

United States v. University Hospital (1984)

The US Second Circuit Court of Appeals' 1984 decision *United States v. University Hospital*, State University Hospital of New York at Stony Brook set a significant precedent for affirming parental privilege to make medical decisions for handicapped newborns, while limiting the ability of the federal government to intervene. The ruling stemmed from the 1983 case involving an infant born with severe physical and mental congenital defects; the infant was only identified as Baby Jane Doe. After her parents opted against corrective surgery for some of her deformities, Baby Jane Doe became the epicenter of a national right-to-life debate that had been previously sparked one year prior with the case of Baby Doe, an Indiana infant born with similarly severe handicaps.

Representing the US, the Department of Health and Human Services' (HHS) case relied heavily on the Baby Doe Rules under Section 504 of the Rehabilitation Act of 1973. Under these rules, the actions taken by both Baby Jane's parents, as well as the State University Hospital at Stony Brook by supporting the parents' decision potentially constituted medical discrimination against the handicapped.

The controversy centered on whether parents had the right to make medical choices for children born with serious congenital malformations, when those choices either allowed the child to die or did not provide the best curative options available. In the 1982 Baby Doe case, the parents, with the advice of physicians, withheld nutritional care and surgery to repair the infant's malformed esophagus (trachoesophageal fistula). Due to that decision, the baby died six days later of dehydration and pneumonia. Outrage from right-to-life groups encouraged President Ronald Reagan and his close adviser, Surgeon General C. Everett Koop—both well-know pro-life supporters—to prevent similar cases from happening again. Koop, with the assistance of the HHS, issued the Baby Doe rules as a notification to all hospitals receiving federal funds. Utilizing Section 504, the HHS announced that refusing to treat severely impaired infants on the basis of their handicaps was discrimination, and any hospital found in violation could lose their federal funding. Furthermore, the rules also mandated that signs displaying Section 504 and a 24-hour federal hotline to report instances of discrimination must be posted in every ward. When cases were reported, teams of state Child Protective Services (CPS) and HHS agents were dispatched to investigate.

Three months after the HHS issued the new rules, Baby Jane Doe was born on 11 October 1983 at St. Charles Hospital in Port Jefferson, New York. The infant suffered from an incomplete development of the spinal cord (spina bifida), an abnormally small skull (microcephaly), a buildup of cerebrospinal fluid in the brain (hydrocephalus), and a malformed brain stem. The infant was immediately transferred to State University Hospital at Stony Brook so that surgery could be performed to improve her spinal condition and drain the excess fluid from her brain.

Physicians informed the parents that without surgery, the baby could survive a few weeks to two years, and performing surgery could possibly increase her life expectancy. However, regardless if the surgery was performed or not, she would be mentally handicapped, epileptic, paralyzed to some degree, and routinely suffer from kidney and bladder infections. It was highly likely that Baby Jane would never be able to interact with her environment or the people in it. Her parents, after a litany of consultations with surgeons, physicians, clergymen, and a social worker, finally decided to treat her with antibiotics and nutrition instead of surgery. Although this treatment had a significantly higher mortality rate, it still offered a chance for success and avoided some of the risks posed by surgery. The parents' decision initiated a national right-to-life debate.

One month after the parents refused surgery, Surgeon General Koop authorized the Justice Department to sue University Hospital for Baby Jane's medical records after repeated refusals by the

hospital to hand them over. Before University Hospital's refusal, there had been forty-nine other investigations of infant discrimination, and in each one the hospital had immediately opened its records. When the Justice Department sued, it was the first time that the federal government had gone to court to obtain private medical records. The parents' requested, and received, the right to be represented in the suit.

The Justice Department, however, wasn't the only one pressing litigation against Baby Jane. During the month prior, an unrelated attorney, Lawrence Washburn, had sued Baby Jane's parents, through several of the New York State courts culminating in *Weber v. Stony Brook*, to have the surgery performed. The swirl of litigation around the infant created considerable confusion, so much so that even the federal government's decision to become involved was partly based on incorrect information.

Nevertheless, the Justice Department continued with its action, claiming that HHS required the medical records to assess whether Baby Jane Doe was being discriminated against. Furthermore, the Justice Department claimed that because University Hospital was a recipient of federal Medicaid funding, it was violating Section 504 by refusing to turn over the medical records. The hospital and the parents argued that Congress had never intended Section 504 to apply to handicapped infants and that Section 504 only required hospitals to provide equal access to the handicapped, something University Hospital had done. They also added that Medicaid payments were not a valid form of federal funding under Section 504, and that Baby Jane Doe's records were protected by doctor-patient privilege.

The US District Court decision delivered by Leonard D. Wexler determined that the HHS had no claim to Baby Jane's records. Although Wexler precluded the hospital's arguments that Medicaid was not a form of federal assistance and that the records were protected by doctor patient privilege, he ultimately found that no discrimination had taken place. Instead, University Hospital had displayed continued willingness to perform surgery on the infant; however, in the absence of consent, it had no legal right to do so. Furthermore, because the parents' decision against surgery was based on valid medical rationale and the baby's best interest, the hospital was absolved from liability.

The Justice Department appealed Wexler's ruling in the Second Circuit courts. In challenging the previous decision, the government argued that the parents' decision against surgery did not prove that the hospital had treated Baby Jane Doe fairly. Under Section 504, the hospital's failure to seek a state order to invalidate the parents' decision against surgery could also constitute discrimination. Only by having access to the medical records, the government contended, would it be able to establish whether or not discrimination occurred. University Hospital and the parents, meanwhile, adhered to Wexler's ruling and their previous arguments, specifically that Congress did not intend for Section 504 to allow government intervention into treatment decisions.

The Second Circuit Court of Appeal's decision *US v. University Hospital* upheld the lower court's decision by a 2-1 ruling. Delivering the majority opinion, Justice George C. Pratt established that there was a stark lack of evidence in the Congressional Record to suggest that Section 504 was ever intended to apply to treatment options for handicapped newborns. Additionally, Pratt emphasized that the federal government's position was too much of a stretch given that the essential purpose of Section 504 was to ensure that qualified, handicapped individuals had access to federally-funded programs such as education, housing, transportation, and education. The opinion also found the government's notion that it is possible to establish discrimination against a baby with birth defects to be flawed. Within the complexities of every medical decision, it would be impossible to establish that treatment was made solely on the basis of the infant's handicap. Finally, Pratt cited *American Academy of Pediatrics v. Heckler*:

"[G]iven the present absence of a clear congressional directive...[a]ny intervention by an agency of the Federal Government should obviously reflect caution and sensitivity".

Using this precedent, Pratt concluded that allowing HHS to conduct its requested investigation would be a gross judicial oversight.

Sources

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