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A Commentary on the Cases of Baby Jane Doe

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The management of the *Baby Jane Doe* case at Stony Brook was, in many ways, more reprehensible than that of the original *Baby Doe* case in Bloomington. Since the issues in the *Jane Doe* case were, medically, much more complex than the Indiana case, the need for federal intervention is made more crucial. Historically, the conflict cases involving babies with Down's syndrome have been much more susceptible to public understanding. Most laypersons readily understand that a relatively simple procedure for intestinal obstruction is being denied precisely because the infant is mentally retarded. The retardation is entirely unrelated to the abnormality requiring surgical intervention. Meningomyelocele repair, on the other hand, involves surgical procedures directly related to the complex of abnormalities which cause the infant's handicaps. Moreover, the therapeutic process, while lifesaving, inevitably leaves some degree of abnormality uncorrected. After the back is closed to prevent fatal infection and after the shunts are placed to prevent the lethal effects of hydrocephalus, the infant is left with some degree of the motor function of the lower extremities and some degree of loss of urinary function.

These latter abnormalities are caused by maldevelopment of the central nervous system. This maldevelopment cannot be entirely corrected, but the results of the abnormal development are capable of rehabilitation through various orthopedic and urologic procedures. Dr. David McLone, chief of neurosurgery at the Children's Memorial Hospital in Chicago, is director of one of the largest spina bifida services in the country, if not the world. After reviewing the testimony of the *Baby Jane Doe* case, it was his opinion that early corrective surgery would have resulted in a child with normal intelligence, capable of walking with braces outside of the home. There is every indication, in

fact, that the referring physicians who sent the baby to Stony Brook did so with the expectation that early closure of the defect and shunting would be done. It would have been almost impossible for the public to infer this kind of prognosis from the reports in the press. There is also considerable evidence that the medical testimony in the court proceedings put the worst possible construction on the baby's defects and long-term prospects. As with *Baby Doe* in Bloomington, the scenario is portrayed as a choice between two therapeutic options. The choice of withholding surgery is portrayed as a "conservative" choice, made by parents who wish to save their child a lifetime of pain and vegetation. In point of fact, denying surgery guarantees a painful death and cannot be said to be in the best interests of the child.

The decision to perform surgery, on the other hand, results in survival with significant, but manageable, handicaps. The outcome of the choice of surgery in the New York case would have been a life with physical handicaps. The outcome in the Indiana case would have been a life with mental handicap. The denial of surgery in each case is dictated by a conviction that such lives are unworthy to be lived. Denial of surgery in either case would seem to be a clear violation of Section 504 of the Rehabilitation Act of 1973. (It should be emphasized that *some* children with Down's syndrome and *some* children with spina bifida have defects so severe that surgery could legitimately be withheld. This was not the case in the celebrated cases in Stony Brook and Bloomington.)

The final rule, promulgated by HHS (45 CFR, part 84, Nondiscrimination on the Basis of Handicap: Procedures and Guidelines Relating to Health Care for Handicapped Infants) is an attempt to prevent or reduce the frequency of such instances of inordinate discrimination in the future. While not perfect, the final rule is a reasonable compromise of the conflicting viewpoints of the federal agency and the various professional organizations which objected to the interim final rule and successfully sued to prevent its implementation by a temporary restraining order. The regulation and its supporting discussion occupied 33 pages in the *Federal Register*, but a few salient points should be emphasized.

Hotline and Notices

The hotline number survives in the final rule. It is listed as the third option after telephone numbers of the local hospital administrators and the local child protective agency (providing that the hospital has its own Ethical Review Board). It is not inappropriate to list these other numbers. The posting of the notice is not meant to imply that the hospital has a policy of discrimination against handicapped infants. The individual making the report, if not satisfied with the response of the hospital authorities or the child protective personnel,

can resort to a federal report. The problem, in the past, has been establishing a standing for the person on the scene who was neither a member of the family nor of the infant's particular health care team. The retention of anonymity and protection from retaliation are also important retentions in the final rule. Child abuse hotlines have been reasonably successful in the past. HR 1904, which recently passed in the House of Representatives, specifically establishes the requirement that child abuse agencies accept responsibility for Baby Doe-type cases.

The reduction in size of the notice and the granting of some latitude to the hospital as to where notices will be posted, present no insurmountable obstacles to the enforcement of the rule. An 8½" x 11" or 5" x 7" notice is sufficiently visible and the options for the location of the notice are acceptable as long as there is a guarantee that the notices will be clearly available to various professionals in the hospital, including nurses and aides. There was never any real intention to make the notice available to the general public or to casual visitors. The conflicts in the past have largely involved nursing personnel and it would be expected that only those acquainted with the facts of the case would be in a position to evaluate the possibility of discrimination with some reliability. The interim final rule suggested posting in areas (nurseries and neonatal intensive care units) to which the general public does not ordinarily have access. The notice is not intended primarily for parents who have always had an active role to play in treatment decisions.

Infant Care Review Committees

This has been the most controversial aspect of the final rule. The principal objection to such committees has been the suggestion that they would be the final arbiters of conflict cases or that their decisions would be irrefutable in a court proceeding which might arise. The final rule states emphatically and specifically that the existence of a hospital committee does not negate the established legal framework governing decision-making. The establishment of an infant care review committee does not exclude the requirement for posting the hotline notice, nor does it exclude the prerogative of the federal government to enforce Section 504 after due investigation. Under terms of the final rule, the establishment of such committees is an option, but not a requirement under federal law.

The infant care review board would broaden the decision-making process beyond the physician-parent-infant triad. A matter of continuing concern has been that repeated polls taken of pediatricians and pediatric surgeons in the past have indicated that over 75% would concur in a decision of parents not to treat an infant, even if such a denial of therapy were not in the infant's best interest. Some have

questioned the current applicability of such polls and have alleged a recent change of heart on the part of my pediatric colleagues. Such a change of heart is not indicated by the commentaries sent to HHS on the interim final rule which was opposed by 72.3% of pediatricians. In contrast to the position of pediatricians, almost all other groups commenting on the regulation approved of it. For example, 97.5% of nurses approved the rule as did 95% of parents of handicapped infants, 100% of handicapped advocacy organizations, and 55.3% of physicians (other than pediatricians and neonatologists). In fact, 97.5% of the 16,739 commentaries on the regulation have been in support of it. The American Academy of Pediatrics has suggested a model committee to include nurses, clergymen, pediatricians and other physicians, parents, and handicapped child advocates. The aforementioned statistics would not indicate that the makeup of such a committee would tend to reinforce the biases of the pediatricians and neonatologists.

It is difficult to rebut the notion that judges would be strongly influenced by the decisions of such committees because it is difficult to predict what facts will be persuasive with judges. The judge in Bloomington approved of nontreatment in spite of the fact that both the attending pediatrician and the pediatric surgical consultant had recommended treatment. How is the present situation made worse by the addition of a committee's deliberation? If parents decide to deny indicated surgery and the physician defers to their wishes 75% of the time, who will protect the handicapped infant under the present system? If no one calls the hotline, the issue is foreclosed. While the influence of the infant care review committee on the courts will remain a calculated risk, unknown until tested, some benefits of a committee are undeniable, as noted herewith.

- 1) They could establish guidelines for situations where therapy is always indicated (e.g., Down's syndrome with duodenal atresia).
- 2) They could establish guidelines for instances where extraordinary care is never indicated (e.g., anencephaly).
- 3) They could review, on an emergency basis, specific cases where withholding of life-sustaining therapy is being considered and where the best interests of the child are not clearcut and incontrovertible.
- 4) They could monitor hospital policies and procedures by retrospective record review.
- 5) They could guarantee that parents are given up-to-date scientific information and also information regarding available community support structures.

It must be conceded that there are, in fact, extremely complex and conflicted cases in which the choices to be made in the best interests of the child are by no means clear. Not all of these cases can be properly adjudicated by the courts. Most of the celebrated cases which

have been publicized have involved situations where the indications for surgery were clearcut or strongly persuasive. This is, by no means, invariably the case. There are many agonizing situations in which the best interests of the infant are not served by prolonged extracranial care. Arbitrating such cases by a mechanism to include parents, attending physicians and advisory committees is not unreasonable as long as resort to the courts is not foreclosed.

Educational Process

There is substantial evidence that both sides have learned a great deal from the litigation which surrounded the interim final rule and from the negotiations which followed the court case. Certainly a great learning process resulted from the many thousands of commentaries sent to HHS.

The American Academy of Pediatrics, in particular, has clarified and altered its public position dramatically. After alleging in court that the interim final rule was "an unwarranted intrusion" into the physician-patient decision-making process, the Academy has recently joined in a formal statement with various advocacy organizations representing handicapped children. The statement concludes as follows: "The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among those rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimination against individuals with disabilities including those afforded by Section 504 of the Rehabilitation Act." In contrasting the two positions, one is inclined to ask, "Will the real Academy of Pediatrics please stand up?"

The Academy and the other litigants in the suit found themselves in conflict with their traditional allies in the health care of the handicapped. They realized that their court success was a pyrrhic victory and that the endorsement of their position in the press was not reflective of any broad popular support in the community.

The final rule is not an emasculated version of the interim final rule. It retains the essential protective features of the original. The professional organizations have achieved a procedural goal in the infant care review committees, but they have totally failed to substitute these committees for the traditional safeguards of legal sanction at all levels of government. There is an opportunity now for the previously polarized groups to accept the final rule as a valid compromise and to test it over time. It is not and will not be perfect, but it is not carved in stone. In the orderly processes of a democracy, it can evolve into a suitable safeguard for parents, physicians and handicapped infants.