

Latest Supreme Court ruling condemns handicapped newborns

by Linda C. Everett

The Supreme Court's June 9 decision to strike down the Reagan administration's controversial Baby Doe Rulings opens the floodgates for Sparta-like slaughter of the nation's handicapped newborns.

In the opinion of four judges, an infant born with a handicap cannot be considered a "qualified" handicapped individual who has his right to life-saving medical treatment protected by the federal government, if his parents refuse to consent to medical treatment. The 5-3 decision argues that since it is usually the parents who instruct doctors not to treat their child but to "let him die," then there is no "evidence" of discrimination by doctors or hospitals against the handicapped child, and thus no "reasoning" that warrants federal intervention into the state's traditional role of protecting handicapped infants' lives. After reducing the role of the nation's highest court in protecting and guiding its people, to a mechanical exercise, this court goes on to eliminate that responsibility altogether.

The decision states that the Rehabilitation Act of 1973 did not authorize the government "to give unsolicited advice to parents, to hospitals, or to states who are faced with difficult treatment decisions concerning handicapped children." Justice John Paul Stevens announced the decision which was joined by Justices Thurgood Marshall, Harry Blackmun, and Lewis Powell. Chief Justice Warren E. Burger concurred with Stevens's conclusion, but undercut the majority opinion by not joining in its reasoning and in an unusual move, provided no concurring opinion to explain why. Justice White entered a dissenting opinion with Justice Brennan joining. Justice O'Connor wrote a separate dissenting opinion, agreeing with four of the five points discussed by Justice White.

Four years of legal battles

The hotly contested issue of government intervention into the fate of handicapped newborns began in April 1982, when an Indiana baby, born with mild Down's Syndrome, was starved to death when its parents refused to allow life-saving surgery to remove an esophageal obstruction that blocked oral feeding. Within weeks of the murder, President Reagan directed the Secretary of Health and Human Services (HHS)

to instruct all federally funded facilities that Section 504 of the Rehabilitation Act of 1973 provides: "that no otherwise qualified individual . . . shall solely by reason of his 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."

HHS established procedures to assure enforcement of Section 504 by posting notices in health-care facilities, requiring state child-protection agencies to prevent unlawful medical neglect of the handicapped, expedited access to medical records, and expedited action compliance to protect the infant's life, with a temporary restraining order if necessary. These Interim Rules, which require the availability of a telephone "hot line" to report suspected violations, were overturned in April 1983 by the U.S. District Court of Washington, D.C. which called the regulations "arbitrary and capricious."

By February 1984, the "Baby Doe" regulations were re-tailored into "interpretive guidelines" calling for no "heroics" to prolong the "dying process" and for setting up Infant Care Review Committees to decide who gets treatment. In March, these, too, were challenged by the American Medical Association, the American Hospital Association, American Academy of Pediatrics, etc. in the District Court for the Southern District of New York, which held that the regulations were beyond HHS's statutory authority under Section 504 and enjoined the HHS Secretary and its officers and agents in a sweeping nationwide injunction against undertaking any decision, investigation, or regulation regarding the treatment of handicapped newborns in any federally funded program.

The U.S. Court of Appeals affirmed that judgment in December 1984, based on its own prior decision that the government had no right to the medical records of a New York infant with spina bifida ("Baby Jane Doe"), because Section 504 is "wholly inapplicable to the withholding or withdrawal of nutrition or medically beneficial treatment from handicapped infants—no matter how egregious the circumstances."

HHS then petitioned for the Supreme Court to review the district court decision, citing directly the dissenting statement

of Judge Winter. Judge Winter stressed that Congress explicitly patterned Section 504 after Title VI of the Civil Rights Act of 1964, which prohibits discrimination on the basis of race in federally assisted programs, and had determined that "discrimination on the basis of handicap should be on a statutory par with discrimination on the basis of race." Winter concluded that the logic of the government's position is "about as flawless as a legal argument can be." The Supreme Court agreed to review the case, and heard oral argument in January 1986.

The Supreme Court's conclusion is based on a review of the two possible categories of violations of Section 504 which HHS offered: 1) when a hospital refuses to treat a handicapped newborn "solely by reason of his handicap" or 2) when a hospital fails to report cases of medical neglect to a state child-protective agency. According to HHS, the 49 cases investigated "resulted in finding no discriminatory withholding of medical care" because it was the parents, not the hospitals, who refused to allow treatment. HHS also conceded that its Final Rules show that Section 504 cannot mandate that a hospital overrule a parental decision not to treat, no matter how discriminatory. Thus, Justice Stevens concludes there is neither evidence of violation of Section 504, nor need for federal intervention.

The overly narrow and mechanical application of the 504 law by Justice Stevens totally misses the attempt by HHS to address the slaughter of thousands in the nation's nurseries. The Senate Committee on Labor and Human Resources conducted hearings on the incidence and denial of medical treatment to the handicapped newborns and concluded, "This practice is not isolated to one or two instances." Of the estimated 30,000 severely handicapped children born yearly in the United States, non-treatment results in the death of 5,000 of them. In 1985 the U.S. Commission on Civil Rights concluded: "While occasional denial of routine medical care has been reported, a much more serious problem involves the apparent withholding of life-saving treatment for . . . infants, solely because they are handicapped."

Properly, the dissenting opinion of Justice White et al. attacks the sleight-of-hand justice that Stevens displays in the decision. It suggests that regulation of health-care providers is justified since doctors' attitudes play a large role in shaping a parent's decision to treat or not. Increasingly, hospitals and doctors are pressed to buckle under to treatment restrictions devised by cost-benefit analysis, insurance coverage, and, even more insidious, as the following case demonstrates, by the "new medicine" shaped by the "new ethicists," who are not out to save your life. This new breed, which includes the hospital "ethics" committees, decides that only those whose quality of life would benefit from treatment, will get it.

The American Academy of Pediatrics, which brought suit to stop HHS's Baby Doe intervention, published in its October 1983 *Pediatrics* magazine the results of a five-year experiment by a group of Oklahoma doctors, who unbeknownst to the parents decided which of 69 babies born with

spina bifida would receive life-saving treatment based on the doctors' quality-of-life assessments of the child and family. The doctors recommended against life-saving treatment for 33 of the infants; 24 died.

Justice Stevens faults HHS for imposing an "absolute obligation" on state agencies, and quotes an earlier decision that Section 504 is concerned only with discrimination in the relative treatment of the handicapped and not with the absolute right to receive a particular treatment. He states that nothing in the statute authorizes the Secretary of HHS "to dispense with the law's focus on discrimination and instead to employ federal resources to save the lives of handicapped newborns without regard to whether they are victims of discrimination by recipients of federal funds or not."

The focus of Section 504 was to save lives, as one of the principal sponsors of Section 504, Sen. Hubert Humphrey, originally cited in congressional testimony in 1972: "I am insisting that the civil rights of 40 million Americans now be affirmed and effectively guaranteed by Congress . . . the 22 million people with a severe physically disabling condition . . . the hundreds of thousands crippled by accidents and the destructive forces of poverty, and the 100,000 babies born with defects each year. These people have the right to live, to work to the best of their ability—to know the dignity to which every human being is entitled. . . . Every child—gifted, normal, and handicapped—has a fundamental right to educational opportunity and the right to health."

Majority ruling 'indefensible' and 'misguided'

Justice White slams the majority opinion in his dissent for oversimplifying the complexity of the crisis which Section 504 and HHS address. The majority, he says, never denies that discrimination occurs, yet it resolves the issue for the nation at large, not by fully determining what situations Section 504 might cover, but by focusing on whether the cases which HHS presented qualify in the two narrow types of discrimination defined by HHS. White says the majority decision is "sidetracked from the straightforward issue of statutory construction that the case presents." White sees no justification for the majority's acceptance of the lower court conclusion that the HHS Secretary was "without power to issue any regulations whatsoever that dealt with infants' medical care."

The Supreme Court had only one real issue before it, the one which the principal sponsor of Section 504, Congressman Vanik, presented in his testimony in 1973: "In ancient Greece, in the city-state of Sparta, the people would take the handicapped newborn, and leave them to die of exposure on the mountainside. Are we guilty of the same type of gross neglect in this country?"

The Supreme Court gave its answer, along with those medical institutions like the American Medical Association which fought for and received, from the nation's highest court, the right to choose which infants get treatment and which starve.