

# The Baby Doe Rules (1984)

The Baby Doe Rules represent the first attempt by the US government to directly intervene in treatment options for neonates born with severe congenital defects. The name of the rule comes from the controversial 1982 case of a Bloomington, Indiana, infant Baby Doe, a name coined by the media. The Baby Doe Rules mandate that, as a requirement for federal funding, hospitals and physicians must provide maximal care to any impaired infant, unless select exceptions are met. If a physician or parent chooses to withhold full treatment when the exceptions are not met, they are liable for medical neglect. After a prolonged legal battle, President Ronald Reagan signed the law on 9 October 1984 as an amendment to the Child Abuse Prevention and Treatment Act (CAPTA) of 1974. Since then, the Baby Doe Rules have influenced both the parents' right to make medical decisions for their child and the way laws can affect treatment options in the US.

Treatment for impaired infants garnered national attention in April 1982 when Baby Doe was born with Down syndrome and an abnormal connection of the trachea and esophagus. The baby required immediate surgery to correct the defect. However, the parents, with the advice of their physician, chose to withhold surgery and medical care because the child would still be cognitively impaired. Officials at the hospital had the Indiana Juvenile Courts appoint a guardian to determine whether or not to perform the surgery. The court finally ruled in favor of the parents and upheld their right to an informed medical decision. The infant, by then known nationally as Baby Doe, died five days later of dehydration and pneumonia. The Indiana Supreme Court refused to hear the case. Baby Doe died shortly after the refusal, which prevented an appeal to the US Supreme Court.

Response to the Baby Doe case was particularly vocal from pro-life and disability rights groups, which decried the death as infanticide. Reagan, who was himself concerned by the case, ordered US Surgeon General C. Everett Koop and Secretary of the US Department Health and Human Services (HHS), Richard Schweiker, to notify all public health care institutions that they could lose federal funding if they did not provide treatment to handicapped infants under Section 504 of the Rehabilitation Act of 1973, the first civil rights statute for handicapped.

With the Reagan administration's interpretation, Section 504 extended to infants with congenital defects. On 3 March 1983, the HHS issued the first set of Baby Doe Rules. All hospitals affected were required to post signs throughout their wards that detailed Section 504. Furthermore, they had to provide a 24-hour telephone hotline for people to anonymously report discrimination. Teams of HHS officials and state child protective services agents, termed Baby Doe Squads, were in charge to inspect all discrimination reports and had unlimited access to patients' medical records.

The HHS rule was an unprecedented intrusion into the traditional physician's domain. Adamant opposition from medical groups led the American Academy of Pediatrics to sue the HHS, seeking to block the rule from going into effect. In *American Academy of Pediatrics v. Heckler* (1983), Judge Gerhard Gesell ruled the rule invalid on procedural grounds, because it had not allowed the mandatory sixty day public comment period. Also, Gesell denounced the rule as taking advantage of fear for prosecution, with little definition of appropriate medical standards. Reagan and the HHS chose not to appeal the decision. Instead, they submitted an almost identical proposal in July 1983, this time allowing for the required comment period. The only important change was to solidify the medical criteria by defining Section 504 as applicable to neonates that would benefit from treatment, as opposed to those who had fatally inoperable conditions.

The new rules faced their first judicial test on 11 October 1983 when Baby Jane Doe was born at University Hospital at Stony Brook in Long Island, New York. The infant suffered from an incomplete development of the spinal cord, an abnormally small head, a buildup of fluid in the cranium,

and kidney damage. Although the attending physicians disagreed on treatment, they informed the parents that the child would be cognitively impaired, possibly paralyzed, and suffer from kidney and bladder infections. The parents opted against corrective surgery, and decided to provide the infant with palliative care consisting of antibiotics and dressing of the exposed spinal sac.

However, Lawrence Washburn, a pro-life attorney, tried to have the parent's decision overruled by the New York Supreme Court's trial division. Washburn's maneuvers quickly found the national spotlight, and the case became embroiled in controversy. The court ruled in Washburn's favor, but the appellate division reversed the ruling one day later. The case then went to the New York Court of Appeals, the highest state court, which upheld the appellate ruling in *Weber v. Stony Brook Hospital* (1983). In their decision, the justices ruled that it would be wrong to allow Washburn, who had never met the child or her parents, to override parental responsibility.

Yet, even as the appeals court made its decision, the US Justice Department ordered the University Hospital at Stony Brook to turn over the baby's medical records to HHS investigators. When the hospital refused, the Justice Department sued. On 17 November 1983, the US District Court ruled against the Justice Department, determining that the parent's decision was reasonable and concerned with the child's best interest. In February 1984, The Second Circuit Court of Appeals upheld the ruling in *United States v. University Hospital* (1984). In a 2-1 decision, the court determined that Congress had never intended Section 504 to apply to the medical care of disabled newborns. The decision, though only addressing the case of one newborn, was nevertheless a major setback both for the Reagan administration and for the viability of the Baby Doe rules as a whole. The ruling marked the end of Washburn's attempts to intervene in Baby Jane Doe's case. The New York attorney finally withdrew his appeal request in April. Baby Jane Doe had been discharged from University Hospital several weeks prior.

The administration and the HHS, however, remained undeterred. While Baby Jane Doe's fate was being decided, the government issued its final Baby Doe regulations in January of 1984. Government revisions had done away with the Baby Doe Squads, labeled as intrusive in several court cases. In their place HHS administration nominated local, voluntary Infant Care Review Committees (ICRCs), which were more easily integrated into hospital ethics boards. Despite the change, the regulations still strongly favored maximum treatment. In cases where parents refused to consent to treatment, the ICRCs were to advise the hospital to alert the courts or a child protective agency. The HHS made it clear that these committees were local extensions of their own investigatory teams.

However, in March of 1984, the American Hospital Association (AHA) and the American Medical Association (AMA) sued the HHS to invalidate the rules. In successive rulings, both the US District Court and the 2nd Circuit Court of Appeals declared the regulations unlawful. The case, *Bowen v. American Hospital Association (AHA), et al.* (1986), reached the US Supreme Court in early 1986. In June, the Court ruled in favor of the AHA in a 5-3 decision. The court not only concluded that the Reagan administration's interpretation of Section 504 was wrong, but also that the Baby Doe rules interfered with the best interests of the child standard. Furthermore, the court determined that the rules were naïve to medical decision-making representing an unjustifiable intervention into medical standards.

Although its legal avenue for instituting the Baby Doe rules under Section 504 was closed by the Supreme Court's decision, the Reagan administration did not concede defeat. Instead, it shifted its focus to Congress. By 1982, lawmakers had entered the national debate raging over selective non-treatment. By 1984, legislative interest had materialized with a bill to amend the Child Abuse Prevention and Treatment Act. On 2 February 1984, the House passed a version of the bill that would make withholding life-saving treatment and nutrition from any impaired infant punishable as child abuse.

Liberal groups, for the most part strongly opposed the bill, while conservatives championed it. Major medical organizations also utilized their resources to lean heavily on lawmakers, as did pro-life and disability groups. The Senate argued the bill for five months. Only after a thorough reformulation of the language, enough votes emerged to approve it. The revised bill, the Child Abuse Amendments of 1984 (P.L. 98-457), was approved by both houses in October of 1984, and went into effect at the start of the following year. Overall, however, there were very few changes from the

initial Baby Doe Rules under Section 504.

To regulate hospital and physician compliance with the law, a toll-free, anonymous hotline was initially created which would then alert federal investigators to specific cases. However, the courts deemed this system intrusive, and the CAPTA amendments have instead transferred responsibility to hospital ethics boards and state child protective services agencies. Currently, if a case involves parents or their doctors choosing to withhold treatment, the review boards are obligated to report the case to child services as an instance of medical neglect. Under the rules, withholding treatment is only permissible if the newborn is irreversibly comatose, if treatment would only prolong its death, or if treatment would be inhumane. Furthermore, the law also holds that a physician's decision for neonatal care cannot be based on quality of life, or other abstract concepts.

The enforcement of the Baby Doe Rules still hinges on the threat of removing federal funding from public hospitals, thus forcibly encouraging states to adopt the policy. In fact, despite the controversial nature of the Baby Doe rules, compliance has been high among hospitals, pediatricians, and neonatologists. Even medical bodies such as the AMA that dissented from the original law have issued guidelines for equal treatment along very similar lines. The law has also shifted some of the traditional powers of parents to make medical decisions to legally bound obligations for care. Parents wishing to withhold treatment must now show that their child falls into one of the three exceptions, or they can be reported to state social services.

## Sources

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