Government Intercedes in "Baby Jane Doe"

In the first case in which the federal government has gone to court to protect the rights of a defective baby, the Department of Justice has sued the State University Hospital in Stony Brook, New York, to obtain the medical records of "Baby Jane Doe." The intervention is based on section 504 of the Rehabilitation Act, which forbids discrimination against the handicapped.

Baby Jane Doe was born on 11 October in nearby Port Jefferson, with spina bifida, a small head, and water on the brain. The same day she was transferred to University Hospital. There, doctors said surgery to drain the skull and join the spine might enable her to live into her 20's—profoundly retarded, partially paralyzed, probably epileptic, and incontinent. Without the surgery they said she might live 2 years. The parents decided not to permit the surgery, a decision that was supported by Catholic clergymen and social workers they consulted with, as well as all the physicians involved in treating the infant.

What followed was a highly irregular series of events initiated by Albany attorney Lawrence Washburn, who was apparently alerted to the existence of the baby through a hotline operated by right-to-life advocates. Washburn, instead of notifying the local child protective agency, went straight to the judicial system, according to Howard Oaks, vice president for health sciences at the university. Oaks says a judge showed up unannounced at the hospital one Saturday afternoon, accompanied by an entourage including Washburn, and ordered hospital officials to appear in court the following Tuesday with the baby's medical records, to show cause why a guardian should not be appointed for the child. The next day, another judge, Melvyn Tanenbaum, announced that it was he who had jurisdiction and that he had already appointed a guardian, attorney William Webber.

The case sped through three courts in 4 days. The New York Supreme Court, presided over by Tanenbaum, who was elected largely by right-to-lifers, ruled that the baby should have surgery despite the fact that even the child welfare agency testified in support of the doctors' decision. Tanenbaum's decision was overruled by the appellate court. Webber thereupon took the case to the New York Court of Appeals, which on 28 October unanimously upheld the appellate decision. It called the suit "offensive" because the plaintiff had no connection with individuals in the case. It asserted that the case had no justification and was "an abuse of judicial discretion."

Then the federal government, responding to a complaint by the American Life Lobby, got into the act. The President's chief counselor Edwin Meese and Surgeon General C. Everett Koop reportedly set the process in motion. According to Oaks, the university had no hint of the planned action until Koop announced, in a 2 November press conference, that the Justice Department would intercede in the case. The university refused to surrender the infant's medical records so Justice filed suit in the federal district court in Brooklyn. The government claims a right to the records since the university is a federal grantee. The university invoked privacy laws and maintains that child welfare issues are covered by state law, and that section 504 does not apply.

The government claims it needs the records to decide whether the medical decision is the proper one. Actually, Koop already has copies of the child's early medical records, made available by Webber, and he has already arrived at a prognosis. He said on television that it was too early to predict how badly retarded the child would be, and said he had "never seen a child like this live a life of pain." Said Koop: "If we do not intrude into the life of a child such as this, whose civil rights may be abrogated, the next person may be you." According to Oaks, Koop has somewhat inflated his knowledge of the case, claiming he discussed it with a member of the medical school faculty. In fact, he telephoned the chief of pediatric surgery, who said he was not familiar with the case and relayed Koop's request to a neurosurgeon who was involved in it. The neurosurgeon declined to talk with Koop.

Oaks predicted that the loser in this case will probably take it to a higher court—"It's moving rapidly towards those marble halls." The original Baby Doe case, involving a child born with Down's syndrome in Bloomington, Indiana, was on its way to the Supreme Court when the case was rendered moot by the baby's death. Baby Jane Doe, after being treated successfully for a brain infection, is feeding normally and not showing any signs of decline.

The case raises a plethora of issues relating to privacy, state-federal relationships, intervention in medical judgments, and the proper purview of section 504. That legislation was originally drafted to smooth access to jobs and education by handicapped persons. Alexander Capron of the Georgetown Law Center, who headed the President's bioethics commission, finds it unfortunate that a law designed to enable people to "get the treatment they want" is now being used as a "club" to foist undesired treatment on people "we would ordinarily regard as appropriate" to stand in for incompetent. "There are already lots of other mechanisms to make sure that guardians are not behaving irresponsibly."

Physicians and others fear that if a precedent is set, it is just a matter of time before litigation is brought to prolong the survival of someone who is comatose and terminally ill. "By the stroke of a pen they can call it 'handicapped' and the federal government could intervene," says Capron.

He further observes that the current situation could lead to instances where heroic early efforts to save a potentially salvageable neonate will be foregone. Doctors, he says, might choose to give up on a marginal infant at birth rather than risk having to make the decision later in a more public setting, where there is the risk of whistle-blowers calling up the federal Office of Civil Rights.

The case has arisen as the Department of Health and Human Services continues to cull over responses it has received on the revised version of its "Baby Doe" regulations. The regulations, which have already been struck down once in court, would explicitly put handicapped newborns under the protection of section 504. The original version of the rules, modeled in accordance with right-to-life interests, were vehemently opposed by representatives from the entire medical community, who said they were disruptive, intruded into medical judgments and patient privacy, and adversarial in nature.—**CONSTANCE HOLDEN**