

Public Health and the Law

The Case of Baby Jane Doe: Child Abuse or Unlawful Federal Intervention?

GEORGE J. ANNAS, JD, MPH

Baby Jane Doe was born on October 11, 1983, suffering from spina bifida, hydrocephaly, and microcephaly. She was the first child of young parents who had been married for approximately one year. Her physicians recommended immediate surgery to reduce the fluid in her skull and close her meningomyelocele. This could increase her life expectancy from a matter of weeks to 20 years, but she would likely be severely retarded, epileptic, paralyzed, bedridden, and subject to constant urinary tract infections. After lengthy consultations, the parents refused to consent to the surgery, opting instead for antibiotics and bandages to prevent infection. The physicians did not disagree with the reasonableness or appropriateness of this decision, and even though the child had already been transferred to State University Hospital at Stony Brook, it is likely that had the decision been made even a year earlier, or in another part of the country, none of us would ever have heard of Baby Jane Doe.

In the "Baby Doe" regulation era, however, it was predictable that at least one child like Baby Jane Doe would be chosen to be a test case to determine the proper role of the state in decisions to withhold surgery from handicapped newborns.¹ In this case, a "right to life" Vermont lawyer, Lawrence Washburn, received a confidential tip about Baby Jane Doe and brought suit in New York to obtain an order to have the surgery performed. The trial judge, Melvyn Tanenbaum, who had accepted the Right-to-Life party nomination when he ran for his judgeship in November 1982, appointed Attorney William E. Weber as guardian *ad litem* to represent the child, and held a hearing on October 20. Weber, who the night before the hearing had told the parents he agreed with their decision, reversed himself at the hearing itself and argued for immediate treatment on the basis that the medical records disagreed with what the physicians had told him and the parents about the child's prognosis. Judge Tanenbaum thereafter ruled the infant in need of immediate surgery to preserve her life and authorized Weber to consent to it. The parents appealed.²

The Appellate Division reversed Judge Tanenbaum the following day, ruling that the parents' decision was consistent with the best interests of the child, and therefore there was no basis for judicial intervention. The court found both that the child was not "in imminent danger of death," and that the recommended shunt and spinal closure carried their

own risks, including loss "of what little function remains in her legs."³ Seven days later New York's highest court, the Court of Appeals, ruled that Judge Tanenbaum had abused his discretion in hearing the case in the first place, because Attorney Washburn had "no disclosed relationship with the child, her parents, her family, or those treating her illness." The court ruled that allegations of child abuse or neglect must be made to the state's Department of Social Services for appropriate investigation, and dismissed the suit on these procedural grounds.⁴

Meanwhile, the US Department of Health and Human Services (HHS) received a "hotline" complaint from an unidentified private citizen that Baby Jane Doe was being discriminatorily denied indicated medical treatment. HHS referred the complaint to the New York State Child Protective Services, which on November 7 concluded that there was no cause for state intervention. Prior to this, however, HHS had obtained the record in the state court proceedings, which contained the child's medical records through October 19. After personally reviewing them, Surgeon General C. Everett Koop concluded that he could not determine the basis for denial of treatment, including whether it was based solely on handicap, without "immediate access to, and careful review of, current medical records . . ." Therefore, beginning on October 22, HHS repeatedly asked University Hospital to make Baby Jane Doe's medical records (after October 19) available to it so it could conduct an investigation under section 504 of the Rehabilitation Act of 1973. The hospital refused, and in early November HHS brought suit in US District Court to obtain the child's medical records so it could conduct its sec. 504 investigation. The District Court focused the issue on whether or not it could be "clearly determined" from the record that the hospital was not in violation of 504. The court concluded that the hospital failed to perform the surgery not because of the child's handicap, but because of parental refusal; therefore, the hospital was not in violation of the Act. The court also found the decision of the parents "reasonable" based on "the medical options available and on a genuine concern for the best interests of the child."⁵ HHS appealed, arguing that the hospital has a duty under 504 to seek judicial review of a parental refusal under certain circumstances. The parents and hospital, on the other hand, argued that section 504 was never intended to serve as a basis for governmental intervention in medical decision making.

Stated simply, the government's position was that examination of the child's medical record was necessary to determine if she was denied surgery *because* of her microcephaly, which it argued would be as unlawfully discriminatory as refusing to perform surgery on an individual because the person was Black. Such decisions, the government

This is the second of a three-part series on governmental regulation involving the treatment of handicapped newborns. Part I dealt with the drafting and promulgating of Baby Doe regulations; the final column will deal with alternative methods of decision making.

Address reprint requests to George J. Annas, JD, MPH, Utley Professor of Health Law, and Chief, Health Law Section, Boston University School of Public Health, 80 East Concord Street, Boston, MA 02118.

argued, are not based on medical criteria and are thus not "bona fide medical judgments." To get to this question, the Court of Appeals assumed, *without deciding*, that section 504 applied to the hospital's neonatal intensive care unit because the hospital received Medicare and Medicaid payments. By bypassing this issue for another day, the court was able to focus on just one: Does section 504 authorize the type of investigation of medical decision making HHS sought to engage in with regard to Baby Jane Doe?⁶

In reviewing the regulatory history of HHS and its predecessor HEW (US Department of Health, Education, and Welfare), with respect to section 504, the court noted that in 1976 HEW adopted the position that 504 did *not* give it authority to regulate regarding patients' rights to "receive or refuse treatment." Rather HEW's authority was to make services "accessible" or available to the handicapped, so as to provide them with "an equal opportunity to receive benefits." In May 1977, HEW explained the difference in this way:

A burn center need not provide other types of medical treatment to handicapped persons unless it provides such medical services to nonhandicapped persons. It could not, however, refuse to treat the burns of a deaf person because of his or her deafness.

In fact, it was not until the May 1982 letter to hospitals that HHS ever suggest that 504 might reach to actual medical treatment decisions.¹ After reviewing the development of the Baby Doe regulations, the court found that "the regulatory history of 504 is inconclusive," and that HHS's current position on the scope of the enabling statute is "flatly at odds with the position originally taken by HEW."

This left the court with the task of interpreting the statute based on its language and legislative history. Section 504 provides:

No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, or be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (emphasis added)

The Court of Appeals concluded that Baby Jane Doe fit the definition of a "handicapped individual," but determined she was not "otherwise qualified" because this phrase referred to handicapped individuals who could benefit from services *in spite of* their handicap rather than cases, like Baby Jane Doe's, in which the handicap itself is the subject of the services. The court bolstered its conclusion with two reasons, neither of which adds much: medical decision making is "comparatively fluid" and "lengthly litigation" would be required to determine the actual basis for many treatment decisions. More persuasive is the legislative history of the Rehabilitation Act of 1973 which had to do primarily with employment and vocational education, and never envisioned any governmental role in medical treatment decisions. Moreover, the court notes that Congress has a consistent policy "against the involvement of federal personnel in medical treatment decisions" and the court will not construe Congressional intent to be different in "the field of child care . . . which has traditionally been occupied by the states," without an explicit Congressional expression.

The court therefore concluded that the Rehabilitation Act did not give HHS any authority to interfere with "treatment decisions involving defective newborn infants." Accordingly, HHS's request to continue its investigation by

obtaining access to Baby Jane Doe's medical records was denied.⁶

Although devastating to the HHS's Baby Doe regulations, the decision makes no attempt to answer the much more important question: what should the role of the government be in treatment decisions for handicapped newborns? Since the Second Circuit Court dealt only with legislative intent, Congress could pass a statute every bit as unpalatable as HHS's Baby Doe regulations. Indeed, the legislative process was already under way. About two weeks prior to this decision, the US House of Representatives voted favorable on HR 1904, The Child Abuse Amendments of 1984. This Act provides, among other things, that all state child protective service agencies, health care facilities, and health professionals develop procedures within a year "to insure that nutrition (including fluid maintenance), *medically indicated treatment*, general care, and appropriate social services are provided to infants at risk with life-threatening congenital impairments." (emphasis added) The Act also includes specific requirements for HHS to determine the most effective means of financially supporting the medical treatment of such infants, to publish guidelines "to encourage and assist health care providers desiring to establish local health care mechanisms for the review of care provided to infants at risk with life-threatening congenital impairments," and to develop a complete and up-to-date directory of available medical and community resources. The Act does not, however, empower the federal government to get directly involved in individual cases, but only to support state child abuse efforts with financial and technical information.

While superficially appealing, the thrust of the Act seems to be toward requiring state child protection agencies to spend much more time and effort on potential abuse and neglect in neonatal care. It is, however, a solution in search of a problem, since HHS has not been able to uncover even one case of child abuse or neglect in more than a year of operating its "hotline,"⁷ and current state laws already permit state child protection agencies to be involved in investigations of alleged abuse and neglect of infants. Encouraging further resources to be devoted to this area, while other much more prevalent forms of child abuse go under-investigated, seems unwarranted.

By focusing on child abuse, we leave the entire legal field precisely as it was before the Administration's May 1982 letter to hospitals: withholding customary medical treatment can be child abuse under certain circumstances.⁷ The originally perceived problem was that the child abuse standards were vague, and somehow permitted Down Syndrome children with treatable esophageal or intestinal atresia to die untreated.¹ This, however, was never lawful, and conflicting perceptions of the reasonableness of parental refusals, rather than purposeful maliciousness, probably accounted for the hospital's failure to act in the few reported cases relied upon by HHS in adopting its original proposals.¹

On the other hand, the child abuse standard of "customary medical care" does not state a cognizable legal standard in many areas of infant care simply because there is no such thing as "customary medical care" in many difficult and problematic cases. This is precisely what makes them so difficult for physicians. HHS believed it was being helpful in its January 1984 regulation by requiring only "medically beneficial treatment" to be used; but, of course, this is no better since doctors "customarily" use only treatment they consider "beneficial." Nor do the four examples HHS recites in the Appendix to the regulations provide more

useful guidance. The first three deal with Down Syndrome, spina bifida, and anencephaly, respectfully. The fourth is more general:

Withholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504. (emphasis added)

This simply substitutes another vague phrase, "reasonable medical judgment," for "medically beneficial care." It also further complicates the issue by adding the terms "success" and "risks" without identifying their limits. In fact, in the context of example 3 which immediately precedes it, and approves withholding of all medical treatment from an infant with anencephaly "who will inevitable die within a short period of time," the HHS examples seem to permit physicians to utilize quality of life criteria in making "medical" judgments—precisely the opposite of what Dr. Koop has stated he intended the regulations to do. HHS attempts to justify its position by stating that in such cases treatment would be "futile" since it would "merely temporarily prolong the process of dying." The problem, of course, is that if we have the medical technology to prolong the life of an anencephalic child or one with a severe intracranial bleed, and yet opt not to do so, this is *not* a medical judgment, but an ethical one based primarily on the desirability of prolonging that particular life. The real answer seems to be that it is not "beneficial"—medically, ethically, or any other way—to prolong the life of infants (or adults like Karen Ann Quinlan) who will never experience anything.^{8,9} This is, however, a non-medical judgment based entirely on the consequences of living in the absence of a brain. The point is not necessarily that HHS permits quality of life factors. It is rather that without taking such factors into consideration, we would be left with technologically driven rules that would require all treatments that prolonged life to be used under all conditions.

HR 1904's "medically indicated treatment" is, of course, no better. That is why we are left standing exactly where we were when we came in: call it "customary", "indicated", or "beneficial", what must be provided is that care necessary to avoid violation of the state's child abuse and neglect laws. The idea that more specific standards are likely to be developed in any other way than through articulation by national professional associations and individual court decisions seems fanciful. Certainly randomly assigned Baby Doe squads dispatched from Washington are not the answer; nor do vaguely worded notices provide helpful guidance for would-be child protectors.⁷

We can certainly do better in protecting the handicapped, both in the neonatal intensive care unit and in the community. We need more reflection, more accurate information, consultation, and public involvement. But we pay too high a price by assuming every doctor is a potential child abuser and that every nurse must be an informant. Hospitals

must continue to be seen as safe havens for children. Medical, nursing, and handicapped groups should jointly develop guidelines with national application for the treatment and referral of handicapped patients. Those guilty of abusing the handicapped by denying them appropriate treatment should be prosecuted; and questionable cases should be referred to court by hospitals. In court, the relevant facts can be examined by a politically appointed and accountable decision maker, in a neutral, public forum, on the basis of clearly articulated principles. There is no simple solution to this complex problem, but the combination of carefully crafted professional standards, and public review of individual problematic cases in court provides the most likely method by which the best interests of the child will remain central in decision making. The development of hospital "ethics committees" can be effective in educating and sensitizing hospital personnel to the difficult ethical and societal issues at stake in treatment decisions for the handicapped. But they are no substitute for the investigative power of the state's child protective services, nor for the protective power of the state courts in cases of alleged child neglect involving the withholding or withdrawal of treatment.

We could all applaud a federal initiative that made more funds available for medical treatment, follow-up care, education, job training, and residential facilities for the handicapped. A vague regulation aimed solely at medical treatment decisions in the newborn nursery, however, clumsily introduces the federal government into an area that has traditionally been one of state law enforcement, without providing any meaningful guidance to decision makers or assistance to those handicapped children whose lives may thereby be prolonged. Unless and until the state and federal governments are willing to provide the funding and support necessary to properly care for severely handicapped children, parents should retain the primary decision-making authority in the arena, subject, of course, to state child abuse laws and supported by factual information about their child's prognosis and the community resources available to them and their child.

REFERENCES

1. Annas GJ: The baby doe regulations: governmental intervention in neonatal rescue medicine. *Am J Public Health* 1984; 74:618-620.
2. Steinbock B: Baby jane doe in the courts. New York: Hastings Center Report, February 1984; 13-19.
3. *Weber v. Stony Brook Hospital*, 467 N.Y.S. 2d 685 (AD 2 Dept. 1983).
4. *Weber v. Stony Brook Hospital*, 456 N.E. 2d 1186, 469 N.Y.S. 2d 63 (1983).
5. *United States v. University Hospital, State U. of New York at Stony Brook*, 575 F. Supp. 607 (E.D.N.Y. 1983).
6. *United States v. University Hospital, State U. of New York at Stony Brook*, 729 F.2d 144 (2d Cir. 1984).
7. Annas GJ: Baby doe redux: doctors as child abusers. *Hastings Center Report*, October 1983; 26-27.
8. Singer P, Kuhse H: The future of baby doe. *NY Rev Books*, March 1, 1984; 17-22.
9. Singer P: Sanctity of life or quality of life. *Pediatrics* 1983; 72:128-129.