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HANDICAPPED INFANTS: THE FINAL SECTION 504 REGULATION AND LEGISLATIVE PROPOSALS

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February 8, 1984

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BACKGROUND

In May of 1982 in Indiana, a handicapped newborn died because the parents and the physician decided to withhold treatment and sustenance. This and similar cases became known as the "Infant Doe" issue.

In response to this issue, the White House instructed the Secretary of Health and Human Services (HHS) to remind health care providers that handicapped persons are not to be discriminated against by agencies receiving Federal financial assistance. It was the Administration's contention that handicapped infants are discriminated against in cases similar to the Indiana case. The HHS issued the reminder to over 6,800 hospitals on May 18, 1982, and section 504 of the Rehabilitation Act was cited as the legal authority for this action. 1/ Section 504 is the basic civil rights statute relating to handicapped persons, but the section 504 regulations do not specifically address the issue of health services for handicapped newborns. The reminder sent to hospitals stated that failure to comply with section 504 subjects reciplients of Federal funds to possible termination of such funds which could include Medicare and Medicaid.

On March 7, 1983, the Administration published an interim final rule in the Federal Register requiring hospitals to post public notices in conspicuous places in delivery, maternity and pediatric wards and in nurseries, including

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1/ Rehabilitation Act of 1973, P.L. 93-112, as amended.

intensive care nurseries. The notice was to state: "Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by Federal law." A toll-free hotline number was provided for any person wishing to report a case of suspected discrimination. This rule was to go into effect on March 20, 1983, rather than at the end of the customary 60-day comment period.

Public reaction regarding the Infant Doe incident and the Administration's response was immediate and varied. Advocates associated with the right-to-life movement stated that the mentality which brought about legalized abortion was expanding to encompass the legal withholding of treatment and health care services from handicapped newborns who are unwanted by their parents. Others felt that withholding treatment was evidence of discrimination against the handicapped. Yet others issued public statements saying that the Government ought not regulate in the sensitive area of doctor-patient relationships, that parents ought to have considerable influence on the decision, and that the infant may, in fact, be better off dead if his or her condition would cause great pain and/or profoundly incapacitating disability. The statements in the appendix are intended to be representative samples of the comments and opinions issued in response to the Infant Doe issue and the HHS notice, or to the broader issue of decision-making regarding treatment of handicapped newborns.

On March 18, 1983, the American Academy of Pediatrics, the National Association of Children's Hospitals, and the Children's Hospital Medical Center in Washington, D.C. filed suit to block the Administration's March 7 rule until these organizations had a chance to comment on the rule. The medical groups expressed concern about possible Government intervention in medical decisions and in the patient-doctor relationship. On April 14, 1983, a U.S. District Court judge struck down the Administration's March 7 rule and indicated that it

constituted "arbitrary and capricious agency action" that could disrupt the medical care of handicapped infants. 2/ On April 22, 1983, the Federal appeals court denied the Administration's request that the rule remain in effect pending appeal.

In an effort to address the objections of the Distict Court judge, the Administration published a second proposed rule on July 5, 1983. This rule was very similar to the March 7 interim final rule except that a 60-day comment period was provided.

This paper discusses the final rule regarding handicapped infants published in the Federal register by HHS on January 12, 1984. Legislative action in response to the Infant Doe issue is also discussed.

2/ Statement of Judge Gesell reported in the Washington Post, Apr. 15, 1983, p. A5. "Court Strikes Down U.S. 'Baby Doe' Rule."

THE FINAL REGULATION REGARDING HEALTH CARE FOR HANDICAPPED INFANTS

On January 12, 1984, the Department of Health and Human Services published the final rule on procedures and guidelines relating to nondiscrimination on the basis of handicap in connection with health care for handicapped infants. 3/ The effective date of this rule is February 13, 1984. The final rule contains four main provisions:

1. Hospitals are encouraged to establish infant care review committees.

2. Informational notices regarding the legal rights of handicapped infants are to be posted.

3. Child protective service agencies are required to establish procedures for applying their own State laws protecting children from medical neglect.

4. Hospitals are to provide expedited access to records and expedited action to affect compliance when HHS officials determine that immediate access is necessary to protect the life or health of a handicapped infant.

The final rule also includes guidelines related to health care for handicapped infants. 4/

3/ 45 CFR Part 84.55.

4/ For additional information, see "Nondiscrimination in Health Care of Handicapped Infants: An Anlysis and Comparison of Final Regulations and House and Senate Legislation. CRS white paper by Nancy Lee Jones. Jan. 24, 1984.

Infant Care Review Committees

The final rule encourages health care providers who are recipients of Federal funds and who provide services to infants to establish an infant care review committee. The purpose of the review committee is to assist the hospital in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning treatment in specific cases. Although such review committees are encouraged, they are not required. The guidelines state that the review committees should be composed of at least seven individuals representing a broad range of perspectives and should include a physician, a representative of a disability organization, a nurse, a hospital administrator, an attorney, and a lay community member. The review committee is to develop policies concerning the withholding or withdrawing of medical treatment for infants with life-threatening conditions. The policies and procedures are to help assure that, while respecting reasonable medical judgments, treatment and nourishment not be withheld solely on the basis of present or anticipated physical or mental impairments if the infant would benefit medically from such nourishment or treatment. Futile treatment, or treatment that would do no more than temporarily prolong the act of dying of a terminally ill infant, is not to be considered treatment that would medically benefit the infant. Whenever parents withhold consent for medically beneficial treatment, hospitals may not, solely on the basis of the infant's present or anticipated impairment, fail to report such incidents to the child protective services agency or to seek judicial review.

Informational Notice

The regulations require hospitals receiving Federal financial assistance to post an informational notice on principles of treatment of handicapped infants.

The notice is to be posted where nurses and other medical professionals providing health care to infants can see it. Hospitals may choose between two notices: one notice would state hospital policy regarding the prohibition on withholding medically beneficial treatment or nourishment; the other notice would emphasize the prohibitions of Federal law. Both notices include an HHS hotline number for reporting suspected violations.

State Child Protective Services Agencies

The regulations require State child protective service agencies receiving Federal funds to establish methods of administration and procedures to prevent medical neglect of handicapped infants. These methods and procedures would include a requirement that health care providers report, in a timely fashion, known or suspected cases of unlawful medical neglect of handicapped infants to the State agency. State child protective agencies would provide for an immediate review of such reports and on-site investigations where appropriate. Procedures would be developed to provide for child protective services to medically neglected infants including, where appropriate, for the initiation of a court order to require medical treatment and nourishment. Child protective agencies would notify the Department of Health and Human Services of each report of suspected unlawful medical neglect and the agency's final disposition of such report. The Department encourages the State child protective agencies to consult with the hospital review committees regarding cases of suspected neglect being reviewed by the committees.

Expedited Access to Records and Expedited Action to Affect Compliance

Current regulations regarding access to hospital records and facilities limit access to normal business hours. The final rule regarding health care for handicapped infants provides an exception to this requirement when the responsible HHS official determines that immediate access is necessary to protect the life or health of a handicapped individual. When immediate action is necessary to protect the health of such person, the recipient of Federal financial assistance (the hospital) need not be given prior notice that an investigation or legal proceeding is being initiated. Oral or written notice of failure to comply with the regulation is to be given as soon as practicable.

LEGISLATIVE ACTION

Both the House and the Senate are considering bills which include provisions regarding handicapped infants. These provisions are included in H.R. 1904 and S. 1003, bills which would reauthorize the Child Abuse Prevention and Treatment and Adoption Reform Act, P.L. 93-247, as amended. H.R. 1904 passed the House, amended, on February 2, 1984. S. 1003 was reported from the Senate Labor and Human Resources Committee on May 16, 1983.

The House bill would require that the Secretary of HHS publish "procedural guidelines to encourage and assist local health care providers desiring to establish local health care mechanisms" to review the care given to impaired newborns. The guidelines would "address procedures to be implemented in instances in which such infants may be denied nutrition, . . . medically indicated treatment, and general care." The House bill would the require the Secretary to provide training and technical assistance to the States to help them develop and improve their procedures for dealing with impaired newborns, based on the guidelines. Within 1 year of the promulgation of the guidelines, States would have to follow the required procedures in order to receive State grant funds under the Child Abuse Prevention and Treatment Act. In addition, in order to receive State grant funds, States would have to include in their child abuse reporting laws procedures for reporting known or suspected withholding of nutrition and care from impaired newborns.

The House bill would also require the Secretary to instruct the HHS regional offices to: 1) develop a directory of physicians with expertise in the care of impaired newborns; 2) provide a toll-free number through which hospitals,

physicians and child protective service agencies would use the directory; and 3) develop a directory of community resources to help parents of impaired newborns. Finally, the H.R. 1904 would require the Secretary to study the most effective means of providing Federal financial support, other than through the use of funds under the Social Security Act, for the treatment of impaired infants.

The Senate bill would establish a committee to carry out the study of existing procedures and issues involved in treating impaired infants; the proposed committee would be appointed by the Secretary and would include representatives of HHS, the medical and legal professions, and organizations for the handicapped. This committee would report on its recommendations to the Secretary within 6 months and the Secretary would submit the report to Congress. Based on this report, the Secretary, within another 4 months, would publish regulations setting up "local decision-making procedures" in all health care facilities to deal with situations involving impaired newborns. These procedures would be required to ensure, at a minimum, that "all seriously ill newborns be provided relief from suffering, including feeding and medication for pain and sedation, as appropriate." Hospitals that did not comply with these regulations could lose all Federal financial assistance including Medicaid and Medicare funds until the hospital complied with such regulations.

APPENDIX: PUBLIC REACTION TO INFANT DOE ISSUE AND GOVERNMENT INVOLVEMENT

STATEMENTS WHICH MAY SUPPORT GOVERNMENT INVOLVEMENT IN DECISIONS REGARDING TREATMENT OF HANDICAPPED NEWBORNS

[As regards the case of an 800 gram premature baby,] we're not interjecting the government into the medical decision-making process . . . . We're not talking about prolonging a life that inevitably is going to die. What we're talking about here is discriminating against children who, if it weren't for the fact that they were handicapped, would be given appropriate medical treatment. The government is not going to say what is appropriate medical treatment and what isn't, when reasonable physicians will disagree about the appropriate method of therapy. That's correctly not the realm of government; that's the realm of medicine . . . . [Statement of Dr. Robert Rubin, Assistant Secretary for Planning and Evaluation, HHS. Regarding HHS notice to health care providers.]

--The MacNeil-Lehrer Report: Saving Newborns, May 18, 1982, Transcript #1732

Practices such as withholding of treatment and sustenance in the Baby Doe case are 'blatant discrimination and a violation of basic rights,' according to the national executive director of the Association of Retarded Citizens. At its meeting on April 30, 1982, the National Board of Directors of the Association for Retarded Citizens passed a resolution reaffirming its 1973 position condemning such practices.

--ARC's Government Report, May 1982

Fatal discrimination against Down's syndrome and other handicapped infants has been increasing for years in this country. This discrimination consists of denial of medical treatment, even food and water, which would be routinely provided to non-handicapped infants. The ethic which promotes infanticide is related to the elitist 'quality of life' argument used to justify abortion-on-demand. Infanticide is a form of barbarism which our nation should emphatically reject.

--Statement of J.C. Willke, M.D., President, National Right To Life Committee, Inc. Press Release, May 26, 1982

. . . By sanctioning a million-and-a-half abortions annually, the United Sates has made it official policy, with rationale to match, that there is such a thing as a life that is not worth living. Some human beings, we are told, are simply better off dead than alive . . . we have crossed some kind of hellish threshold, into a land where 'quality of life' becomes a license for inflicting death.

--How Quality of Life Killed Infant Doe, by M. Stanton Evans, Human Events, May 1, 1982.

. . . Such homicides [as the death of Infant Doe] can no longer be considered aberrations or culturally incongruous. They are part of social programs to serve the convenience of adults by authorizing adults to destroy inconvenient young life. The parents' legal arguments, conducted in private, reportedly emphasized - what else - 'freedom of choice.' The freedom to choose to kill inconvenient life is being extended, precisely as predicted, beyond fetal life to categories of inconvenient infants, such as Down's syndrome babies.

--The Killing Will Not Stop, by George Will, Washington Post April 22, 1982

. . . At his parents' request [Infant Doe] wasn't fed. The decision, the family lawyer said, was a 'private matter.' Why private? Had that baby been normal, his death by starvation would have been a public concern. But because he had been inadvertently robbed of perfection, he was deliberately robbed of life. His flaws somehow cancelled out his rights. . . . Whether to carry a fetus to maturity is still, and should remain, a woman's choice. But once born, a child is no longer part of another human being; he is a part of society and entitled to its protection. Their undoubted anguish explains the decision made by Infant Doe's parents, but not the courts' refusal to intervene. The death of Infant Doe is not a 'private matter.'

--"Private" Death, New York Times, April 27, 1982.

. . . Ten couples sought to adopt the infant [Infant Doe]. Shirley and Bob Wright of Evansville filed a petition for legal guardianship. 'We feel that we have lost this particular battle, but we are not going to stop fighting for the rights of handicapped children,' said Mrs. Wright, who has a 3-year-old daughter with Down's syndrome.

--Charges Weighed for Parents Who Let Baby Die Untreated, New York Times, April 17, 1982

In 1973 [a study was conducted regarding] the case histories of 299 babies who died in the intensive-care unit of the Yale-New Haven Hospital to see what treatment they had been given. In 43 of the cases 'some treatments were withheld or stopped with the knowledge that earlier death and relief from suffering would result. In other words, it was decided that these 43 babies should die. They did: because the treatment they were given - or the lack of it - ensured that that was the inevitable outcome. These were babies that might have lived but were not allowed to.

--Richard Lindley with quote from 1973 study, How Far Do Doctors Feel Able To Go In These Sad Cases. The Listener, November 12, 1981

Notification is not enough to make sure that these babies' lives are saved. There is going to have to be thorough surveillance for compliance with these laws and vigorous prosecution if they are violated.

--Statement attributed to Gary Curran, Consultant to the American Life Lobby, in, Hospitals Warned on Handicapped Babies, Washington Post, May 19, 1982

STATEMENTS WHICH APPEAR TO BE CRITICAL OF GOVERNMENT INVOLVEMENT IN DECISIONS REGARDING TREATMENT OF HANDICAPPED NEWBORNS

. . . The Academy [American Academy of Pediatrics] is deeply concerned that the effort of the executive branch to solve this complex problem through strict interpretation and enforcement of the letter of section 504 may have the unintended effect of requiring treatment that is not in the best interest of handicapped children. Handicapped persons are often born with conditions that are incompatable with long life. Handicapped persons acquire illnesses that are refractory to medical care. These dying and critically ill patients need health care providers who will carefully examine the appropriateness of specific medical intervention . . . . It will frequently be the case that the use of a specific technology or procedures will not be the best interest of the handicapped person. Withholding a medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients. . . . These highly complex situations involving health care providers, hospitals, patients and families, are not easily addressed by federal regulations. The Academy feels that attempts to force the commendable philosophy and intent of section 504 into specific substantive directives affecting health care providers and hospitals is an inappropriate response to the problem . . . . One recommendation which may result [from a review and analysis of policies governing decision-making in cases involving handicapped newborns] may be that such problems are best approached by a formal review process for any decisions involving withholding or withdrawing of life-sustaining treatment for handicapped children.

--From statement of the official position of the American Academy of Pediatrics, June 21, 1982

. . . The American Hospital Association (AHA) takes strong exception to HHS' drawing an implication that hospitals have in any way been guilty of discrimination. . . . The AHA is further concerned with, and will investigate thoroughly, HHS' apparent intent, as expressed in the letter, to create an adversarial relationship between hospitals and parents who elect not to have complicated surgery performed on their children. HHS would apparently mandate that hospitals not allow 'the infant to remain in the institution' under such circumstances. AHA considers this an abdication of responsibility on the part of HHS and will make every effort to assure that such simplistic solutions to complex situations involving health care delivery are avoided.

--Statement from The American Hospital Association, released May 18, 1982, Washington, D.C.

. . . The costs [of saving the lives of high-risk infants] are enormous; in some cases the hospital bills are more than $100,000. Not all high-risk babies survive even with every possible treatment . . . and some survivors have permanent handicaps, including less than normal intelligence . . . .

--Infanticide: A Growing Issue, Chicago Tribune, May 24, 1982

At one time or another during Andrew's six months of life he had diseases of the bones, of the brain, of the blood, of the eyes, the urinary tract, the liver and the lungs . . . . I'm very uneasy about the heaviness of the federal government involving itself in decisions on cases which are not only complex in all of their medical and philosophical and legal ramifications, but upon which neonatologists, those who take care of the newborn, disagree themselves. I'm worried about rules for cases on which there is no agreement . . . . When we argued with the doctors for six months that they not pursue Andrew's life, we did it out of love . . . . [Statement of Mr. Stinson, father of 800 gram premature infant.]

--The MacNeil-Lehrer Report: Saving Newborns, May 18, 1982, Transcript #1732

. . . It's easy to understand what it means to starve to death. It's normal to rage at a health system and a judicial system that, in effect, agree to kill. But it's hard to imagine what we cannot see - the baby, its possible agony, the quality of life that lay ahead of it. It's death might have been awful, but it's life might have been worse. No slogan like right-to-life would remedy that . . . .

--It Depends, by Richard Cohen, Washington Post, April 20, 1982

. . . This highly technological society has come up against the same moral dilemma faced every day by the most primitive societies: Who shall live and who shall die and who shall decide? . . . The costs that spiral with our technological aids can overwhelm our society as much as any primitive one. For all the pains involved, the moral and ethical questions we face are necessary and legitimate ones. We, too, make choices about how we allocate our unlimited resources - medical, emotional, financial - among those who need them. How much should be, can be done to maintain human beings who cannot think or respond, but only breathe? How much of a family's energy and life can be, should be drained by those who barely exist?

--Who Lives, Who Dies: Who Chooses? by Ellen Goodman, Washington Post, August 22, 1982

. . . We tend to regard anything less than whole-hearted commitment of parents to every new child as a clear sign of a psychological disorder. But we forget that the social goal of rescuing all human offspring is a relatively recent idea. And this notion, which represents a kind of extremism that might be called Reverse Social Darwinism, has not been ratified by any formal action. On the contrary . . . no extensive and continuing communication has taken place between physicians and the rest of society on this issue. Society has not sanctioned the assumption of authority by those who do not live day-to-day with the long-term consequences of decisions made in neonatal matters . . . . The rescue fantasy of many physicians is not necessarily shared by most people in contemporary society. . . .

--Mismatched Attitudes About Neonatal Death, by William A. Silverman, The Hastings Report, December 1981

. . . The care of a child with a severe birth defect can be emotionally difficult. Studies show that in at least half of the families involved, the parents' marriage breaks up, usually leaving the mother to struggle alone with a child who will need extraordinary care all of its life. Social supports such as special education are increasing, but the responsibility is still the parents' and this makes it difficult to deny them the major voice in determining a baby's early treatment . . . .

--Infanticide: A Growing Issue, Chicago Tribune, May 24, 1982