to him before it became public property.

Relative to Dr. Engelhardt's testimony about the incidence of undertreatment of handicapped newborns, it is regrettable that we are unable to make a judgment based on this report. With respect to his more substantive arguments, some I find reassuring, while disagreeing with others. In particular, I am not so sanguine as he about the power of the Hippocratic Oath to guide physicians through these trials. Because I discussed that central point in my previously published comments, I will produce that discussion here, to conclude my remarks, and then permit Dr. Engelhardt immediately to respond.

Life and Health the Ends of Medicine

The reason Hippocrates came to my mind during our preliminary discussion of discrimination against handicapped newborns was that much of what I read, and much of what was presented before us, seemed to present the question as one about thresholds for humanity, as if protoplasm quickened into humanity on some measurable scale to which our art or science could point us. Hippocrates had taken rather a different view, one which founded knowledge and applicability of the arts on "knowledge of the nature of man in general." [*Regimen*, I, ii] That is, he made knowledge of the arts (of the end of the

purported denial that medical professionals discuss euthanasia and other sanguinary approaches to human life. This sleight-of-hand is totally unjustifiable. Happily, however, it rather serves to blast than confirm his case. For, on the premise that people are surely doing what they say they would be willing to do, Mr. Destro concludes widespread abuse for which he adduces not one shred of *direct* evidence. Since most of the discussions he relies upon are academic in character, it would not be difficult to set right this sophomoric use of those discussions. Let it suffice, though, to note that it is akin to believing that cannibalism has been morally justified simply because philosophy and law professors use the lifeboat example! Even if every such classroom and journal in the country used the example *in speech* (and that is close to accurate!), we would still need evidence beyond the incident at Donner Pass to declare the *practice* pervasive.

arts) to depend upon knowledge of humanity, while today we seem to do the reverse—no matter what side of the “Baby Doe” debate we fall on.

This is curious, indeed. Those who defend for handicapped newborns a right to treatment, no less than they who deny it, seem to believe that medical art should not be informed by any notion of moral or human ends. For the former, this leads to a powerful emphasis on legal and administrative procedures to prevent the medical arts deciding questions not appropriate to them; while for the latter, it leads to emphasizing medicine as a neutral art that may serve any purpose medical consumers desire for themselves. The idea that medicine is a neutral art was certainly foreign to Hippocrates, for whom the art was informed by the idea of human health, and it was no less foreign to the generations of physicians who subscribed to Hippocratic standards.

What we must note today is that physicians no longer subscribe to Hippocratic standards, and certainly not to the Hippocratic Oath. That oath, among other things, contained the following pledge:

I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly, I will

⁵ At pp. 211-12 Mr. Destro profoundly, and sadly, misconstrues the slight mention of abortion made in my original statement. (Can anyone fail to see the relevance of the Oedipus tale?) Following the improvident lead of Ms. Berry, Mr. Destro struggles vainly to separate the questions, never noticing that he attempts to cleave the physician’s soul. For the burden of my observation was nothing more than to remark the reason for Hippocrates’ coupling of the pledges not to render abortions and not to assist suicides. They are not two choices, but one; and they are not dilemmas at all, from Hippocrates’ perspective. It is, in fact, the assumption that moral choice implies dilemmas that is most profoundly the cause of our unwonted tolerance of moral weakness. Dilemmas exist where grounds of judgment are unclear. If, in our reasonings, we cannot state clear grounds of judgment, as I have tried to do, we will make matters worse, as this report and Mr. Destro’s comments do.

In that light, we might do worse than to recall Thomas Jefferson’s admonition. Describing the moral sense that makes man man, even when some persons seem to lack that very sense, Jefferson turned to example: “. . . there is no rule without exceptions; but is false reasoning which converts exceptions into the general rule. Some men are born without the organs of sight, or of hearing, or without hands. Yet it would be wrong to say that man is born without these faculties, and sight, hearing, and hands may with truth enter into the general definition of man.” (Letter to Thomas Law, June 13, 1814, *Writings*, p. 1337, Library of America)

⁶ This report is not about medical neglect, nor its corollary in civil law, medical malpractice. The law offers guarantees to all citizens alike in this regard, whether handicapped or not. “Mere” medical neglect is not a civil rights problem, whereas systematic and discriminatory medical neglect would be. It may seem strange to say, but it is nevertheless true that civil rights guarantee the *fair* distribution not only of advantages, but also of burdens.

not give to a woman an abortive remedy.⁵ In purity and holiness I will guard my life and my art. [Kass translation]

If every American physician adhered to this pledge, there would be no Baby Doe problem. In fact, however, American medicine has replaced the Hippocratic oath with its own “Principles of Medical Ethics,” which dropped altogether the opposition to suicide and abortion. This is the history that, more than anything else, creates our contemporary difficulties—the deliberate, conscious adoption of suicide and abortion as medical remedies.

In the United States, however, we depend not merely on the self-restraint of physicians. The organic law of our society proffers a guarantee of the right to life to persons, a guarantee that parallels the Hippocratic pledge. When, therefore, our physicians ceased to believe in the Hippocratic commitment, *they nevertheless were subject to the constitutional commitment*. 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.⁶

In this respect our report does us a disservice. By presenting the plight of the handicapped newborn as the logical development of unbroken historical

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 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 condemnation of the effort devoted to it and the taxpayer funds expended on it.

The report opened with a sensible awareness of this difficulty, affirming that the “equal protection clause. . . creates a nondiscrimination standard” while the “constitutional procedural (sic) due process rights also considered. . . presuppose an existing substantive benefit which they ensure may not be denied by processes that fail to meet standards of fundamental fairness.” (Report, 1.3n) But it lost its way in the attempted application, trying to distinguish the medical decision from the fairness decision. “If kidney dialysis, for example, is withheld from someone because it is medically contraindicated, such a judgment is outside the scope of the Commission’s purview.” Good, as far as it goes!, but compare that confident statement with the following: “A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment.” The fact is, however, that one’s being black routinely enters into medical judgments, and particularly in the case of kidney dialysis! We know that medicine decides against kidney dialysis in black people, based on a reported judgment of lower tolerance likelihood. The case of the handicapped is not less intricately wound up with medical judgments. These are debatable judgments, but not isolable judgments. The civil rights response to the kidney dialysis is shaping up to be a program of organ donor quotas—that is, a decision that the medical decision is simply wrong! (Report, 1.4 and n.5)

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.

The history is also false in terms, to the extent that it denies generally humane social instincts toward the “feeble-minded” in the era prior to the emergence of 20th century nihilism and eugenics. Indeed, the 18th and 19th century prison reform movement (which gave us penitentiaries, houses of repentance) aimed as much to distinguish the criminal from the “feeble-minded” and the insane as to provide rehabilitation. The fact that these primitive reforms fell short of modern necessities—and may by our lights even seem blighted—can by no means diminish the significance of that liberal impulse which gave birth to them.

The report rightly condemns the eugenicist movement and Margaret Sanger. I do not need conversion on that score. It is nevertheless unsound to seek to derive the eugenicist movement from mere historical conditions or the cultural milieu. The significance of

this observation becomes manifest when we reflect that at the heart of the report, we find an assumption of *deriving rights from needs* (cf., ch. 8, n. 63).

Rights are neither defined nor illustrated by needs, not for the handicapped nor any other category of Americans. The reason black people ought to enjoy equal rights of citizenship is not that most of them are poor. It is rather that they are human beings to whom the rights and arts of self-government pertain no less than to any other humans.

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. (I might point out that there is also a moral corollary, namely, that occasion be left for other folk to be considerate.)

Comments on the Recommendations Regarding Section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984

By H. Tristram Engelhardt, Jr., Ph.D., M.D.*

At times the most well-meaning and intelligent of men and women, from the best of motives, come to see an issue in a distorted light. Frequently this is the result of circumstances that have skewed the process of data acquisition and interpretation. Unfortunately, this appears to be the case with regard to the report and recommendations concerning section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984. The report appears to have been written under assumptions that are false and misleading. 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.

Because of a failure to appreciate the range of harms to which seriously ill newborns may be exposed (especially the risk of useless and painful overtreatment), the report erroneously suggests that the task is one of encouraging further overtreatment rather than making some judicious changes in the Child Abuse Amendments of 1984, so that they will not constitute a threat to the best interests of a significant class of very seriously ill newborns.

Nor does the report appreciate the kind of cooperation among parents, physicians, and child protective services agencies that will be necessary if our society is to adapt to an environment of rapidly changing high-technology medicine. In what follows I respectfully submit some substantive criticisms of the draft report and recommendations with respect to section 504 of the Rehabilitation Act of 1973 and the Child Abuse Amendments of 1984. The central thrust of my comments is that there is no

evidence of significant undertreatment of severely ill handicapped neonates since 1985. If anything, there is evidence of overtreatment. Moreover, were there evidence of the failure to provide indicated treatment, the proposed approach would not be the preferred solution to the problem. If the recommendations of the report are aggressively followed, the interests of seriously ill newborns will be imperiled.

The Bias Toward Overtreatment: Overtreatment Is a Form of Abuse

To begin with, I find matters as described in the report not to accord with my experience as a physician and a bioethicist, or with my conversations with neonatologists and with parents of children with severe disabilities. In particular, the bias since 1983 or at least 1985 has been to overtreat, not undertreat, severely ill handicapped neonates. In my experience, families often wish to discontinue treatment, despite the recommendations of the physicians to the contrary. Moreover, physicians, especially neonatologists, as well as a preponderance of lay persons, often have an exaggerated view of what can be contributed by intensive medical interventions.

Physicians whose careers are dedicated to the saving of human life, and who often must spend many grueling hours in attempting to save a child, tend to regard parents who wish to stop treatment as quitters, as individuals disloyal to the therapeutic enterprise. One sees this phenomenon in other areas of medicine such as cancer treatment, where patients are frequently aggressively overtreated, subjected to therapies that involve significant pain and suffering, but little if any real promise of extension of life. The difficulties in this regard have in particular been

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illustrated by the resistance to hospice care, where futile treatment is avoided in order to give more appropriate comfort care. The reason that it is often very difficult for health care givers to move from futile curative care to humane supportive care is in part due to their becoming so involved in a desperate hope to cure that it is difficult to recognize the limitations of medicine.

The Distortion in Perspective Due to the Therapeutic and Technological Imperatives

Technology has a force and momentum of its own, often described as the technological imperative. People tend to apply a technology in medicine if it is available, even if there is no evidence that the application will benefit those who are treated. The technological imperative involves an augmentation of what can be termed the therapeutic imperative: the view that it is always best to treat aggressively. It is worth recalling that physicians aggressively bled patients for over 2,000 years, even though this treatment conveyed no benefit, except perhaps for those suffering from acute congestive failure. It is very difficult for individuals to do nothing for a patient, even when doing something harms the patient more than it helps. It is because of this seduction born of the inclination to intervene that the Hippocratic maxim, "First do no harm [*primum non nocere*]," was articulated. This maxim was extraordinarily important, then as now, because physicians (and now hospitals) are not only inclined to treat aggressively because of vain hopes born of the therapeutic, now the technological imperative, but because they take money from and derive esteem from their roles as heroic therapists. Since we often unrealistically expect so much from medical treatment, it is difficult to appreciate how easily we as individuals and societies are seduced by the technological imperative. However, it is important to recognize that overtreatment, the use of treatment that causes more harm than benefit, is a form of child abuse.

The Misguided Tendency to Regard Criticism of the Child Abuse Amendments of 1984 as Hostility Towards the Handicapped

In reviewing the draft recommendations regarding the Child Abuse Amendments of 1984, along with the attached appendices and supporting information, I am struck by the underrepresentation of

the critics of the Baby Doe regulations and the subsequent Child Abuse Amendments of 1984 and how their arguments are treated. The considered judgments of the President's Commission are by implication styled rhetoric (see chapter 6). Beyond that, there does not appear to be any testimony from an official representative of the American Medical Association or the American Academy of Pediatrics; at least their views of matters since 1985 are not given in the report. Moreover, there is a remarkable underacknowledgement of the criticisms in the literature about the Baby Doe regulations and the subsequent regulations published pursuant to the Child Abuse Amendments of 1984. Finally, substantive criticisms have been construed as hostile opposition.

It may seem somewhat out of place to suggest that criticisms of the Child Abuse Amendments of 1984 should be entertained at this juncture. However, it is important to recognize how ill-stated some of those requirements are. According to the current requirements, one is explicitly mandated, under certain circumstances, to provide treatment that rational and prudent decisionmakers would agree is inhumane, that is, conveys more harm than benefit. The current law would allow the nonprovision of treatment only if "(A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."¹ Rubric (C) would require inhumane treatment. That is, in cases where the treatment is not also virtually futile, it would require treatment that from the perspective of a reasonable and prudent observer would cause more harm than benefit to the person being treated.

Such an approach to treatment has generally been held to be unethical and immoral. The American Academy of Pediatrics, for example, has required the provision of treatment only when it is clearly beneficial. "When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate

¹ Pub. L. No. 98-457, 121, 98 Stat. 1749 (1984).

medical facility. Considerations such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be sole focus of the decision. These are very strict standards."² Moreover, the American Medical Association quite properly has emphasized the legitimate role of parents in deciding on the scope of treatment when that decision reflects a reasonable judgment regarding the best interests of the child.

In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks, and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected the parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.³

Finally, it is important to note that a major element of Western moral reflections regarding the obligation to provide treatment has drawn a distinction between ordinary and extraordinary care, which has not been equivalent to usual versus unusual care, but rather which has been equivalent to that treatment constituting an undue or disproportionate burden, versus that involving only a proportionate burden given likely outcomes, and that is therefore obligatory. There are many articulations of this moral viewpoint, but a recent one of classical force was provided by Pope Pius XII in 1957: "normally one is held to use only ordinary means—according to the circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden [*aucune charge extraordinaire*] for

oneself or another. A more strict obligation would be too burdensome [*trop lourde*] for most men and would render the attainment of the higher, more important good too difficult."⁴

It is crucial that one recognize that such distinctions between ordinary and extraordinary treatment were never meant to focus simply on economic considerations. In contemporary medicine, physicians are usually reluctant to treat severely ill neonates when the therapeutic intervention is likely to effect more harm than benefit. The focus is on the best interests of the patient. There is primarily an intention to avoid painful interventions that have little prospect of saving life. The testimony in a distorting fashion suggests that the decision not to treat depends primarily on a prejudicial and biased appreciation of the future quality of life of the neonate. Instead, the inclination not to treat is usually based on the judgment that the treatment will itself cause more suffering than benefit.

Because of the failure to appreciate the contemporary guiding ethos of neonatal medicine (i.e., that there is an inclination to overtreat and the usual interest in not treating is based on a concern not to harm the neonate), there is also a failure in the report and its recommendations to take seriously negative appraisals of the Child Abuse Amendments of 1984. For example, in chapter 9, the article by Kopelman, Irons, and Kopelman is described as disclosing "widespread hostility to the standards of treatment adopted by the Child Abuse Amendments of 1984." The data are more accurately described as giving substantive empirical basis for criticizing those amendments. To use the word "hostility" is to suggest an emotional disposition to disregard the amendment. However, the Kopelman et al. article gives good grounds for agreeing with the Office of the Inspector General, which in 1985 concluded that the current regulations are sufficient and that "most states feel that existing child abuse and neglect procedures would have been adequate to respond to baby doe reports."⁵ Indeed, in light of this statement it is important to put the Kopelman et al. report, published in the *New England Journal of Medicine*, in proper perspective. On the basis of a

² American Academy of Pediatrics, "Principles of Treatment of Disabled Infants," *Pediatrics* 73 (Apr. 4, 1984), 559.

³ *Current Opinions of the Judicial Council of the American Medical Association—1984* (Chicago: American Medical Association, 1984), p. 11.

⁴ Pope Pius XII, Allocution "Le Dr. Bruno Haid," Nov. 24, 1957, *Acta Apostolicae Sedis* 49 (1957), 1031. English translation

from Pius XII, "Address to an International Congress of Anesthesiologists," Nov. 24, 1957, *The Pope Speaks* 4 (Spring 1958), 395-96.

⁵ Office of Inspector General, Office of Analysis and Inspections. Survey of state Baby Doe programs, September 1987. (Pub. no. OA1-03-87-0018.)

questionnaire sent to the 1,007 members of the Perinatal Pediatric Section of the American Academy of Pediatrics, of which 494 members (49 percent) responded, 56 percent agreed that "infants with an extremely poor prognosis for survival were being overtreated."⁶ This is not a statement supporting a quality of life judgment. But it is an opinion made by expert physicians in the field that more harm than good is being done in the treatment of a certain class of severely ill neonates.

There is indeed an inclination in the report to construe medical decisions as merely technical decisions regarding the likelihood of success or failure of a particular treatment. In medicine traditionally, and today in areas outside of the treatment of handicapped neonates, this has not been the understanding of appropriate medical decisionmaking. Appropriate medical decisionmaking has traditionally and still is generally held to include consideration of whether treatment will provide more benefit than harm. Indeed, physicians are morally obliged to refuse to provide treatment that produces substantially more harm than benefit. Insofar as the recommendations of the Civil Rights Commission undermine this ethos, one can only conclude that the recommendations as currently written will make matters far worse, not better, for the citizens, including the handicapped citizens, of the United States.

Is There Sufficient Protection Already?

Whatever may have been the state of affairs prior to the Baby Doe regulations and the Child Abuse Amendments of 1984, those changes in law and public policy combined with the ever-increasing level of exposure to malpractice litigation strongly bias physicians in favor of treating a severely ill neonate, even in cases where physicians believe such a treatment will be inhumane, will in fact involve more harm than benefit to the neonate who is treated. In addition, the issue of whistle blowing is radically different in areas of child abuse than in other areas of American society. Anonymous information can be provided to State child protective services agencies for investigation, so that the whistle blower is not placed at any risk. There is no analogy between the risk to whistle blowers currently making reports regarding child abuse and other areas of whistle blowing, where there is little

possibility of anonymity nor an agency obligated and equipped to investigate anonymous reports.

The interaction between parents and physicians must be appreciated within this perspective. There are already substantive requirements to provide sufficient information to parents so that they can make an informed choice with regard to the treatment of their severely ill neonates. These requirements are already supported by substantial malpractice awards. In addition, the threat of being charged with child abuse has keenly focused the attention of physicians on the rights of severely ill children. To find that improper persuasion of parents by physicians occurs in this context is to judge that it is bad social policy for parents to rely on the best available expert medical care when needing to make decisions about the treatment of their children, bearing in mind the presence of subsequent sanctions against physicians, should they acquiesce in child abuse or provide improper treatment.

It may very well be the case that, in many areas, the best of physicians are not fully informed regarding likely prognoses. This will be a difficulty that medicine will face generally as technological progress accelerates, requiring accelerated and intensified continuing medical education. But this general problem is unlikely to be solved simply by heightening government-bureaucratic enforced interventions. A much more plausible alternative approach to this problem, which is not restricted to any one area of medicine, is to find ways of cooperating with and assisting specialty societies in the continuing education of their members. In short, *IF* physicians are still undertreating patients, it is unlikely that the measures suggested by the Civil Rights Commission will be a salutary remedy for this difficulty. Only by working with such organizations, trusting them and encouraging their trust, will the nuanced self-regulation be ensured, which is needed in such rapidly changing technological areas.

But this contention about undertreatment involves a very large *IF*. As the Kopelman and other articles suggest, the current climate supports overtreatment, that is, causing more harm to patients than good.⁷ For example, Dr. Stuart F. Spicker (professor in the Department of Community Medicine and Health Care, School of Medicine, University of Connecticut Health Center), who, under a grant from the

⁶ Kopelman, Irons & Kopelman, *Neonatologists Judge the "Baby Doe" Regulations*, 318 *New Eng. J. Med.* 683 (1988).

⁷ John C. Moskop and Rita L. Saldanha, "The Baby Doe Rule: Still a Threat," *Hastings Center Report* 16 (April 1986), 8-14.

Fund for the Improvement of Postsecondary Education, Department of Education, is engaged in an educational project to improve the functioning of hospital ethics committees throughout the United States, states that from his experience, "there is no indication from numerous cases discussed in the project by members of U.S. hospital ethics committees that there is any significant abuse of the rights of children as alleged by statements recorded in the U.S. Civil Rights Commission Report. There is no substantive abuse or endangerment of children that would justify the proposed additional interventions in established medical practice."⁸

Handicapped Neonates Should Not Be Obligatory Subjects of Medical Experimentation

If the therapeutic and technological imperatives are not contained, it will appear to be obligatory for physicians to apply experimental treatment to children, even if the treatment is considered inhumane, unless the results of that treatment are known to be virtually futile. The result is that at the edge of developing new medical technologies, physicians will find themselves obliged to subject handicapped newborns to treatment which would ordinarily not be permitted because of its adverse harm-benefit ratio, but which an overly zealous interpretation of the Child Abuse Amendments of 1984 would require. That is, the rapidly developing frontiers of medical technology will continually create opportunities to subject handicapped newborns to heroic medical and surgical interventions, where it will not be able to be shown that those interventions are virtually futile, but where a reasonable medical judgment will be that harms will outweigh benefits.

The Family as the Key to the Decentralization of the Authority of Experts in a Technological Society

Unquestionably, parents are highly influenced by the physicians they consult about treatment of their children. Nor will there ever be perfect physicians or perfect transfer of information to parents in circumstances where life and death decisions must be made. On the other hand, bureaucratically enshrined regulations and guidelines are unlikely to fare as well. Indeed, they are much less able to provide the nuanced, situation-dependent guidance necessary in areas of rapid technological advance. There is, as

a result, a strong argument in favor of relying on the good will of families and physicians to make reasonable judgments, especially given the substantive societal restraints already in place.

One might observe that one of the major lessons to learn from Nazi Germany is that the government should not be given primary authority regarding life-and-death choices. Hitler's Germany, it should be recalled, both forbade abortions and enjoined euthanasia. The lesson of history suggests that the costs in the long run from relying on families are much less than relying on governments. This may explain why in the Federal Republic of Germany, where the lessons from the history of Nazi atrocities consciously guide contemporary public policy in order to avoid a repetition of those atrocities, there has been explicit effort to avoid rules such as those incorporated in the Baby Doe regulations. At a conference held in Germany, June 27-29, 1986, the German Society for Medical Law recommended that the physician be excused from providing treatment for handicapped newborns whenever:

- (1) life cannot be maintained for any length of time, but instead one will only be postponing a certain death, e.g., in the case of severe dysrhabhia-syndrome or inoperable heart defects;
- (2) in spite of treatment it is determined that the newborn will never have the possibility of communicating with his environment, e.g., severe microcephaly, very severe brain damage;
- (3) the newborn's vital functions can be maintained for any length of time only by means of intensive medical intervention, e.g., breathing difficulties without possibility of restoring health, loss of kidney function without possibility of restoring health.⁹

These decisions should be made as far as possible with the family. The above recommendations were made not in order to avoid the continued life of handicapped infants, but rather to avoid therapeutic interventions that would cause more harm than benefit.

The decentralization of important decisions has been the genius of Anglo-American countries. One belittles the opinion of the plurality of the Supreme Court in *Bowen v. American Hospital Association* if one overlooks the implied criticism by the Court of government intrusions in family decisionmaking.

Recent Guidelines in the Federal Republic of Germany," *Journal of Medicine and Philosophy* 12 (1987), 287.

⁸ Personal communication, Jan. 8, 1989.

⁹ Hans-Martin Sass, "Moral Dilemmas in Perinatal Medicine and the Quest for Large Scale Embryo Research: A Discussion of

“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.”¹⁰ Here I think it is reasonable to see the Court in part reflecting the judgment that “The history and culture of Western civilization reflect a strong tradition of parental concern for the nurture and upbringing of their children. This primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition.”¹¹ To undermine this central role of parental choice is to depart substantially from the tradition of our law.

In this respect, the report seriously misstates the situation when it alleges in chapter 1 that only when children have severe disabilities is the claim of parental autonomy given serious consideration. In fact, parents are generally held to be free to choose any medical treatment endorsed by a recognized group of medical practitioners. This recognized right at law plays a substantial role when parents choose among different chemotherapeutic approaches for their children with cancer, often selecting a treatment that offers a reduced chance of survival, but involves less suffering and pain. Such choices are made regularly throughout health care and are considered proper, and are proper. Thus, one can see why the plurality in *Bowen v. American Hospital Association* emphasized that “it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent.”¹² The moral basis of this legal consideration would lead one to hope that, at the very least, the recommendation regarding section 504 of the Rehabilitation Act of 1973 would include a recommendation that no treatment be provided, other than on an emergency basis, over the protests of parents, without a court order.

Reliance as far as is feasible on parents choosing among acceptable medical options, which take into account the pain and suffering of severely ill neonates, will not in all cases provide protection to those neonates. But over the long run, such a policy will constitute a step away from a paternalistic elitist posture on the part of government and towards encouraging responsible choices by parents in consultation with their physicians and within the context of current legal protections. Still, one must

observe that one of the reasons it is safer to walk in East Berlin at night than in West Berlin is that the populace is more effectively monitored on the eastern side of the border. But that commitment to security has its own substantial societal costs.

The important point in all this is that, if we as a society are not to be enslaved to our medical technologies, we must help empower patients or their surrogates, not physicians or bureaucrats, with the authority to make the crucial decisions. We must as far as possible tolerate decisionmaking within the context of the family. Otherwise, democracies will be overwhelmed by the technological imperative. Democratic societies will succumb to the seduction of using all possible treatment, even when such treatment is inhumane or violates human dignity, that is, even when it is the source of more harm than benefit for those treated.

A State-by-State Approach to the Implementation of New High-Technology Medicine

A Federal system in which the States have different punishments for such serious crimes as murder and rape should easily tolerate a number of States exempting themselves from the Child Abuse Amendments of 1984. We as a society have only begun the serious task of developing policy for the application of high-technology, high-cost health care, which can often offer only limited promise of success but at the price of significant pain and suffering for the patients treated. There is unlikely to be one single morally appropriate way to make moral decisions regarding when such treatment should be applied. This is the case in medicine generally and with respect to the treatment of very low-weight neonates, as well as neonates who are born seriously ill with serious handicaps. Our Federal system can but benefit from the experience of those States that wish to forge their own approaches to responsible policymaking in these areas.

Quality of Life and Artificial Hydration and Nutrition

With regard to issues of quality of life, the report mixes apples and oranges. For example, in considering the role of quality-of-life assessments in chapter 3 of the December 2, 1988, draft, the report asks why so many support and practice the denial of life-saving medical food and treatment. To begin with,

¹⁰ At 647.

¹¹ *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1971).

¹² At 630.

reports such as Kopelman et al. demonstrate that the primary contemporary interest in restricting treatment involves cases of severely ill neonates where the course of treatment would be painful and inhumane to the child and the chance of success minimal, but not necessarily clearly "virtually futile." Moreover, the current interest in restricting hydration and nutrition primarily concerns neonates who have permanently lost consciousness. In this regard, it should be noted that the last Federal substantive examination of this issue led to the conclusion that "The decisions of patients' families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the exception of basic nursing care that is needed to ensure dignified and respectful treatment of the patient."¹³ It should also be noted that medical care, at least in the case of adults, has been interpreted to include artificial hydration and nutrition. This considered recommendation conflicts with the holding of the Redwood County Court, Family Division, in "The Matter of the Welfare of Lance Tyler Steinhaus," which was substantively guided by the Child Abuse Amendments of 1984. There the county court required the provision of nutrition and hydration, although the child was permanently and irreversibly vegetative. However, an infant, or for that matter an adult, in a permanently vegetative state has no capacity to experience anything. Again, these cases are radically different from those that involve comparing different levels of the quality of life of individuals who have not permanently lost consciousness. The members of the Commission might consider what moral interests they would have in having their bodies maintained with artificial hydration and nutrition, were they permanently and irreversibly to lose all consciousness, and their next of kin approved the cessation of all treatment, including artificial hydration and nutrition. Whatever the Commissioners might consider, it should be clear that quality-of-life judgments in such cases are radically different from

those that concern the "quality of life" of a perceiving, profoundly retarded child. In the case of a permanently and irreversibly vegetative individual, there is simply no quality of life whatsoever, so that the next of kin might very well properly judge that the provision of artificial hydration and nutrition would be an indignity that violates the moral and constitutional rights of the afflicted, which may then be protected through the choices of the next of kin. This view has increasingly been sustained by recent court cases, which have recognized a constitutional right to have such treatment refused. In this respect the report's consideration of constitutional issues is onesided at best.

Fixing What Isn't Broken Can Harm Rather than Help

The proposed recommendations appear directed to a problem that does not exist; they are very likely to do much more harm than benefit to severely ill neonates. Moreover, they do not propose a realistic solution to the challenge of the continuing education of medical specialists, whose lack of current information would be the basis of a problem, were it to exist. Furthermore, there is a failure to take adequate account of the actual overtreatment of extremely ill neonates with poor prognosis for survival. To put the matter in perspective, one would need to talk to the numerous parents who have been forced to overtreat a severely ill neonate who dies despite a long, painful, and protracted therapeutic intervention.¹⁴ In addition, one would need more sympathetically to review information such as that produced by Kopelman and others regarding the overtreatment of severely ill neonates. If one does not do this, one will run the risk of again forcing the critical judgment of the courts, as from Justice Leonard D. Wexler, who held that "the government has taken an oversimplified view of medical decision-making."¹⁵ By proceeding as if massive abuse were occurring, one is likely further to encourage physicians to overtreat severely ill neonates who also have significant physical and other disabilities. Moreover, the acquisition of data and the review of medical records are not harmless endeavors. They not only are costly in terms of health-provider time and

¹³ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: U.S. Government Printing Office, 1983).

¹⁴ For a popular presentation of the plight of such parents, see Robert Stinson and Peggy Stinson, "On the Death of a Baby,"

Atlantic Monthly (July 1979), 64-65. Numerous discussions with parents have confirmed to me that their experience is far from unique.

¹⁵ University Hospital, State of New York at Stony Brook, U.S. Court of Appeals of the Second Circuit, No. 6779, Docket 83-6343, Feb. 23, 1984.

trouble, but can distract from the effective treatment of patients needing care. On this point, one should note that the original Baby Doe regulations spawned reviews of patient records that impeded the care of ill patients.

In concluding, I encapsulate the foregoing reflections in terms of three general maxims:

1. Avoid seduction by the therapeutic and technological imperatives.

Just because a treatment offers some benefit of preserving life, it does not follow that it is a humane treatment. 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.

2. Encourage responsible choices on the part of individuals and avoid the intervention of government bureaucracies, wherever possible, in individual life-and-death choices.

Given the complexity of modern medical technology, there is the temptation to generate new regulations rather than to rely on existing civil and criminal remedies. If our society gives in to this temptation, this will lead to a bureaucratization of medical technology, not to a responsible and informed citizenry who can use technology responsibly. This will make responsible choices more difficult and harm patients, not help them. Democratic

societies should depart from already well-tested criminal and civil remedies only when there is clear and convincing evidence that current approaches are substantively ineffectual. One must find ways to encourage responsible choices by individual parents with their physicians regarding the treatment of severely ill neonates that minimize the intrusions of third parties.

3. Recognize that a treatment that has a chance of saving life may be appropriately declined, if the harms are likely to outweigh the benefits.

A good example is provided in adult health care by cancer of the pancreas, which has at best a 3 percent survival rate, subsequent to very aggressive surgical resection. However, the morbidity associated with the surgical attempt to cure is so great that many well-informed individuals, including physicians deciding for themselves, will reject the small chance of cure in order not to be subjected to very significant suffering in the remaining months of life. There is no reason to believe that courts would not allow parents to make analogous choices with regard to their children. There should be no restriction in the ability of parents to make such choices with regard to their newborn children, even if those children are born with serious physical and mental handicaps. There should be no obligation to provide inhumane treatment.

Appendix 1

EXPOSING OUR CHILDREN, EXPOSING OURSELVES

Comments on the Report
"Medical Discrimination Against Children with Disabilities"
of the U. S. Commission on Civil Rights

by

William B. Allen
Chairman

TWO PHYSICIANS

Doctor That's-Too-Bad, along with his colleague, Doctor So-Much-The-Better, went to see a sick man.

The latter expressed hope while his comrade maintained that the bed-ridden patient was headed to his forebearers.

The two being divided in mind for a cure, the sick man paid Nature's price, After which Doctor That's-Too-Bad seemed a prophet.

Their profit rose further from the malady. The one boasted, "He's dead, as I well foresaw." -- "Had he believed me," said the other, "He would live well still."

Fontaine

My colleagues hate it when I introduce literary, historical, or philosophical allusions. But Fontaine's little fable captures so evocatively the plight of the handicapped newborn, I cannot avoid opening with it. Perhaps seeing it written out will make it more bearable than merely hearing it read.

I comment on the disinclination to indulge my academic penchants because this is one case in which it makes a substantive difference in the report we are about to approve (and there is a majority of this body that has already indicated a resolve to approve it no matter what). Such a substantive effect emerged in our preliminary discussion last November. At that time I opened my remarks with the reflection that my reading of Hippocrates suggested a possible explanation of the difficulties. As the name Hippocrates fell from my lips, and just as swiftly, I discerned in the body language of my colleagues a considerable degree of frustration and bemusement -- so much so, in fact, that I detoured the comment I intended to make into innocuous channels and let the matter drop.

I now apologize for my faint-heartedness. While I expect the sympathy of everyone who knows how difficult it is to speak what no one wishes to hear, I recognize nonetheless that I had then an obligation to persevere. The fact that the question I wished to broach at that time looms still more ominously now reproaches

my timidity. Accordingly, I will set forth succinctly the concerns that emerge from Hippocrates, before continuing with my appraisal of this report.

LIFE AND HEALTH THE ENDS OF MEDICINE:

. . . .

RIGHTS NEITHER DEFINED NOR ILLUSTRATED BY NEEDS:

Rights are neither defined nor illustrated by needs, not for handicapped nor any other category of Americans. The reason black people ought to enjoy equal rights of citizenship is not that most of them are poor. It is rather that they are human beings to whom the rights and arts of self-government pertain no less than to any other humans. 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 opposition position on this crucial question, we cannot approve it. The correct application of this principle to the handicapped is to insist that they suffer no further burdens (above all civil burdens) than are already intrinsic to their circumstances. [I might point out that there is also a moral corollary, namely that room be left for considerateness by others.]

HANDICAPPED OR DISABLED:

Consider this more closely. Even the language we use is revealing. We must choose between the words "handicapped" and "disabled." There is an orthodoxy, to be sure. Nevertheless, where meanings count we remain free to question even orthodoxies. There is a difference between "handicapped" and "disabled" which is obvious -- namely, the one term is relative, the other absolute. A handicapped golfer is one who golfs, though never so well as another. To consult the terms alone, a disabled golfer is one who can not, or can no longer, golf. Disabled means to lack an ability, while handicapped means to possess an ability in qualified form. I have preferred handicapped in this general discussion because, in the matters that count (above all rights of citizenship), I am persuaded that the handicapped rather are abled than disabled, even if sometimes in qualified form.

If this reasoning be correct, then we can see the relevance of maintaining that rights are neither defined nor illustrated by needs. Insofar as rights relate to

abilities or functions, they are defined rather by that to which the ability points than by the ability itself. But the ability is nothing other than the need, either actualized or in some state of development. The ability to take nutrition points to the right to life; the need for nutriment is the ability to take nutrition either functioning or impeded in its functioning. Only what needs nutriment can have the ability to derive nutrition from sources of nutriment or to be impeded in that regard. Thus, only a being endowed with the right to life can have the ability to take nutrition and therefore needs sources of nutriment. We do not say, because a being needs nutrition, it has the right to life, except inductively. Nor, then, can we say, because a being needs nutrition, it has a right to sources of nutriment.

I will be prosaic: if doorways in buildings were characteristically just six feet high in our society, such that I would have to stoop to enter, it would not constitute the violation of any right I have, even though it were more commodious if I did not have to stoop. It would represent a need but not a right for me to have doorways tailored to my height, any more than it did, from the middle to the end of the 18th century, for George Washington, who stooped to pass through most doorways.

Architects and carpenters cut doors, when constructing buildings, to the general dimensions of the people who order them. Therefore, over time and in the aggregate, architecture and carpentry constructs buildings to what we might call an average of humanity. That average is not arrived at by looking at humankind altogether; it is arrived at by fitting the peculiar needs of the individuals who execute the orders. Over time through that process one will arrive at an average for all individuals, since most will fall within certain ranges.

This notion of the average of humanity, which the architect ends up approaching indirectly by serving the needs of the individual human, can be distinguished from the objective of health, that the physician consults. The notion of health is an absolute. It is certainly the case that in any given individual the physician has to inquire what condition of body and mind will be healthful. That inquiry, moreover, is carried out on the basis of a standard of health which is not in fact arbitrary or derived from the individual. The ultimate goal of health serves as a guide for the physician in elaborating such functioning of body and mind as makes it possible for the individual human being to attain the end of health. That human end has been described or defined for us in the Declaration of Independence and the American tradition largely as the "pursuit of happiness." What we may take that to mean is that the peculiar function of a human being is the pursuit of happiness, and that healthful functioning for a human being is to be able to carry on that pursuit with all of the abilities at the particular human being's disposal. We say, then, that for the human being health is not any given physical or bodily and mental or spiritual functioning. It is rather the harmonizing of physical and mental functions or abilities in the pursuit of happiness. Such abilities as any human being has, and insofar as those abilities can be properly harmonized in the pursuit of happiness, would denominate that human being a healthy human. Such a one would function in the ultimate way that humans function -- namely, in the pursuit of happiness.

On that kind of measure one can see that handicapped or nonhandicapped alike may all enjoy health. They do not require the identical capabilities physically or mentally in order that their capabilities may be harmonized in the pursuit of happiness. Insofar as this report denies that there is such a standard as health for human beings, it does not advance the cause of the handicapped. It

rather undermines standards moral and physical for all human beings in general. It places the handicapped at a greater disadvantage by treating the standard of health as if it were arbitrary and merely subjective rather than fixed and absolute. Such a position would surely scandalize Aristotle and Aquinas, were they to see it set forth by students of theirs. And I must confess that it does no honor to this Commissioner to see it come from the staff of this Commission.

THE REPORT:

Our report, in its own words, "focusses solely on questions of discrimination." [p. 3] This is the correct posture for the Commission on Civil Rights, seeking to carry out its mandate under laws enacted by Congress. But that noble profession is belied by the note [#4] which addresses "the legal right of children with disabilities to receive equal treatment." This might represent only an infelicity of language. It concurs, however, with the language at page 17, which maintains

Treatment decisions resulting in the denial of lifesaving medical treatment to children with disabilities cannot be viewed in isolation. Together with discrimination in employment, barriers to access to transportation and physical facilities, and a tradition of institutionalization, these decisions can only be understood in the context of longstanding attitudes and practices toward people with disabilities.

I believe that this is false; while it is true that discrimination against handicapped persons has been pervasive, it is not true that it has been systematic. Further, there is present here the common fallacy of subjecting ancient reforms to the modern standard of criticism, finding them wanting, and then concluding that they must have proceeded from ill motives.

This is the very argument -- the right to equal treatment, based on historical deprivations -- which I said above creates problems in our understanding of civil rights. In this case, it obscures the responsibility of physicians and hospitals. In the Carlton Johnson case, for example, we focus on procedures, when erroneous judgment was at fault. These kinds of decisions are not medical decisions -- they do not take life and health as their end. And just as the one most skilled at concocting an antidote is also the most successful poisoner, here we see the technology and judgment of medical practitioners warped out of its natural order. I believe our report needs to tell us how this came to be, but it does not.

To undertake that mission, however, would have meant forswearing the attack on ideas of "normality." We cite testimony attacking that standard at page 18 (ch. 1), and in note 34 our own language, indicating that "society" structures its tasks and activities unfairly, shows the extent of our agreement with it. But society does not structure its tasks and activities. Men and women structure their tasks and activities, as architects and carpenters build for particular individuals. Society is nothing other than the resulting aggregate. There is of course a spectrum of abilities, and such a spectrum by definition must express a statistical norm. When folk say there is no normal they might just as well insist that "reality is whatever we say it is." Those two statements have the same truth value. That kind of radical subjectivity is fundamentally nihilistic and ultimately incompatible with a stable moral order.

My principal reason for objecting to the attack on the idea of normality is that we know that the ab-normal contains genius as well as deficiency, and we normals are unable to distinguish them. The purpose for attacking the distinction seems to have been the just desire to remove arguments from those who would support "elimination of people with some disabilities" [p. 58, ch. 3]. The handicapped would derive greater protection, however, from being integrated with normal people on the score of humanity than from attempts to deny the obvious. Consider: All newborns are thrown on the resources and care of their parent(s). Thus, in the absence of medical/community care, most would survive on the combination of parental love and their own eventual natural abilities. On those grounds, many of the handicapped also would survive. Some, however, would not (just as many of the normal children would not). Then arises the question, what affects the prospects of those who would not survive, whether handicapped or normal? To answer that question, we introduce medical science and community care. It turns out that art -- medical science -- can supply much of what is needed to fight off pneumonias and other life-threatening menaces. Thus, the parent once informed, the initial love is bolstered by access to arts otherwise not imagined. This process should differ not at all for the handicapped child and the normal child -- it is the normal process!

HOW TO AVOID INVIDIOUS DISCRIMINATION:

If the goal of protection for handicapped newborns is to assure them access to the normal process of nurture and care, and to avoid subjecting them to unfair civil burdens on the basis on their handicaps, then we have a strong basis for issuing a report that calls for changes in the way we do things. This report has done an excellent job of case-building. It is a work of advocacy rather more than a dispassionate analysis. As a work of advocacy, it is not a sufficient basis for every judgment and recommendation we might care to make. Nevertheless, enough evidence is apparent here that we are enabled to tackle certain egregious oversights in the legal framework through which we seek to protect the rights of handicapped newborns.

The report lists fourteen recommendations for action. Among those fourteen one does not find the one which I regard as most urgent and, likely, most efficacious. Since the Hippocratic Oath no longer exists for us apart from the organic law of this republic, it is extremely important that we subject medical practitioners to the judgment of American law in light of the promises of those organic principles. Congress possesses and has before exercised every power required to make good the pledge of the Fourteenth Amendment. The Section 5 powers of Congress inform the Child Abuse Amendments.

FIRST RECOMMENDATION:

Those powers were not exercised in such a way as to guarantee that we could assure ourselves that the rights of handicapped newborns were being protected. Yet, nothing is more common in our society than the meticulous reporting of births and deaths! It would require little in the way of additional expense, and still less in labor, to require that the births and deaths of handicapped newborns, with notation as to course of treatment, be systematically reported to the Department of Health and Human Services. We have opted instead

for a cumbersome, jerry-rigged structure of monitoring that consumes resources and delivers next to nothing by way of service. To my mind, this would be the most valuable recommendation we could make, *a universal reporting requirement*. This requirement, I must add, is nothing unusual, paralleling what many firms are subject to in other respects with EEOC or OFCCP or other agencies.

RECOMMENDATIONS IN THE REPORT:

I concur with recommendations 1 and 2 and 4 through 7, though not always for the reasons set forth.* I dissent from recommendations 3 and 8, as expressive of the author's intention to reinterpret the language of "equal protection" into a language of "equal or better treatment." I agree with the thrust of recommendation 4, but doubt the Commission's jurisdictional basis for making it.

Concerning recommendations 9 through twelve, I regard the entire P & A structure which they seek to strengthen to be misconceived in the important respect that, as the record here shows, they elaborate a system whereby the rights of handicapped newborns are made tenuous and imperilled by the apparent substitution of procedural for substantive fairness. The P&A responsibilities under the Child Abuse Amendments would make greater sense if, independently, someone were maintaining the applicability of substantive standards. That would be the case under a universal reporting requirement which facilitated routine monitoring. A system of intervention (the P&A system is relevant only where guarantees to govern intervention are evident) must be understood as a system to protect life, not to judge it. The current system operates primarily to provide a framework for making life-death judgments, and our procedural recommendations do not change that. The problem becomes apparent when one notes that the P&As are hip deep in medical judgments (and criticized for not making them well), although this report maintains that we aim to isolate problems of discrimination from medical judgments.

CONCLUSION:

I said above that it causes me distress to receive from the staff of this Commission a report which treats health as an arbitrary and subjective standard. But I do not entirely blame the staff; I have to assume that what they have done is to react to what they have thought others desired, rather than to think originally about how it is the handicapped may come to enjoy the rights of persons guaranteed in the Constitution and the Declaration -- the rights persons have to be treated individually in terms of the firm objective of the pursuit of happiness and therefore of health.** Others not understanding that could perhaps be led to make demands ostensibly in the interests of the handicapped, though in fact harmful to them.

* These are the recommendations as set forth in the "Introduction." The recommendations are numbered differently in the concluding chapter, and there are two more besides!

** This is certainly to be expected when the work of an independent commission such as ours comes to be captured by advocacy groups, as this has been. The very process which, last September, I described as harmful in the extreme to this agency's prospects for making a meaningful contribution to our nation's future, seems to have been the process by which this report was produced. Some say what's good for the goose is sauce for the gander. I think it the very poison. If we have any saving grace in this hour, it is that some of us remain sufficiently alert to sound the alarm. It will not happen again!

I derive this hint from the many communications I have received in recent days from organizations urging me to approve this report without having read it and indicating thereby that for them the ideas are not what count. They seem under the spell of the view that there is a kind of politics, a kind of lobbying that is essential to defend fundamental rights and which transcend the actual content of those rights. Whether they accept the view of our staff that rights are positive and developmental (historically developmental, that is) as opposed to being inalienable and fundamental, I cannot say. They certainly accept the view that we do not require to think much about them in order to defend them.

This Commissioner cannot accept that view. I telephoned the author of the first of these letters and inquired whether he had read the report; he responded that he had not, but that he was taking the work of someone who has read it, someone here at the Commission, and whom he trusts. Now we all know that it is important to be able to trust people when we make certain kinds of practical and moral judgments. For no human being is capable of reviewing all the facts and circumstances that come to our attention and demand a moral judgment. But, having said that, one must add that it is therefore essential that the persons whom we trust indeed deserve our trust, that they possess such capacities mentally and morally as to make us confident that we are not likely to be led astray. Whoever it be my correspondent trusts here at the Commission clearly does not rise to such a standard of ability -- and perhaps not of honesty -- as to have merited that trust.

I assume that my correspondents do not trust me. After all, they do not know me, and what they have heard of me concerning this report is a lie. But what I have to say, I say not to gain their trust but to serve the cause of truth. I can think of no better way to emphasize to you how that operates than by returning to a frequent source of ore for my reflections -- Abraham Lincoln.

As I said at the outset, this report is going to be approved today. It's going to be approved without my having had serious opportunity to contribute to its shape or structure. I am just proud enough to be reluctant to add my name to anything that I have been denied occasion to shape -- not that I lack time, not that we lack the opportunity at this Commission, which is here today, will be back next month, and, as everybody knows, will be here through this year, but -- because others have willfully structured the process with the purpose in mind to deny me such an opportunity. Having been denied that opportunity, then, I will attach this statement to the report -- and I will do it in the spirit of Abraham Lincoln, in that spirit he expressed in the "Subtreasury Speech of 1839" and with which I now close:

It may be true; if it must, let it. Many free countries have lost their liberty; and ours may lose hers; but if she shall, be it my proudest plume, not that I was the last to desert, but that I never deserted her. . . I cannot deny that all may be swept away. Broken by it, I, too, may be; bow to it I never will. The probability that we may fall in the struggle ought not to deter us from the support of a cause we believe to be just; it shall not deter me. If ever I feel the soul within me elevate and expand to those dimensions not wholly unworthy of its Almighty Architect, it is which I contemplate the cause of my country, deserted by all the world beside, and I standing up boldly and alone and hurling defiance at her victorious oppressors. Here, without contemplating consequences, before High Heaven, and in the face of the world, I swear eternal fidelity to the just cause, as I deem it, of the land of my life, my liberty and my love. . . Let none falter, who thinks he

is right, and we may succeed. But, if after all, we shall fail, be it so. We still have the proud consolation of saying to our consciences, and to the departed shade of our country's freedom, that the cause approved of our judgment, and adored of our hearts, in disaster, in chains, in torture, in death, we NEVER faltered in defending.

APPENDIX

AN EDIPUS COMPLEX TOWARD LIFE (An Essay, as it appeared in THE CRA NEWS, fall 1986)

Abortion deprives us of the deepest instincts of humanity. This is the conclusion which lies at the bottom of the heated debate which still rages within the United States and ought to stir the world itself. From the racist, eugenics-oriented movements which introduced the idea of systematic abortion early in this century, to the current righteous defense of indifferent abortion, the results are the same: they rest on the premise that we can become dull, insensitive to the claim of humanity which is at stake.

The preferred philosophical base of pro-abortionists resembles the Oedipus prophecy -- there are exceptional cases in which humanity itself recoils from demanding that a pregnancy be carried full term. Rape, incest, and deformity usually head the list. This kind of reasoning has a glaring default. It will be understood best if one rehearses the college philosophy example of the life-raft scenario. Two persons adrift at sea on a life-raft are starving. Their chances are minimal at best and absolutely nil if nourishment is not found. In that situation, is it just that one of the two might resort to cannibalism (eating the other) in order to have any chance at all of surviving? Generally, everyone answers yes, just as most people are inclined to say, "yes, in the case of incest I can conceive of abortion as at least a justifiable homicide." Ought we to conclude from this exception, however, that the general moral rule must therefore admit the propriety of cannibalism or abortion in any case? Clearly that is not so, and we require above all today to make clear why it is not so.

When a decade ago I asked the "right to life" movement to speak of the "unborn child" instead of the "foetus", the motivating idea was that language plays an important role in focussing our moral antennae and such a tactic was needed to fend off the insensitivity with which we were surrounded. I continue to believe that this is necessary, but we now require more than words, we need to resurrect an entire humanitarian tradition in order to prevail in this struggle.

moral distinction. A girl is a human being! No one who has ordered the death of his unborn girl can claim to have any doubts about her humanity. What he is saying to us is that he prefers boy humans to girl humans. As occurs so often in human affairs, we discover in the practical arts of human beings a much surer guide to answering difficult moral questions than in mountains of abstruse scientific disputation. While the scientists continue to debate about just when the onset of humanity occurs, the people of South Korea demonstrate that they know full well: namely, from the moment one can determine the unborn child's gender!

One would imagine that this discovery merited headlines and huzzahs: The long sought answer found! Unborn child determined to be human boy or girl! Supreme Court now has guide to follow! But no. The news is rather different. "S. Korean Parents Tip Birth Ratio." "In the first ten months of the year, there were 117 male births for every 100 females." Normally, male births outnumber female births only slightly, and the numbers are evened up later by a higher mortality rate among males. One of the Korean doctors who sounded the alarm, Dr. Roh Gyung Byung, declared it "a terrible situation," and rightly so.

Nothing demonstrates the necessity of this conclusion so strongly as the recent report from South Korea, that selective abortion is there being practiced to indulge social prejudice about the preferred gender of offspring. Unborn girls are being aborted to make room for boys in South Korea. One needs to pause and think over the implications of this. The progress of modern science has made possible a pre-term identification of gender in the unborn child. What has followed is this systematic abortion -- a eugenics. But don't stop there. Note that the very idea of identifying a child's gender entails a necessary

Do we understand, however, just how terrible it is? This story is in fact confirmation of just how low we have descended in the scale of humanity. Abortions are not new to mankind. Mankind, however, have not always been so insensitive to them. The classic story of abortion -- exposure of the unwanted infant -- was written by Sophocles and inspired Sigmund Freud with the lynchpin of his psychological theories, the Edipus complex. Sophocles' Oedipus was to be exposed just after his birth, but the nurse entrusted with the chore could not look upon the "bundle of joy" with the required callousness. Rather than leave the child to the tender mercies of wild beasts, she left it in the care of a peasant who raised him to a mature humanity. The tragedy which resulted for Oedipus' family has often been misinterpreted as resulting from the nurses'

tenderness. A more understanding reading would show that it derived rather from the decision to abort -- an attempt to avoid a prophecy of tragedy, which misread the prophecy as referring to events yet to come and not to the character of the very persons who attempted the abortion.

The children who are exposed today are less fortunate. They never meet with such nurses as Oedipus' even when they might have a chance of being raised to mature humanity by strangers. Despite the feeble efforts of government to mandate care for aborted children who, with the assistance of science, might yet survive, the prevailing moral climate produces virtually no examples of such heroics. Is it not clear that the child who is exposed by being ripped from the womb is at a great disadvantage compared to Oedipus? Those whose souls would have to resonate with the instincts of humanity are already dulled into insensitivity by the very operation through which they eliminate the child.

The modern world cannot depend on second thoughts to preserve the instincts of humanity. Modern science leaves no room for second thoughts. Lest we are to part forever from the tradition of humane caring, we have no alternative but to place abortion itself under a severe proscription. The Edipus Complex -- a son's rivalry with his father and love for his mother and its converse, the Electra Complex -- acquires a perverse meaning in a world in which fathers and mothers make the choices which South Korean parents are now making. The new Oedipus must die, unless we collectively, as a generation, make a commitment to him before he is exposed to the danger. This is the possibility we now await, assuming that he is not already among the lost.

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Appendix 2

**SURVEY OF
STATE BABY DOE PROGRAMS**

**RICHARD P. KUSSEROW
INSPECTOR GENERAL**

SEPTEMBER 1987

OAI-03-87-00018

[Executive Summary and Appendices omitted.]

INTRODUCTION

The term baby doe refers to a severely disabled infant with a life-threatening condition who is denied appropriate medical treatment. Two highly publicized court cases called national attention to baby doe in the early 1980s, and led to Federal legislation to protect the rights of such infants.

In the first case, an infant known as Baby Doe was born with Down's syndrome and a surgically correctable blockage of the esophagus. The baby's parents and doctor agreed that surgery should not be performed and that food and water should be withheld from him. The hospital sought a court order to permit surgery, but the court upheld the parents' decision, and the State supreme court refused to disturb the lower court's ruling. Baby Doe died before the case could be filed in the U.S. Supreme Court.

The second case involved an infant known as Baby Jane Doe, who was born with multiple neural tube defects, including spina bifida (an open lesion on the spine), microcephaly (an abnormally small head), and hydrocephaly (an accumulation of fluid on the brain). The parents approved medical treatment to reduce the chance of infection, but refused surgery to close the spinal lesion and drain excess fluid from the baby's brain. The parents' decision was later upheld by the State courts. It is not known what became of Baby Jane Doe.

In March 1983, the Department of Health and Human Services (HHS) published an interim final rule stating that section 504 of the Rehabilitation Act of 1973 applied to handicapped infants and establishing a Federal hotline for reports of failure to feed and care for such infants. One month later, the interim final rule was struck down in U.S. District Court. The Department published revised proposed regulations in July 1983 and final regulations in January 1984. These final regulations were struck down in U.S. District Court in June 1984.

The two baby doe cases and the subsequent debate among medical, professional, pro-life and disabilities groups regarding the ethics of treatment/nontreatment decisions affecting disabled newborns, including the role and responsibilities of States and the Federal Government, culminated in passage of the 1984 amendments to the Child Abuse Prevention and Treatment Act.

The amendments required State CPS units receiving formula grant funds under the Act to define baby doe situations as medical neglect, to establish procedures for responding to reports involving such infants, and to have liaisons designated in hospitals where babies are born or treated to

insure the immediate referral of potential baby doe cases to CPS. Final implementing regulations were published in April 1985.

The amendments also required HHS to publish model guidelines encouraging hospitals to establish Infant Care Review Committees (ICRCs). Model guidelines were published in April 1985. The ICRCs are intended to educate hospital personnel and families of severely disabled infants, recommend policies and guidelines concerning the withholding of treatment, and review cases involving such infants.

This inspection was initiated at the request of the Surgeon General and the Administration for Children, Youth and Families, which administers the Act within HHS. The purpose of the inspection was to determine (1) how States are carrying out their baby doe responsibilities, and (2) how a group of hospitals with responsibility for acute infant care are structured and functioning to address potential baby doe situations.

The inspection was carried out in two phases. One phase consisted of a telephone survey of CPS units in all 50 States and the District of Columbia. A second phase involved visits to 10 large hospitals in 8 major cities around the country. Seven were children's hospitals identified with assistance from the Surgeon General.

This report, entitled "Survey of State Baby Doe Programs," describes the results of our survey of State CPS agencies. A companion report, entitled "Infant Care Review Committees under the Baby Doe Program," presents the findings of our hospital visits.

FINDINGS

STATE BABY DOE PROCEDURES ESTABLISHED

The Child Abuse Amendments of 1984 (P.L. 98-457) require that in order to qualify for formula grant funds under the Act, States must define baby doe situations as medical neglect, and establish procedures within the State Child Protective Services (CPS) system for responding to baby doe reports. State procedures were required to be in place by October 1985, and to include provisions for:

- o designating individuals in hospitals to serve as the official liaison with CPS for all baby doe matters,
- o prompt notification of CPS by these individuals of suspected baby doe cases, and
- o authority for CPS to pursue legal remedies to prevent the inappropriate withholding of treatment from these infants.

Under the Act, States may apply for two types of grants: Basic Grants and Disabled Infant (Baby Doe) Grants. In Fiscal Year 1986, Basic Grants to States totalled \$9 million, and \$2.4 million was distributed nationwide in Baby Doe Grants. In order to qualify for a Baby Doe Grant, a State must first qualify for and receive a Basic Grant.

We surveyed CPS agencies in all 50 States and the District of Columbia. Forty-one jurisdictions received both Basic and Baby Doe Grants for Fiscal Year 1986. Seven other States applied for and received only Basic Grants, and three States (California, Indiana and Pennsylvania) did not apply for either Basic or Baby Doe Grants. Appendix A summarizes the types of activities undertaken by States with their Fiscal Year 1986 Baby Doe Grants.

Ten States reported they have passed special State laws or amended existing legislation to address baby doe situations. An eleventh State has developed a baby doe regulation which is expected to become law during 1987. The remaining States indicated that new legislation has not been necessary because their existing child abuse and neglect legislation covers baby doe situations.

Forty-eight States, including the seven which did not apply for Fiscal Year 1986 Baby Doe Grants, reported that state baby doe procedures have been established. Our survey found that all State procedures include provisions for prompt notification and CPS legal intervention, and nearly all have met the hospital liaison designation requirement in the Act.

Hospital Liaisons Designated in Most Hospitals

The following table depicts States' progress in designating hospital liaisons for prompt reporting of potential baby doe cases to CPS.

HOSPITAL LIAISONS DESIGNATED (as of March 1987)

<u>RESPONSE</u>	<u>STATES</u>	
	<u>NUMBER</u>	<u>PERCENT</u>
All hospitals with NICUs or OBs	27*	53 †
More than two-thirds of hospitals with NICUs or OBs	13**	25
Less than two-thirds of hospitals with NICUs or OBs	6**	12
Don't Know	3	6
Liaisons not required (Nonparticipating States)	2	4
TOTAL	51	100 †

* Includes 6 States not receiving Federal baby doe funds.

** Includes 1 State not receiving Federal baby doe funds.

According to CPS respondents in 40 States, hospital liaisons have been designated in at least two-thirds of all hospitals where babies are born or treated. In six States, fewer than two-thirds of such hospitals have designated liaisons, while three States do not know the percentage of hospitals which have designated liaisons. Eight States not currently receiving baby doe funds are nevertheless following the Act's requirement to designate hospital liaisons.

Of those States providing information on frequency of updating their lists of hospital liaisons, 28 indicated their lists are updated annually, and 5 others update periodically or as needed.

Prompt Notification Systems Established

Our survey found that all States have systems in place to insure that CPS agencies can be notified immediately of any suspected instances of child abuse or neglect, including potential baby doe cases. These systems have been in operation for many years. Major features of prompt notification systems include:

- o legal requirement for all professionals to report any suspected instance of child abuse or neglect to CPS;
- o procedures for hospital liaisons to follow in reporting potential baby doe cases; and
- o toll-free phone numbers.

About 80 percent of the States indicated that they have either statewide or local 24-hour toll-free phone numbers for receiving reports. While the remainder do not have toll-free numbers, they receive and respond to reports through local CPS offices during normal working hours, and have provisions for 24-hour phone coverage using a variety of arrangements. These include keeping local CPS switchboards open 24 hours and using the 911 emergency number or local police department as the first point of access.

Legal Intervention Authority Already Available

All States reported that CPS agencies have historically had legal authority, under State laws, to intervene when necessary to protect the well-being of abused or neglected children. Potential baby doe situations are covered under this authority. The CPS respondents indicated that if their investigation of a potential baby doe case determined that medically indicated treatment was being withheld, they would seek temporary custody of the infant and a court order to allow the needed treatment to be provided.

BABY DOE COMPARED WITH REGULAR CPS INVESTIGATIONS

We asked CPS respondents how their baby doe procedures differ from those used when investigating other reports of child abuse or neglect. Three major differences were cited consistently: immediate response, use of medical consultants and State level involvement.

1. Immediate Response

States report that due to the urgency and potentially life-threatening nature of baby doe situations, these reports are considered emergencies and are investigated immediately. In general, States require that the investigation begin with an immediate call to the hospital liaison where the infant is located to ascertain the basic facts in the case. In some States, a preliminary report is required within as little as 2 hours.

2. Use of Medical Consultants

All States report they have access to medical consultants to make medical determinations in baby doe cases. States use a variety of arrangements to insure immediate access to and availability of qualified medical consultants. Those mentioned most frequently were State level contracts with medical schools, children's hospitals or private pediatricians; and agreements with medical professionals employed by the State (frequently in State health or social services departments).

In a few States, local CPS offices are responsible for obtaining medical consultants. Several States have established multidisciplinary teams to investigate baby doe reports. These teams typically consist of a pediatrician or neonatologist, a social worker and a CPS worker, and could also include other medical specialists and legal expertise.

3. State Level Involvement

Abuse or neglect reports are routinely investigated at the local level. State CPS offices set policies, provide guidance and monitor the performance of local offices, but rarely conduct investigations. Because of the sensitivity of potential baby doe situations, many States have elevated the level at which these cases are handled. Nine States reported that the initial baby doe investigation would actually be conducted by State CPS staff. Several others require that the State office be notified immediately when a baby doe report is received; while the initial investigation would be handled locally, the State office would be kept informed and could step in to lead or participate in the case if needed.

ESTABLISHMENT OF HOSPITAL INFANT CARE REVIEW COMMITTEES

As required by the baby doe amendments, HHS published model guidelines to encourage hospitals with acute infant care responsibilities to establish infant care review committees (ICRCs). ICRCs are intended to educate hospital staff and families about baby doe situations, develop hospital policies and review potential baby doe cases.

We asked CPS units how many hospitals in their States have established ethics committees or ICRCs. State responses are shown below.

HOSPITALS WITH INFANT CARE REVIEW COMMITTEES

<u>RESPONSE</u>	<u>STATES</u>	
	<u>NUMBER</u>	<u>PERCENT</u>
All hospitals with OBs/NICUs	13	25%
More than half of hospitals with OBs/NICUs	2	4
Half or fewer hospitals with OBs/NICUs	22	43
All large hospitals with OBs/NICUs	4	8
Unknown/No response	10	20

Thirteen States (25 percent) reported that all hospitals with OBs or NICUs have ethics committees or ICRCs. The CPS respondents in 22 other States (43 percent) estimated that committees have been established in half or fewer such hospitals. Ten States (20 percent) did not provide any estimate. Additional detail on the number of hospitals with ICRCs established is provided at Appendix B.

State estimates are generally consistent with the findings of a national survey recently completed by the American Academy of Pediatrics (AAP). The AAP survey found that as of August 1986, about 52 percent of hospitals with over 1,500 births annually or an NICU were using committees to address ethical questions related to the care of severely disabled infants. An additional 8 percent were considering forming such a committee. [National Collaborative Survey of Infant Care Review Committees, AAP, March 1987].

We also asked State CPS offices what efforts they had made to encourage hospitals to establish ICRCs. Their responses are summarized in the following chart.

STATE EFFORTS TO ENCOURAGE ESTABLISHMENT
OF INFANT CARE REVIEW COMMITTEES

<u>RESPONSE</u>	<u>STATES</u>	
	<u>NUMBER</u>	<u>PERCENT</u>
Some encouragement	23	45%
Little or no activity	14	27
Local responsibility	4	8
Function contracted out	3	6
No response	7	14

Nearly half of the States mentioned activities to encourage hospitals to establish ICRCs. Efforts range from letters to hospital administrators and CPS-sponsored seminars for hospital personnel to development of ICRC models and hosting conferences. About 25 percent of the States have done little or nothing in this area. In some States, most or all hospitals with NICUs have already established ICRCs or ethics committees, and no encouragement from CPS agencies is needed. Other States feel that such a decision rests with the hospital and it would be presumptuous of CPS to assume any role in that decision.

SIX BABY DOE CASES CONFIRMED SINCE OCTOBER 1985

We asked CPS agencies how many baby doe reports had been received in their States, both before and after October 1985, when the baby doe regulations took effect. As the following chart shows, the volume of reports received did not increase after October 1985.

BABY DOE REPORTS RECEIVED BY CPS AGENCIES*

	<i>pre-85</i>	<i>post-85</i>
Alabama	0	2
Alaska	0	1
Arizona	0	1
Arkansas	1	0
Connecticut	1	0
Florida	0	1
Georgia	4	1
Illinois	3	0
Indiana	1	0
Kansas	0	1
Kentucky	1	0
Maryland	0	1
Minnesota	0	1
New Hampshire	1	0
New Jersey	2	1
New York	0	2
North Carolina	1	0
North Dakota	1	0
Oklahoma	0	3
Oregon	2	0
Pennsylvania	1	0
Texas	0	1
Virginia	1	0
Washington	0	3
Wisconsin	1	0
Wyoming	1	0
<u>TOTALS</u>	<u>22</u>	<u>19</u>

* Does not include States which have never received a baby doe report or for which no information is available.

According to respondents, 22 baby doe reports were received in 15 States before October 1985, and 19 reports were received in 13 States since 1985. Twenty-four States have never received a baby doe report, and one State does not keep records at the State level.

Limited information was available on 13 of the 22 baby doe reports received before October 1985. The CPS intervened in 5 of the 13 cases and treatment decisions were changed in 4 instances. It is believed that two of the affected infants survive. In six cases, CPS review determined that the charges were unfounded, and two reports were not considered true baby doe cases. See Appendix C for additional detail on individual cases.

In 6 of the 19 reports received since October 1985, CPS investigation resulted in intervention by the agency to insure the proper application of the baby doe treatment guidelines. Four of these cases involved infants born with severe birth defects, one was a low-birthweight infant, and one baby was born healthy but suffered severe physical abuse. Treatment decisions were changed in all six cases, and five of the affected infants were living at the time of our inspection.

In nine cases, CPS investigation confirmed that the baby doe treatment guidelines were being applied appropriately and no further action was required. Six of the affected infants were severely disabled at birth, while three were born normal. Two of the three suffered child abuse while the third was injured in a fire.

Of the remaining four reports received by CPS agencies, two were determined not to be true baby doe cases, and no information is available for two reports.

Additional information on the 19 baby doe reports received since October 1985 is provided at Appendix D.

STATE COMMENTS ON BABY DOE RESPONSIBILITIES AND FUNDING

In Fiscal Year 1986, nearly \$11.5 million in Federal funds was distributed to States in the form of Basic Grants and Baby Doe formula grants. Over \$2.4 million (21 percent) of this total was for Baby Doe Grants.

We asked CPS agencies to comment on the appropriateness of their baby doe responsibilities and the need for continued Federal Baby Doe Grants. Some States made more than one comment, while others chose not to comment at all. The range of opinions expressed by respondents are highlighted below.

<u>CPS COMMENTS</u>	<u>STATES</u>	
	<u>NUMBER</u>	<u>PERCENT</u>
A. <u>CPS Responsibility</u>		
It is appropriate for CPS to handle baby doe cases at State level.	28	55%
Because of medical and ethical issues involved, CPS responsibility for baby doe cases is not appropriate.	11	22
B. <u>Federal Funding</u>		
Baby doe funds are useful, but State would continue to carry out program without special funding.	13	25
Baby doe funds could be put to better use on general child protective programs, medical neglect or other priorities identified by States.	12	24
State could not operate baby doe program without special funds.	11	22
Federal set-aside funds were useful initially, but are no longer needed.	8	16
Baby doe problem is too small to warrant special Federal funds or attention.	5	10

While over half of the respondents stated that CPS is the appropriate State agency to handle baby doe reports, nearly

one-quarter felt that baby doe cases involve medical and ethical issues which should be dealt with in hospitals between parents and medical professionals.

Opinions on the continued need for special Federal funding differ as well. About one-quarter of the States indicated that their baby doe programs would suffer without special Federal funding. Another quarter felt that States should have the discretion to determine how to spend their available Federal funds. States could continue to devote these resources to baby doe programs exclusively, but would also have the flexibility to use their grants for medical neglect in general or other priorities.

OBSERVATIONS

The Federal baby doe amendments appear to have been successful in focusing CPS attention on the needs of severely disabled infants with life-threatening conditions. The CPS units in 48 States, including 7 which did not apply for Fiscal Year 1986 Baby Doe Grants, have established procedures to respond to reports involving such infants. All procedures include the provisions required in the law for hospital liaisons, prompt notification and legal intervention authority.

In addition, CPS units have generally fulfilled their responsibilities to have liaisons designated in hospitals with NICUs or OBs, and to provide information and training to these individuals on their role in reporting potential baby doe cases to CPS. The CPS units in some States have also played a role in encouraging affected hospitals to establish ICRCs or ethics committees.

It is not clear what impact the Federal legislation and increased State responsibility have had on the incidence or handling of baby doe reports. There has been no significant increase in the volume of reports received after October 1985, and most States reported that they handled cases essentially the same way even before the Federal law was passed. Prior to the baby doe legislation, States used existing child abuse and neglect procedures to respond to reports of medical neglect, including baby doe reports. Such cases were treated as emergencies, and medical expertise was sought as needed.

In view of the heightened awareness and attention to baby doe, many States feel that the special Federal baby doe set-aside funding is no longer needed. They believe that States should have the discretion to use these funds for child abuse and neglect priorities identified at the State level, including baby doe if needed. In contrast, other States feel that they would be unable to operate their baby doe programs without the set-aside funding.

Appendix 3

INFANT CARE REVIEW COMMITTEES

UNDER

THE BABY DOE PROGRAM

**RICHARD P. KUSSEROW
INSPECTOR GENERAL**

SEPTEMBER 1987

OAI-03-87-00042

[Executive Summary and Appendices omitted.]

INTRODUCTION

The term baby doe refers to a severely disabled infant with a life-threatening condition who is denied appropriate medical treatment. Two highly publicized court cases called national attention to baby doe in the early 1980s, and led to Federal legislation to protect the rights of such infants.

In the first case, an infant known as Baby Doe was born with Down's syndrome and a surgically correctable blockage of the esophagus. The baby's parents and doctor agreed that surgery should not be performed and that food and water should be withheld from him. The hospital sought a court order to permit surgery, but the court upheld the parents' decision, and the State supreme court refused to disturb the lower court's ruling. Baby Doe died before the case could be filed in the U.S. Supreme Court.

The second case involved an infant known as Baby Jane Doe, who was born with multiple neural tube defects, including spina bifida (an open lesion on the spine), microcephaly (an abnormally small head), and hydrocephaly (an accumulation of fluid on the brain). The parents approved medical treatment to reduce the chance of infection, but refused surgery to close the spinal lesion and drain excess fluid from the baby's brain. The parents' decision was later upheld by the State courts. It is not known what became of Baby Jane Doe.

In March 1983, the Department of Health and Human Services (HHS) published an interim final rule stating that section 504 of the Rehabilitation Act of 1973 applied to handicapped infants and establishing a Federal hotline for reports of failure to feed and care for such infants. One month later, the interim final rule was struck down in U.S. District Court. The Department published revised proposed regulations in July 1983 and final regulations in January 1984. These final regulations were struck down in U.S. District Court in June 1984.

The two baby doe cases and the subsequent debate among medical, professional, pro-life and disabilities groups regarding the ethics of treatment/nontreatment decisions affecting disabled newborns, including the role and responsibilities of States and the Federal Government, culminated in passage of the 1984 amendments to the Child Abuse Prevention and Treatment Act.

The amendments required HHS to publish model guidelines encouraging hospitals to establish Infant Care Review Committees (ICRCs). Model guidelines were published in April 1985. The ICRCs are intended to educate hospital personnel and families of severely disabled infants, recommend policies

and guidelines concerning the withholding of treatment, and review cases involving such infants.

The HHS model guidelines are advisory only. There is no Federal requirement for hospitals to establish ICRCs or to adhere to any aspect of the guidelines. Nevertheless, a national survey by the American Academy of Pediatrics (AAP) found that as of August 1986, about 52 percent of hospitals with over 1,500 births annually or a neonatal intensive care unit (NICU) were using committees to address ethical questions related to the care of severely disabled infants. An additional 8 percent were considering forming such a committee. The AAP study also found that the majority of committees already established generally conformed to the structure, procedures and functions outlined in the HHS model guidelines [National Collaborative Survey of Infant Care Review Committees, AAP, March 1987].

The 1984 amendments also required State CPS units receiving formula grant funds under the Act to define baby doe situations as medical neglect, to establish procedures for responding to reports involving such infants, and to have liaisons designated in hospitals where babies are born or treated to insure the immediate referral of potential baby doe cases to CPS.

This inspection was initiated at the request of the Surgeon General and the Administration for Children, Youth and Families, which administers the Act within HHS. The purpose of the inspection was to determine (1) how a group of hospitals with responsibility for acute infant care are structured and functioning in addressing potential baby doe situations, and (2) how States are carrying out their baby doe responsibilities.

The inspection was carried out in two phases. One phase consisted of visits to ethics committees in 10 large hospitals in 8 major cities around the country. Seven were children's hospitals identified with assistance from the Surgeon General. A second phase involved a telephone survey of CPS units in all 50 States and the District of Columbia.

This report, entitled "Infant Care Review Committees under the Baby Doe Program," presents the findings of our hospital visits. A companion report, entitled "Survey of State Baby Doe Programs," describes the results of our survey of State CPS agencies.

FINDINGS

HOSPITAL ETHICS COMMITTEES ARE ESTABLISHED AND FUNCTIONING

We visited 10 hospitals in 8 major cities around the country. Selection was based in part on the fact that they were known to have committees which review problematic cases. The hospitals visited included seven children's hospitals, one large county hospital, one large general hospital and one medical center affiliated with four other hospitals in the same metropolitan area. The children's hospitals visited have NICUs. The other three hospitals have large maternity wards as well as NICUs.

While committees have been established at all 10 hospitals, most are not ICRCs focusing exclusively on baby doe cases. Nine are ethics committees which review the full range of problematic cases encountered in the hospital, including baby doe cases. One of these ethics committees has established an ICRC as a subcommittee. The tenth hospital has a separate infant bioethical review committee.

In nine hospitals, committees were established and functioning prior to publication of the HHS model guidelines. Several have been in place for more than 10 years. One hospital established its committee after the guidelines were published. Historically, this hospital had handled ethical treatment issues on an ad hoc basis.

Committee Membership

The HHS model guidelines recommended that committees be established as multidisciplinary teams with core members and advisors or supplemental members. The suggested core members include: practicing physician (pediatrician, neonatologist or pediatric surgeon), practicing nurse, social worker, hospital administrator, disability group representative and member of the facility's medical staff who serves as the chairperson. A member of the clergy, an attorney or judge, and other medical specialties were suggested as advisors or supplemental members.

We found that while committee membership varies, all include pediatricians and/or neonatologists, social workers, nurses and representatives from hospital administration. Legal expertise is always available, although not necessarily in an official membership capacity. Most committees also include members of the clergy, ethicists, disability group representatives and patient representatives or advocates.

The baby doe amendments require State CPS units to have liaisons designated in hospitals where babies are born or

treated to assure the prompt reporting of baby doe cases to CPS. The model guidelines suggest that the hospital liaison be a committee member. Four committees reported that the hospital liaison is a member. Three of the remaining committees are in States which do not participate in the Baby Doe program and do not require the appointment of hospital liaisons. Committees at all hospitals visited reported they are familiar with CPS professional reporting requirements for all instances of child abuse and neglect, including baby doe. They feel that cases will be reported to CPS promptly whether or not an officially designated liaison sits on the committee.

Meeting Schedule

The HHS model guidelines suggest that committees meet regularly and also as needed to review specific cases. Committees at all hospitals visited meet as needed to review problematic cases prospectively. Eight committees also meet on a regular basis. Five meet monthly, two meet quarterly and one meets twice a month. Most meetings do not deal with baby doe issues or individual baby doe cases, but are devoted to policy development, education, or review of problematic cases involving older patients.

COMMITTEE RESPONSIBILITIES VARY

The HHS model guidelines suggest three major functions for hospital ICRCs: (1) to offer counsel and review in individual cases, (2) to recommend institutional policies and guidelines, and (3) to educate hospital personnel and families. The committees in our sample vary, both in the extent to which they perform these functions and in the importance attached to them.

1. Reviewing Individual Cases

Prospective case review is done by all committees visited, and is considered their most important function. Committee recommendations on individual cases are advisory only, rather than binding on the involved parties. Committee members pointed out that differences of opinion between treating physicians, parents and the committee can usually be resolved through an informal discussion process. If this is not possible, the hospital refers the case to CPS for investigation and possible legal action.

One committee indicated that it also reviews selected cases retrospectively, and a second plans to start soon. Several committees mentioned that patient deaths are reviewed retrospectively by other committees as part of the hospital's ongoing quality assurance process.

2. Recommending Institutional Policies

All committees visited recognized that the development of institutional policies, ranging from the types of cases which should be considered by the committee to guidelines for addressing particular types of cases, as an appropriate function for the ethics committee. The extent to which such policies have actually been developed varies from hospital to hospital. While most committees have adopted at least rudimentary written policies, two committees indicated that they are just beginning to address their policy development responsibilities.

Several respondents noted that the ethics of medical treatment decisions is constantly being rethought, reviewed and revised. This is due in part to continuing advances in medical technology. We were told by one neonatologist, for example, that recent advances now enable 80 percent of infants weighing as little as two pounds at birth to survive. This was not possible prior to the early 1980s. Low birth weight infants are often born with severe medical problems, some of which may result in permanent disabilities despite vigorous medical intervention.

3. Educating Staff and Families

Three committees mentioned they hold regular educational sessions for interested hospital staff where case information is shared and the ethics of particular treatment options and decisions are discussed. These sessions cover the full range of seriously ill patients treated at the hospital, and are not limited to potential baby doe situations.

Committees at all 10 hospitals indicated that their existence and role as advisor on problematic cases are well known to hospital staff, particularly those most likely to come into contact with disabled infants. Neonatologists, NICU nurses, hospital social workers, and members of the administrative staff know of the ethics committees and their case review role. Because of this general knowledge, educating hospital personnel is not considered a major need by ethics committees at the hospitals we visited.

Educating families of seriously ill infants is seen as the responsibility of other hospital staff, usually the patient representative or social work staff, rather than the ethics committee. Typical activities of these staff are to inform families of the existence and functions of the ethics committee, assist families in requesting ethics committee review of their infant's medical care when appropriate, and provide information and assistance in obtaining needed support services in the community following patient discharge.

BASIC CASE REVIEW CRITERIA ARE COMPARABLE

1. Prospective Case Review

The HHS model guidelines suggest that emergency ICRC meetings be called to review cases prospectively under the following conditions:

- o disagreement between family and physician about the proper course of treatment;
- o disagreement between hospital staff members; and
- o when a preliminary decision has been made to withhold or withdraw life-sustaining treatment.

All committees indicated they review cases involving disagreement between principal parties in the case (treating physician, parents, other hospital staff). They also review cases where the treating physician is uncertain about the proper course of treatment. In such instances, the committees serve as a consultative body to advise the treating physician on the most appropriate course of treatment.

Committee practices differ in handling cases where a preliminary decision has been made to withhold or withdraw life-sustaining treatment. One committee requires review of any case in which cessation of life-sustaining treatment is proposed, unless the infant is clearly terminal and continued medical intervention would serve no beneficial purpose. In these instances, a small subcommittee reviews the case to assure that reasonable medical guidelines are being followed. In a second hospital, if the principal physician recommends cessation of treatment, two colleagues must agree before treatment can be withheld. Eight committees reported that they do review cases brought to their attention involving the possible withholding or withdrawal of life-sustaining treatment. Prospective review of such cases is not, however, mandatory.

2. Retrospective Case Review

The HHS model guidelines recommend that ICRCs review records retrospectively in cases involving the withholding or termination of medical treatment, except for cases which were reviewed prospectively. Findings which deviate from hospital policy should be reported to appropriate hospital personnel and hospital policies revised, if necessary.

One of the 10 ethics committees visited reviews cases retrospectively on a selective basis. The hospital itself conducts monthly mortality conferences to review every patient death from a medical point of view. If the death is based on withholding or withdrawal of medical treatment, it is referred to the ethics committee for further review. Review results are sometimes used for educational purposes within the hospital.

A second ethics committee indicated that it plans to begin retrospective case review in the near future. Several committees mentioned that some cases are reviewed retrospectively by other committees as part of ongoing quality assurance activities within their respective hospitals.

COMMITTEE CASE REVIEW EXPERIENCE

Among them, the hospital committees visited estimate they have reviewed between 20 and 36 potential baby doe cases since the Federal regulations went into effect in October 1985. Most committees do not keep individual case records and were unable to provide precise information on the numbers of cases reviewed.

Advising physicians and families on the most appropriate course of treatment for severely disabled infants with life-threatening conditions is a responsibility which is taken seriously by hospital ethics committees. Members are mindful of their responsibilities and strive to apply the baby doe legal requirements while considering the medical, ethical and moral issues associated with each individual situation.

Parental consent is required in order for a hospital to perform surgery or withhold or withdraw treatment. Committees indicated that parents of some severely disabled infants initially refuse consent for surgery or life-sustaining treatment, while others demand that treatment be continued even when the treating physicians and ethics committees agree that continued treatment would be futile and painful, and would merely prolong the infant's dying.

Committee recommendations are advisory only, rather than binding on the affected parties. Committee members noted, however, that most situations involving initial differences of opinion have been resolved in accordance with baby doe requirements, and few cases have been reported to CPS.

Eight hospitals have not reported any cases to CPS. They indicated that all cases reviewed have been resolved informally. If a case could not be resolved within the hospital setting, they indicated that they would seek CPS intervention.

Two hospitals have made three reports. In these three cases, parents refused consent for life-saving treatment or surgery recommended by the hospital. CPS intervention led to continuation of treatment. Two of the affected infants were living at the time of our fieldwork.

While hospital committees declined to discuss the details of individual cases reviewed, several respondents commented generally on the types of cases most often referred for review:

- o The types of cases most frequently reviewed by committees involve low birthweight (less than 2 pounds), extensive internal bleeding associated with premature birth, and

asphyxiation during the birth process. These infants have little chance for survival even with vigorous, and often painful, medical intervention.

- o Committees also review cases involving multiple and severe birth defects, including hydrocephaly (fluid on the brain), anencephaly (most of the brain missing), microcephaly or macrocephaly (abnormally small or large head), deformities of the face and extremities, blocked esophagus and little or no large intestine. Such conditions usually occur in some combination and are frequently associated with severe or profound mental retardation. Some conditions cannot be corrected. While it is surgically possible to open a blocked esophagus, for example, there is no treatment for anencephaly. Committee members indicated that the long-term prognosis for infants born with combinations of conditions such as those described above is uncertain.
- o The two conditions which gave rise to the baby doe amendments, Down's syndrome and spina bifida, are generally not problematic for the hospitals visited in terms of whether or not to provide treatment. Committee members indicated that infants with these two diagnoses have been routinely treated in their hospitals for 15-20 years.
- o Even in an instance when an infant is imminently dying and the decision is made to withdraw or withhold treatment, the infant continues to receive nutrition and hydration and is made as comfortable as possible during the dying process.

DESCRIPTION OF AN ETHICS COMMITTEE

This section describes the structure and functions of a series of interlocking Infant Bioethical Review Committees established in February 1984 in four affiliated hospitals which make up the Albert Einstein College of Medicine and the Montefiore Medical Center in the Bronx, New York. This group of hospitals was visited as part of the inspection. Its committees are generally structured and functioning in conformance with the HHS model guidelines, and may serve as a useful reference for hospitals considering the establishment of similar committees.

Since four institutions are involved, a decision was made to have separate but interlocking committees. A core group of experts serve on all four committees, and additional members have been appointed to each hospital's committee. The core group includes: a neonatologist who chairs all four committees; three other pediatricians with expertise in neonatology, disabilities and rehabilitative medicine; a lawyer working in a medical setting; and two bioethicists. Each institution has appointed nursing, social work, administrative and community representatives for its own committee. An attorney in one hospital's general counsel's office serves as a nonvoting consultant to each committee.

The core group and all members from the four hospitals meet monthly to develop general guidelines and procedures and review cases retrospectively. Ad hoc consultants may attend meetings upon invitation of the chairman, but may not vote. Minutes are kept. Many decisions are reached through consensus. When a vote is required, however, a two-thirds majority of members present is required for passage.

The committees have agreed to a set of principles which serve as the basis for making decisions involving critically ill infants. These principles recognize the intrinsic worth of the infant which entitle it to all appropriate care determined to be in its best interests, irrespective of its disability or handicap. Caregivers are obligated to provide such care. The principles recognize that it is sometimes uncertain what medical treatment is in the best interests of a particular infant. Parents are responsible for making decisions for their infant, unless they choose a course of action that is clearly against the infant's best interests. Withholding or withdrawing treatment may be considered when it is deemed futile and would merely prolong the dying process or when the medical treatment imposes a burden which lacks compensating benefits for the infant. If such a decision is made, the infant and the family are cared for in a supportive and dignified manner.

The committees review cases involving infants up to 2 years of age. Cases are reviewed prospectively as well as retrospectively.

Prospective Review -- Each committee convenes on an emergency basis at the request of the chairman for prospective case review. Mandatory review is required when:

- o withdrawal of life-sustaining treatment is being proposed for a patient who is not imminently dying; and
- o there is disagreement between or among health care providers and families concerning withdrawing or withholding life-sustaining treatment.

Parents are informed when their case is being reviewed, but parental consent for review is not required. Caregivers, parents, clergy and other relevant parties are encouraged to meet with the committee or attend portions of the meeting. They may not be present during final deliberations and voting. Members with direct responsibility for the infant's care do not vote.

Committee recommendations are shared with the involved parties immediately after the meeting. If the parents and treating physician agree with the committee's recommendation, no further committee action is required. If, after extensive discussion, differences of opinion cannot be resolved, the committee recommends that the hospital seek intervention by the Child Protective Service Agency for action to permit appropriate treatment or the withdrawal or withholding of life support.

Full committee review is not required for cases in which no further treatment is being considered because the infant is clearly terminal and continued intervention would serve no beneficial purpose. However, a small subcommittee does review such cases to insure that they adhere to reasonable medical guidelines and that the family has been properly consulted. These cases are reviewed retrospectively at the next monthly meeting.

Retrospective Review -- The full committee reviews deaths resulting from the withholding or withdrawing of medical treatment. Retrospective reviews are held for information and education of the committee, as well as to generate guidelines which will be helpful in reviewing future cases.

Note: This description is based on the following references:

1. Fleischman, Alan R., M.D., "Bioethical Review Committees in Perinatology," Clinics in Perinatology, Volume 14, No. 2, June 1987.
2. Fleischman, Alan R., M.D., "An Infant Bioethical Review Committee in an Urban Medical Center," Hastings Center Report, June 1986.

ETHICS COMMITTEE COMMENTS ON IMPACT OF BABY DOE PROGRAM

We asked hospital ethics committees to comment upon the impact of the baby doe legislation and the effectiveness of the current system. The sample of comments provided below, mostly from physician committee members, illustrate the range of opinions expressed.

- o "The baby doe legislation focused our attention on this issue. We are now more aware of ethics committees and their functions, as well as the requirement to report suspected cases to CPS."
- o "While Federal involvement has raised consciousness about baby doe, these problems involve medical and ethical issues which do not belong in CPS. What is needed is increased sharing of information among involved parties, not regulation by CPS. I find it philosophically, emotionally and professionally repugnant to involve CPS in the decisionmaking process."
- o "The current system is effective. CPS provides the support and legal backing which enable us to provide the most appropriate medical care. The Federal law has heightened our awareness of baby doe issues."
- o "When in doubt, ethics committees and physicians err in the direction of providing treatment, even when the infant's chances of survival are extremely slim."
- o "Fear of malpractice lawsuits has caused many hospitals and physicians to continue treatment for infants who have virtually no chance for survival. The treatment is often painful and only prolongs the infant's dying."
- o "Severely disabled infants born in community and maternity hospitals are routinely transferred to children's hospitals, even when the infant is clearly dying. The birth hospitals fear being accused of failing to do everything possible to save the infant."
- o "Medical technology may be doing a disservice by delaying a death that is imminent. Respirators can now keep nonviable babies alive temporarily, only delaying their inevitable deaths for a month or two."
- o "The real unmet need is for day care facilities and other supportive services specifically designed for these babies who may not receive the special care and attention they require once they leave the hospital."
- o "It is morally repugnant to give treatment that is painful to the child and clearly has no useful purpose."

OBSERVATIONS

The inspection found that while nearly all hospitals visited had established ethics committees prior to passage of the baby doe legislation, most respondents feel that the legislation and model guidelines have helped to focus their attention on potential baby doe situations. While the HHS model guidelines are advisory rather than mandatory, the majority of hospitals with large maternity wards and/or NICUs do have ethics committees which review and advise on neonatal cases, including the treatment of severely disabled infants. All 10 of the committees visited during the inspection report they are structured and functioning substantially in conformance with the HHS model guidelines.

All committees visited recognize their responsibilities to develop hospital policies addressing the treatment of severely disabled infants and to review individual cases on a prospective basis. While specific case review criteria vary somewhat, all committees are available to meet on an emergency basis to consider and recommend the most appropriate course of action in treating these infants. Applying the baby doe provisions in the law, committees are usually able to arrive at consensus regarding the most appropriate course of treatment. Most disagreements are resolved informally, but when necessary, hospitals do not hesitate to seek CPS intervention.

Disagreement between the involved parties appears to be the major criterion for committee review; while committees do review cases brought to their attention which involve the possible withholding or withdrawal of life-sustaining treatment, prospective review of such cases is not mandatory in 8 of the 10 hospitals visited.

The hospitals visited do not believe there is a need for increased publicity or attention to baby doe issues at the Federal level. However, several respondents mentioned a continuing unmet need for specialized day care, adoption assistance and related community-based supportive services to meet the needs of these special infants following hospital discharge. The Department may wish to consider alternative means to increase the availability of such services at the local level.

Appendix 4

American Academy of Pediatrics



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May 1, 1989

William B. Allen
Commission on Civil Rights
1121 Vermont Avenue, N.W.
Room 800
Washington, D.C. 20425

Dear Mr. Allen:

The AAP regrets the process and the substance of the Commission report. There was very little opportunity for groups and/or individuals to explain the current decision-making process in intensive care newborn nurseries. The Commission's process did not allow for a thorough hearing of the issues.

The report takes an extreme position rather than a balanced view of the complex issues involved in caring for critically ill newborns. Its tone throughout is that of a conclusion in search of arguments rather than a reasoned response to the difficult questions involved.

The report dwells on events that occurred in the decade prior to the historic compromise which culminated in the 1984 amendments to the federal Child Abuse Act. It describes case studies and attitudes from an earlier era as if they had some relationship to the present. A number of groups using a variety of monitoring mechanisms have observed that infants with Down Syndrome, spina bifida and other anomalies are now receiving appropriate care.

The Commission seriously understates the importance of the dramatic growth of hospital ethics committees (also called infant care review committees) since 1985. This transformation in the way decisions are made occurred on a voluntary basis with no federal or state requirements. They were a result of the conviction of the Academy and other groups that multi-disciplinary review would facilitate decision making in difficult cases. Those who predicted that hospitals and physicians would not form such committees, or that committees would not become involved in decisions, or that committees would accept decisions without discussion or dissent were wrong. Rather than acknowledge this success, the Commission simply ignores it.

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The Commission advocates an extreme view of the Child Abuse Amendments and related regulations, one that would require maintenance of biologic existence in virtually all infants other than the comatose and the dying. It fails to acknowledge the carefully crafted language which reflected a rejection of that view by many groups and individuals who care for and about infants. It resurrects a position which would not take into account an infant's interests, nor allow any person or group or court to make any judgements about the care of a sick or suffering infant. This view is not only contrary to the spirit and language of the law and regulations, but contrary to a clear trend in American law and opinion which demands that handicapped and critically ill infants, like all patients, be entitled to have decisions regarding life-sustaining treatment made in their best interest.

The Commission advocates a renewal of intrusion of federal authority into complex decision making at the bedside. This view is contrary to federal appellate and US Supreme Court opinion, as well as public opinion. It resurrects an approach which was implemented in the infamous "Baby Doe hotline" and "Baby Doe squads" that failed to achieve its objective. It was an approach which failed to identify serious errors at a time when they were common, and which falsely labelled excellent clinical care as neglect, driving infants and parents fearfully out of intensive care units to avoid onrushing and intrusive federal authorities.

Furthermore, the most recent Inspector General's survey of Baby Doe programs release just last year showed that the problem of undertreatment is being appropriately addressed. In commenting on that report, Surgeon General Koop said that, "It is reassuring to learn...that each state has accepted its responsibility and fully implemented the 1984 amendments to the Child Abuse Prevention and Treatment Act." Dr. Koop went on to say that the report indicates that the "guidelines and procedures are working appropriately."

All evidence points to the fact that the law is working. The Academy continues to support the use of infant care review committees as an important mechanism to assist physicians and parent in making these difficult decisions. The Academy also continues to educate and train our pediatrician members about the use of committees and other methods of aiding children with disabilities and their parents.

Sincerely,



Donald W. Schiff, M.D.
President

Statement of Commissioner Robert A. Destro

It should not have been this difficult. The point, after all, is a fairly simple one: that it is both illegal and immoral to deny necessary medical care to any child, especially one with a disability. That it has taken the Commission nearly 5 years to complete its report and recommendations bears witness to the formidable political and practical hurdles which had to be overcome. But overcome they were, and as the Chairman of the subcommittee responsible for producing and editing the several drafts of the report and recommendations, I am both pleased and grateful to the Commission and its staff for the hard work, late nights, and commitment to seeing this project through to completion.* I write separately to summarize some of 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.

Defining the Problem: Discrimination, Medical Ethics and Family Privacy

The primary conceptual and political problem faced by the Commission has been to distinguish among those issues which are correctly within the realm of antidiscrimination and child neglect laws, those which are properly matters of medical judgment or ethics, and those which are matters of parental choice. Though the dividing line which

* Special thanks go to my friend and colleague Commissioner Esther Gonzales-Arroyo Buckley, for her work as the other member of the subcommittee, and to my former confidential assistant, Deborah Lawrence (now of Fort Wayne, Indiana), whose hard work and persistence were largely responsible for the completion of the hearing record. It is also appropriate to recognize the contribution to the finished product made by the

separates these spheres is far from clear, it is quite real; and the need to make careful distinctions is critical.

It goes without saying, for example, that neither child abuse and neglect nor discrimination on the basis of disability are "private" matters. That a parent's decision to neglect a child's medical needs is either influenced by or acquiesced in by a physician likewise does not transmute the issue of neglect into one of medical judgment, ethics, or confidentiality. The proper (and limited) concern of law is the prevention and punishment of antisocial activity. Medical neglect (that is, the denial of medically indicated treatment) of the physically or mentally disabled is, by definition, antisocial, and the proper concern of the law.

The question addressed in this report is simply stated: is it permissible under either State or Federal law to deny necessary medical care to any person on the grounds that a disability or other immutable characteristic such as race, sex or ethnicity makes that person an unfit subject for treatment? Phrased another way, the question is: whether medically indicated (i.e. necessary) treatment for a given condition becomes any less "necessary" when the patient has a disability?

That this is the issue cannot be doubted. The physician who treated Bloomington Indiana's Baby

Commission's late Chairman, and the original chair of the subcommittee, Clarence M. Pendleton, Jr. Though Penny and I had many a late-night disagreement over the what we might find in the course of additional hearings, he supported additional factfinding. In addition, he also resisted internal and external political attempts to kill the project outright.

Doe¹ admitted on the record of the Commission's June 1986 hearing that he had told the baby's parents that "[they] must realize that if the child has the surgery, and if the surgery is successful, that this child will still be a Down's syndrome child with all that that implies." Since, in his view, "the parents were pretty well-acquainted and had a good knowledge of what this implied[, he] said to them [that] 'There is the alternative of doing nothing, in which case the child will survive a few days and will die.'"²

The baby was not dead, he was not dying, and the indicated surgery was neither futile nor medically contraindicated. The "problem" was that the little boy had Down's Syndrome. Had he been "normal" (i.e. not disabled) not a court in this country would have stood by as he died of starvation and dehydration. Nonetheless, they did—up to and including the Supreme Courts of Indiana and the United States.

Such attitudes and behaviors cannot be tolerated in a civilized society. They are a cancer growing at its very heart. It makes no difference whether the decision is that of the parents, a physician, an "ethicist," an ethics committee, a judge, or a combination of all of them; for whatever the euphemism chosen to describe what is going on in the limited category of cases dealt with in this report, the real names of the practices are eugenic discrimination and euthanasia.

To subsume the question entirely into the realm of medical ethics, as the statement of Chairman William B. Allen³ does, is to unwittingly fall into the trap suggested by Leo Alexander, an observer at the trials of the Nazi war criminals at Nuremberg, who wrote in 1949 that:

The beginnings [of the Nazi terror] at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the

racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick.

It is, therefore, this subtle shift in attitude that one must thoroughly investigate.⁴

Robert Jay Lifton's 1986 book, *The Nazi Doctors*,⁵ described the process decried by Alexander as the gradual "medicalization" of eugenic killing and neglect. The record and the literature reviewed in this report confirm that the same phenomenon is at work here.

This is why many, if not most, of the arguments raised in opposition to this report are either ill-informed or disingenuous. Chairman Allen, for example, argued during the final debate on the report that it lacks "numbers [concerning] what is actually transpiring in the country. That is a relatively simple calculation to effectuate."⁶ Given the difficulty of the legal, medical, and ethical issues, as well as the potentially great legal and financial risks associated with reporting behavior which is arguably illegal under state and federal law, it is incomprehensible that anyone knowledgeable on the subject could allege that the incidence of discriminatory denial of treatment "is a relatively simple calculation to effectuate." The "hard" evidence is all to the contrary.

When the government sought to encourage reporting by posting an informational notice in hospitals for the benefit of families and medical personnel similar to those required by labor and other civil rights laws, the courts enjoined the requirement. Medical personnel have been fired or disciplined for reporting denial of treatment cases to child welfare personnel. The Office for Civil Rights of the Department of Health and Human Services was opposed to investigating alleged cases of medical care neglect of infants with disabilities. The investigatory ardor of the Civil Rights Division of the Department of Justice cooled noticeably after the government lost the *Bowen v. American Hospital*

¹ *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.* State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S. Ct. May 27, 1982), No. 482 S.140 (Ind. S. Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

² *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 224-25, 228-29 (1986) (vol. II).

³ Chairman William B. Allen, "A Dissenting View on the Report *Medical Discrimination Against Children with Disabilities*."

⁴ Alexander, *Medical Science Under Dictatorship*, 241 *New Eng. J. Med.* 39, 41 & n.17 (1949) (quoting J. Bernal, *The Social Function of Science* 44 (6th ed. 1946)).

⁵ Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (1986).

⁶ United States Commission on Civil Rights, *Transcript of Meeting of Jan. 9, 1989* at 49 (remarks of Chairman Allen).

*Association*⁷ case, even though the majority relied on alleged defects in the investigatory record to strike the so-called “Baby Doe” rules.

Thus, it is not surprising that the Commission’s Specific Findings Three, Four and Five Regarding the Child Abuse Amendments of 1984 raise serious questions concerning the legitimacy of internal self-regulation by hospital ethics committees as well as the effectiveness of past and future oversight by the Office for Civil Rights of the Department of Health and Human Services. Discrimination against the disabled in the medical setting has been so thoroughly “medicalized” by physicians and ethicists, and “privatized” by courts and commentators that the Chairman’s argument that the number of cases “is a relatively simple calculation to effectuate” cannot be taken seriously.

In fact, the only real way to get the “numbers” is retrospectively: after the treatment has been denied. Specific Recommendation Eight Regarding the Child Abuse Amendments of 1984 places the Commission on record as urging “retrospective reviews of the medical records of those with disabilities who die in [a] State” by the local Protection and Advocacy [P&A] System.

In my view, however, the focus on “how many” such cases is simply wrong; for it ignores the obvious. Whenever noted physicians, ethicists, and researchers publish articles in major academic and professional journals reporting discriminatory behavior against disabled persons as if there were nothing wrong with it, there are at least two serious problems which make the number of cases almost beside the point.

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 in the face of great public scrutiny, authorized admitted medical neglect of persons with disabilities⁸ means that discrimina-

ry attitudes about the “quality” of their lives are shared by those whose obligation it is to enforce our civil rights laws.

Complicating the matter further, some courts and legal commentators have argued that, due to their difficulty and intensely personal nature of denial of treatment cases, they are (or should be) considered as matters within the zone of constitutionally protected family privacy. To “privatize” the issue is, of course, to argue that it is not only permissible, but also outside the legitimate purview of the law. In my view it is equally wrong to take this approach as it is to accept the arguments of those who would “medicalize” the problem. The result is the same: only the method is different. The Commission quite rightly, and without recorded dissent, rejected both.⁹

Placing the Report in Context

The important facts contained in most reports, including his one, are often the most obvious ones. Though the Commission’s report makes it quite clear that discriminatory denial of necessary treatment to newborns with disabilities was the subject of this study; those opposed to its conclusions have focused instead on overtreatment of patients for whom it may be either useless or harmful, especially neonates (very premature newborn infants).¹⁰ Characterized in this manner, the problem becomes technology gone wild, not discrimination. Ethicists and medical experts can then safely be cast as the victims of an ill-informed, narrow-minded “life-at-any-cost” ethic (termed “vitalism”) which does not take into account the dignity of the individual forced to live a life in which there is no hope.

It is a powerful—and dangerously irrelevant—argument. “Overtreatment” of anyone is, by definition, both “unnecessary” and unethical. Physicians and ethicists cannot be permitted to hide behind the family when the issue is overtreatment, any more than they should be able to do so when discrimina-

⁷ 476 U.S. 610 (1986).

⁸ See, e.g., Destro & Moeller, *Necessary Care for the Retarded Child: The Case of Phillip Becker*, 4 Human Life Rev. 81 (1980) quoting Transcript of Record, *In re Phillip B., A Minor*, No. 66103 (Super. Ct., Santa Clara County, Cal. Apr. 27, 1978), *aff’d*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 749 (1980).

⁹ Though Chairman Allen’s statement recounts that he voted against the adoption of this report, the record clearly shows that he abstained, thus acquiescing in the will of the majority. United States Commission on Civil Rights, Transcript of Meeting of Jan. 9, 1989 at 50 (remarks of Chairman Allen noting that he would

probably abstain); *id.* at 58 (“That makes 7 votes aye, no votes against, and 1 abstention.”) (quoting Chairman Allen’s count of the Commissioners’ votes). That Chairman Allen’s approach to the issue of medical care discrimination is contrary to that of the Commission is clear from his written statement: he rejects the Commission’s conclusions and minimizes its factual findings. Why he simply did not vote “no” remains a mystery.

¹⁰ See comments of H. Tristram Engelhardt, Jr., Ph.D., M.D., appended to the statement of Chairman Allen. See also, *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 79–112, 164–95 (1985) (vol. I).

tion is the basis for failure to treat. Overtreatment was never the focus of this study, notwithstanding the attempt to make it so. The focus is—and should always remain—on the legitimacy of individual and collective decision-making. If the decision is a legitimate medical one, it is not for the law to second-guess. If it is based on social or eugenic factors, we have entered the realm of discrimination.

And that, of course, is the crux of this debate. Were a physician, judge or ethicist to so much as suggest, orally or in print, that race or sex-based denial of medically indicated treatment might be justifiable for any reason, the public outcry for Federal, State, local (and, in some quarters, Divine) oversight, investigation and intervention would be heard round the world.

Yet there is a difference when the object of discrimination has a physical or mental disability. Noted physicians and medical centers have advertised their discriminatory attitudes and practices, and civil libertarians who should know better rush to defend the ability (some would say “the right”) to engage in such discrimination. There is something seriously wrong—morally and legally—when physicians and ethicists concoct “quality of life” formulas so that they might confer a scientific patina on what is essentially medical discrimination (or worse). How many bodies does one need to count as “proof” when those involved admit to discrimination based on non-medical factors? This is the greater context

in which this report should be read. The United States is at an ethical crossroads. A recent survey of 2,218 Colorado physicians concluded that 60 percent of all doctors have attended patients for whom they believe active euthanasia to be justifiable if it were legal, and 58.9 percent of these physicians “indicated that they would have personally been willing to administer a lethal drug if such measures were allowed by law.”¹¹ California voters were asked, and refused by a wide margin, to approve a ballot initiative which would legalize “death assistance” (including lethal injections under certain circumstances),¹² and similar initiatives are planned for Florida, California, Oregon, and Washington in 1990.¹³ To assume that the first candidates for such “assistance” are not going to be the disabled, the incompetent, and the elderly is naive.¹⁴

Other countries have already made their choice. It has been reported that some doctors in the Netherlands perform between 5,000 and 10,000 cases of direct euthanasia per year,¹⁵ protected by court decrees which allow it when a patient makes an informed request.¹⁶ The March 30, 1989, issue of the *New England Journal of Medicine* contains a both plea for the “wide and open discussion” of physician-assisted suicide, and a sympathetic, yet cautious, treatment of “the role that euthanasia may have in the treatment of the terminally or hopelessly ill patient.”¹⁷

¹¹ Center for Health Ethics and Policy, Graduate School of Public Affairs, University of Colorado at Denver, *Withholding and Withdrawing Life-Sustaining Treatment: A Survey of Opinions and Experiences of Colorado Physicians* (May 1988) at 16 [hereafter Colorado Survey]. The center recommended that the Governor should appoint a commission to evaluate, among other things, whether the substantial number of physicians holding these views represent “changing community mores” and urged reevaluation of present Colorado law forbidding active euthanasia to determine whether it is consistent with “the perceptions of right and wrong” of the people of the State. *Id.* at 21.

¹² “Euthanasia Law Fails to Qualify for Ballot,” NEXIS PR Newswire, May 10, 1988 (Hemlock Society news release).

¹³ U.P.I., “Right-to-Die Group Targets Florida in Ballot Drive,” NEXIS, Aug. 1, 1988 (noting Hemlock Society plans to seek assisted suicide initiative in Florida, California, Oregon, and Washington).

¹⁴ In *Gilbert v. State*, 487 So.2d 1185, 1190-91 (Fla. App., 4th Dist., 1986), a Florida court was recently asked (but refused) to rule that intent to commit euthanasia was a defense to a charge of premeditated murder. The offense: the convicted murderer had fired two bullets into the brain of his wife, who had the misfortune of being afflicted with osteoporosis and Alzheimer’s disease. Roswell Gilbert’s case was recently the subject of a made-for-TV movie.

¹⁵ G.T. van der Werf, *Huisarts en euthanasie*, 43 *Medisch Contact* 1389 (1986) and personal communication of P. Admiraal,

cited in S. Wanzer, D. Federman, S.J. Adelstein, C. Cassel, E. Cassem, R. Cranford, E. Hook, B. Lo, C. Moertel, P. Safar, A. Stone, & J. van Eys, *The Physician’s Responsibility Toward Hopelessly Ill Patients*, 320 *New England J. Med.*, 844, 848 & n.28. (hereafter, S. Wanzer et al.).

¹⁶ G.E. Pence, Ph.D., *Do Not Go Slowly into that Dark Night: Mercy Killing in Holland*, 84 *Am. J. Med.* 139 (1988) (estimating that, as of late 1987, between 5,000 and 8,000 patients have been killed by physicians in the Netherlands). A summary of the situation in the Netherlands, France, Denmark, the Federal Republic of Germany, and Sweden is contained in British Medical Association, *Euthanasia: Report of the Working Party to Review the British Medical Association’s Guidance on Euthanasia*, at 49-52. With respect to the Dutch, paragraph 210 of the report concludes that “[i]t therefore seems that, although certain members of Dutch society are against active termination of life for cogent reasons, there is a widespread use of active termination of life, which is motivated by the highest humanitarian ideals but not all of which is reported.” The BMA’s position on the topic of euthanasia was unequivocal: “The active intervention by anybody to terminate another person’s life should remain illegal. Neither doctors nor any other occupational group should be placed in a category which lessens their responsibility for their actions.” *Id.*, Conclusion 4, at 67.

¹⁷ S. Wanzer et al., *The Physician’s Responsibility Toward Hopelessly Ill Patients*, 320 *New Eng. J. Med.*, 844, 848-49 (noting the moral objections of two of the authors J.v.E. and E.H.C.).

Those who need evidence of the growing attitude that death itself is a "treatment" for those whose lives are not of sufficient "quality" need only look to the record of the Commission's hearing, the medical literature, and the cases to see that what the Chairman of this Commission decries as unsubstantiated is freely admitted by those involved. There would be no point in arguing for a "wide and open" discussion of the topic were it not assumed from the outset that the acceptance of euthanasia is good public policy.

Justice James A. Andersen of the Supreme Court of Washington has written:

As recently as five years ago, or perhaps three, the idea that fluids and nutriment might be withdrawn, with moral and perhaps legal impunity, from dying patients, was a notion that would have been repudiated, if not condemned, by most health professionals. They would have regarded such an idea as morally and psychologically objectionable, legally problematic, and medically wrong. The notion would have gone "against the stream" of medical standards of care. [However,] . . . this practice is receiving increased support from both physicians and bioethicists. This new stream of emerging opinion is typically couched in the language of caution and compassion. But the underlying analysis, once laid bare, suggests what is truly at stake: That for an increasing number of patients, the benefits of continued life are perceived as insufficient to justify the burden and cost of care; that death is the desired outcome, and critically—that the role of the physician is to participate in bringing this about.¹⁸

Justice Edward D. Robertson, Jr. of the Missouri Supreme Court has made the same point.¹⁹

Though the Washington State and Missouri cases deal with disabled adults, the basic issues are similar (though not identical) to those involving disabled infants like Baby Doe and Baby Jane Doe. The individual has a medical need which will respond to treatment, but is disabled and the prognosis for rehabilitation or cure is at best uncertain and usually bad. The treatments proposed are not medically contraindicated. The affected individuals are not dead or dying. The argument is over whether or not they might not be "better off" dead.

Recognizing the Obvious: The Abortion "Connection"

At the outset of both hearings, and in many of the debates, both internal and external to the Commis-

sion, the so-called "Baby Doe" issue has been linked to that of abortion. That it should not have been is an entirely different matter, but it is unsurprising that it was. Whenever the politics and law of civil rights, personal autonomy and bioethics confront one another in a field fraught with emotion, human suffering, and deeply-held and divergent moral views, connections will inevitably be made by those termed "liberals" as well as by those who style themselves as "conservatives" or "libertarians." That is what happened here.

And therein lies the most interesting, and personally frustrating, political aspect of this report. The witness list of the June 1985 hearing, assembled by Commission staff, cast the issues as matters of bioethics, medicine, and personal privacy. Discrimination was not the subject of the inquiry. When queried, the medical and ethical experts called to testify quite predictably denied that discrimination has anything to do with denial of treatment. The issue of discrimination was addressed directly by only one panel in the first hearing.²⁰ The focus on medicine and ethics and the relegation of disability or rehabilitation issues to the sidelines spoke volumes. The issue had been "medicalized" and "privatized."

It was not until the June 1986 hearing that disability and rehabilitation issues were highlighted. Testimony of parents and medical experts was included as well in an attempt to "balance" the record of both hearings. But then the 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 "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.

Commissioner Mary Frances Berry captured the nature of the dilemma best shortly before she cast

¹⁸ *In re Guardianship of Grant*, 109 Wash.2d 545, 747 P.2d 445, 459 (1987) (Andersen, J., concurring in part and dissenting in part).

¹⁹ *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo., 1988).

²⁰ *Hearing Before the United States Commission on Civil Rights: Protection of Handicapped Newborns* 113-38 (1985) (vol. I) (disability perspective).

her (much appreciated) vote for this report and its recommendations.

I don't know if my colleague, Mr. Destro, has read [the Chairman's written comments on the report²¹], but if he has he will note that while he may think this issue has nothing to do with abortion, the Chairman seems to think it does and there are other people who I also think will think that it does, however you characterize it. . . .²²

She was (and is) correct. There is a connection. But it is not the political linkage one about which she and others have been so concerned. The nexus is philosophical and moral.

There will always be profound moral, philosophical, ethical and legal dilemmas involved in medical decisionmaking. Each of these dilemmas, in its own way, detracts from the personal choice and autonomy of those involved, but there is no escaping them.

It is also true that the law cannot prevent child abuse or any other anti-social behavior, such as discrimination, which has its roots in human ignorance, intolerance or weakness. The role

²¹ United States Commission on Civil Rights, Transcript of Meeting of Jan. 9, 1989 at 16.

of law is state a norm of acceptable behavior. Those who make and enforce the law can affect attitudes only as "teachers" whose pronouncements and behavior set the social norm. Thus, when the time comes for action, as it did for the Commission when it voted on this report, our duty to advise Congress and the President on policy required us to draw lines in as clear a fashion as our limited capacity for human understanding would permit.

This report rejects discrimination against the persons with disabilities in the context of medical care decision-making. To have ignored the problem, treated it as a matter of medical or parental autonomy, or minimized the seriousness of the attitudes which brought these practices about would have been to take the risk that the public might believe "that [this Commission thinks] it is alright to kill kids—[because] that is one way one could interpret [it]."²³

Arlington, Virginia
May 1989

²² *Id.* at 19 (comments of Commissioner Berry).

²³ *Id.* at 20-21 (comments of Commissioner Berry).