

STUDIES IN LAW & MEDICINE

Infant Doe and Baby Jane Doe: Medical Treatment of the Handicapped Newborn

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An Educational Publication of
Americans United for Life, Inc.

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Law and Medicine Series

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Do children born with severe handicaps have a right to live, to receive the food and medical treatment necessary for them to live, as would a child born without handicaps? Or should the parents of such children be given the private decision to choose whether the child should live or die, on the basis of their judgment of the quality of the child's life and of the degree of burden he or she will pose for their family or society?

That is the issue at the heart of the great national debate now raging over the fate of handicapped children and over what role, if any, government and the law should have in protecting their lives. At stake in that debate is the continued viability of one of the most cherished principles in American jurisprudence: the equality of all persons before the law. Are persons with disabilities to be treated as equal before the law?

This is not really a debate over the respective roles of the state and parents in making decisions about and for their children. That issue has been long settled, as is decidedly shown by the recently publicized cases involving court-ordered treatment for "normal" children over the religious objections of their parents.¹ Parents have traditionally been accorded great autonomy in making decisions for and about their offspring, because it has been presumed that they act for the benefit of their children. But when that presumption is disproved by their conduct — when they engage in child abuse or neglect — the state, in the exercise of its *parens patriae* power, has always had the authority to intervene on behalf of the best interests of the child. Nor, despite all the rhetoric about "Big Brother" and "Baby Doe Squads," is this

authority the subject of controversy. It becomes so only when it is exercised on behalf of a *handicapped* child. The issue for the law, then, is whether the child with a disability ought to be treated the same as or differently from the child with no disability when his parents want to let him die and there is an effort to use the power of the state to let him live.

This article will review the legal precedents and principles at stake, then consider in their light how the courts have dealt with the Bloomington, Indiana Infant Doe case, the Stony Brook, New York Baby Jane Doe case, and the litigation surrounding the various versions of the federal "Baby Doe" regulation.

The Legal Precedents and Principles

All 50 states, the District of Columbia, Puerto Rico, American Samoa, Guam, and the U.S. Virgin Islands have child abuse and neglect statutes which provide for the protection of a child who does not receive needed medical care.²

A review of cases makes it clear that these statutes are properly applied to secure emergency medical treatment and sustenance (food or water, whether given orally or through intravenous or nasogastric tube) for children when parents, with or without the acquiescence of physicians, refuse to provide it.

In *Custody of a Minor (No. 3)*,³ the highest court of Massachusetts held that parental failure to provide medical care to a child with leukemia constituted neglect. The court specifically rejected the contention that parental rights could justify a decision to withhold treatment necessary to save the life of the child:

[W]here, as here, the child's very life is threatened by a parental decision regarding medical treatment . . . the safeguarding of children from abuse clearly supersedes parental prerogatives.⁴

The common law right of parents to make decisions about health care for their children is broad, but it is based on the presumption that parents will act in the child's best interest. The law's traditional deference to parental discretion in selecting health care alternatives for children stops if that choice is adverse to the child's interests, especially the child's interest in continued life even with handicaps. As long as the parents make an informed choice from professionally accepted medical treatment alternatives, courts will be satisfied that the parents are acting in the best interests of the child and will not find parental neglect in such conduct. Just as in the more typical and egregious case of parental abuse or neglect, when a parent's acts or omissions endanger the life or threaten severe damage to the health of the child, the court will intervene to protect the child. "The parent . . . may not deprive a child of lifesaving treatment, however well-intentioned. Even when the parents' decision to decline necessary treatment is based on constitutional grounds, such as religious beliefs,

it must yield to the State's interests, as *parens patriae*, in protecting the health and welfare of the child."⁵

The case of a child who may bleed to death because of the parents' refusal to authorize a blood transfusion presents the classic scenario in which this doctrine is uniformly invoked.⁶

*In re Cicero*⁷ is a New York case in which parents refused consent for lifesaving medical treatment. A baby was born with spina bifida, and the medical testimony indicated that immediate surgery was necessary to safeguard the child's life. When the parents refused to consent to the surgery, the chief executive officer of the hospital petitioned to be appointed guardian of the baby girl. He wished to be appointed for the sole purpose of operating on the baby's spinal lesion. The court found that, because of the infant's physical condition, she was in imminent danger unless the surgery was performed, and that the child's welfare demanded judicial intervention. The surgery was ordered over the parents' objections.

In an unreported case which is similar to the widely publicized Bloomington, Indiana "Infant Doe" case, a boy was born in Maine with gross deformities which encompassed nearly the entire left side of his body. Brain damage was indicated. He also had a tracheal fistula and could not be fed by mouth. Surgery to repair the fistula, which was the only immediate threat to his life, could have been performed, but the parents refused to consent. Several physicians at the medical center, including the pediatric surgeon who had been scheduled to operate, filed a petition alleging neglect. The trial judge granted the petition and ordered that the surgery be performed, stating in his order that at the moment of live birth there exists a human being entitled to the fullest protection of the law, and that the most basic right enjoyed by every human being is the right to life itself.⁸

In *In re Vasko*,⁹ a New York court upheld the validity of a state statute which created a children's court with jurisdiction over neglected children, including in the definition of such children those whose parents refused to provide lifesaving medical care. The trial court had properly exercised its discretion in ordering, despite parents' objection, an eye removal operation when the medical diagnosis showed that the child suffered from glioma, a malignant growth on the eye, which probably would result in death if not corrected.

This sampling of cases provides ample justification for seeking and securing a court order to mandate lifesaving medical treatment and sustenance for a handicapped child despite parental objections. There is also a strong basis in legal theory for the conclusion that those involved in the intentional denial of treatment and sustenance are subject to prosecution for homicide or attempted homicide, as well as criminal child neglect.

Courts have uniformly held that a parent has the legal responsibility of furnishing his dependent child with adequate food and medical

care.¹⁰ Lafave and Scott state that failure to provide one's child with necessities of life, assuming that the parent has the ability to provide the care, is criminally culpable conduct:

Intentional death may be effectively brought about by an omission to act . . . if there is a duty to act. A special example is the duty of a parent to rescue his imperiled infant. So a parent who fails to call a doctor to attend his sick child may be guilty of criminal homicide if the child should die for want of medical care.¹¹

Similarly, Wharton, on *Criminal Law*, notes:

It is said that for a parent having special charge of an infant child to so culpably neglect it that death ensues is . . . murder if there was an intent to inflict death. To constitute murder there must be . . . wilfulness in withholding relief.¹²

The courts have consistently applied this standard to instances in which parents have failed either to feed or to provide lifesaving medical care to their children. A Michigan case, *People v. Lynch*, involved a mother's murder conviction for deliberately withholding food and medical treatment from a handicapped infant.¹³ Although the mother's conviction was reversed on procedural grounds, the *Lynch* court stated unequivocally that if evidence shows that a parent deliberately withholds care from a child and if this results in the child's death, then the "charge would be appropriately classified as murder."¹⁴

Disabled Children Are 'Persons'

Children born with disabilities are "persons" within the protection of the 14th Amendment to the U.S. Constitution. "Like any infant, the deformed child is a person with a right to life — a right that is the basis of our social order and legal system."¹⁵ Under the 14th Amendment, "No state shall . . . deny to any person within its jurisdiction the equal protection of the laws."¹⁶ A state court refusal to enter an order mandating lifesaving sustenance or treatment because the child had a disability would constitute a denial of equal protection on account of disability. If the court would order sustenance and treatment for a "normal" child, but allow it to be withheld from a child with a handicap, then this would constitute invidious discrimination on the basis of disability.

Since a good case can be made that the disabled are a "suspect class,"¹⁷ state action discriminating against them is subject to "strict scrutiny."¹⁸

Under strict scrutiny, discriminatory state action must be justified by a "compelling state interest" to be constitutional. Even if the handicapped are not a suspect class, discrimination against them would still require a legitimate state interest to be constitutional.¹⁹

The elimination of those with a purportedly low "quality of life" can qualify neither as a compelling nor as a legitimate interest in this

context. Even if there is a state interest in reducing the incidence of disabilities because of the possible "burdens" individuals with disabilities impose on family members and society as a whole, it may not constitutionally be fostered by eliminating the *victims* of handicapping conditions. No one would argue that, to advance an interest in reducing the incidence of sickle-cell anemia, the State might constitutionally execute blacks who suffer from the disease, or that, to advance an interest in reducing poverty, the State might constitutionally completely withdraw police protection from poor people while answering all calls for police assistance from those with incomes above poverty level.

These are arguments on behalf of the constitutional rights of the child to equal treatment. On the other hand, attorneys for the parents and doctors are likely to claim that their decision is protected by constitutional rights of physicians to practice medicine, by parental privacy rights, and by the child's right to die. Such claims are unfounded.

The U.S. Supreme Court has held that physicians may rely on no independent constitutional right:

Nothing . . . suggests that a doctor's right to administer medical care has any greater strength than his patient's right to receive such care. . . . If [statutory] obstacles had not impacted upon [the patient's] freedom to make a constitutionally protected decision, if they had merely made the physician's work more laborious or less independent without any impact on the patient, this would not have violated the Constitution.²⁰

Parents do have a right to familial privacy and to the care and custody of their children, but that right is not so broad that it gives them the freedom to bring about their children's deaths by deliberate medical neglect. Parents may not rely on the Constitution to inflict serious harm on their children. Thus, in *Prince v. Massachusetts*,²¹ the Supreme Court held that parental rights could not overcome the government's interest in protecting children from burdensome and exploitive work through the child labor laws. In *Jehovah's Witnesses v. King County Hospital*,²² it summarily held that a parent could not withhold a blood transfusion needed to save a child's life.

It may be argued that the constitutional right of privacy protects an individual's right to die in the sense of a right to refuse medical treatment, at least in some circumstances.²³ Whatever application this view may have to a competent individual or to a once-competent individual whose desires can be inferred from his or her views while competent, it has no application to an incompetent individual who has never been competent to make such decisions — such as a handicapped infant.

The decision of the highest court of New York in *In re Storar*,²⁴ makes the distinction clear. In *Storar*, the New York Court of Appeals was concerned with two individuals: Brother Fox, who had

been a competent man of normal intelligence and capacity until a surgical complication led to his comatose incompetency, and John Storar, who was an institutionalized and profoundly retarded 52-year-old man who had never had a mental age of more than about 18 months.²⁵ Brother Fox's religious superior sought judicial permission to disconnect his respirator, while Storar's mother sought to prevent the giving of lifesaving blood transfusions to her son.

The *Storar* court drew a sharp distinction between the two cases. It held that "clear and convincing evidence" proved that Brother Fox, while competent, had indicated his desire that treatment of the kind at issue should not be provided to him. On the basis of the common law "right of a patient to control the course of his medical treatment," the court held that Brother Fox should be removed from his respirator.²⁶ With regard to John Storar, on the other hand, the court declared that his treatment should have been ordered:

John Storar . . . was always totally incapable of understanding or making a reasoned decision about medical treatment. Thus it is unrealistic to attempt to determine whether he would want to continue potentially life prolonging treatment if he were competent. As one of the experts testified at the hearing, that would be similar to asking whether "if it snowed all summer would it then be winter?"²⁷

The *Storar* court held that in such circumstances "a court should not . . . allow an incompetent patient to bleed to death because someone, even someone as close as a parent or a sibling, feels that this is best. . . ." ²⁸ Similarly, to say that a parent could use "substituted judgment" to exercise a disabled infant's "right to die" would amount to the acceptance of involuntary euthanasia.

Two recent cases have run counter to these general principles. In the Indiana case publicly known as "Infant Doe" (the reaction to which ultimately resulted in the Jan. 12, 1984 regulations of the Health and Human Services under Section 504 of the Rehabilitation Act of 1973) and in the New York case known as "Baby Jane Doe," the parents were allowed to reject medical treatment for the children involved, even though in the Indiana case it meant starvation and death within six days and, in the New York case, life limited to approximately two to four years with an unoperated lesion of the spinal cord. Why is this so? Is the law changing so that parents may now determine that if the quality of the child's life with treatment is unacceptable to them they may reject treatment and allow the child to die? Have we reached the stage sought by Duff and Campbell in their famous 1973 paper calling for such changes in the law?

If working out these dilemmas in ways such as those we suggest is in violation of the law, we believe the law should be changed.²⁹

Can it fairly be said of the New York and Indiana cases that the law now allows parents with severely handicapped children sole discretion in treatment choices for their child?

Infant Doe

On April 9, 1982, Infant Doe was born at Bloomington Hospital at Bloomington, Indiana. He was born with a surgically correctable condition known as tracheoesophageal fistula that prevented him from orally ingesting food and water. However, he could have received fluids and nourishment through intravenous feeding.

Although Bloomington Hospital was not adequately equipped to perform the surgery necessary to enable Infant Doe to eat normally, nearby Riley Children's Hospital was equipped to handle this kind of surgery and employed an excellent pediatric surgeon. This lifesaving surgery, while difficult, has been performed since 1941 and has a probable success rate of better than 90% if performed within the first 24 hours of birth.³⁰ If the surgery and nourishment were withheld, Infant Doe would certainly die.

Despite the favorable success rate for surgery and the certainty of death without it, the obstetrician who delivered Infant Doe offered Mr. and Mrs. Doe the alternative of doing nothing to save the life of their child. He offered this as an alternative course of "treatment" because Infant Doe, in addition to having a tracheoesophageal fistula, also had Down's syndrome.

Feeling that a "minimally acceptable" quality of life could not be obtained by an infant with Down's syndrome and that it would be in the best interests of the infant, their two other children at home, and their family entity as a whole if Infant Doe died, Mr. and Mrs. Doe decided that no corrective surgery should be performed and that no food or water should be administered.³¹

On April 10, 1982, a hearing concerning Infant Doe was held at Bloomington Hospital before Judge John Baker of the Monroe Circuit Court. The hearing was held at the request of Bloomington Hospital, which sought guidance from the court.

Although no record of the April 10 hearing was made, Judge Baker's declaratory judgment of April 12 indicates that the obstetrician testified at the hearing and recommended that Infant Doe be kept at Bloomington Hospital and that he not be given lifesaving surgery, food, or water.³²

In making his recommendation, the obstetrician relied on the fact that although surgery would correct the tracheoesophageal fistula and therefore allow the child to survive, it could not cure any mental retardation associated with Down's syndrome. Accordingly, the obstetrician testified that even if corrective surgery were successful, Infant Doe could not attain a "minimally acceptable quality of life."³³

Three other physicians also testified. They all recommended that Infant Doe be transferred immediately to Riley Children's Hospital for corrective surgery.³⁴

In a hearing held April 13 in a companion case, brought by the

Monroe County Prosecutor to secure treatment for Infant Doe, the testimony was "substantially the same" as in the April 10 hearing of which no record exists.³⁵ In the April 13 hearing, in contrast to the obstetrician's testimony, a pediatrician testified that it was impossible to determine the severity of mental retardation in a newborn infant with Down's syndrome. He also testified that there is a broad range of IQs for Down's syndrome children; they may range from severely retarded children with IQs of 20 to 30, all the way into the normal intelligence range.³⁶ The obstetrician did not dispute this testimony. Indeed, he agreed with it, stating, "As [has been] indicated no one can be absolutely sure of the degree of retardation at the time of birth."³⁷ Despite this, the obstetrician insisted that Infant Doe could not attain a "minimally acceptable" quality of life:

Both [of the other physicians] were prepared to tell the parents to give them only one option. To send the child to Riley Hospital for surgery. . . . I insisted upon giving the parents a choice. I felt that this was not an adequate description of the situation. I insisted upon telling the parents, pointing out to the parents that if this surgery were performed and if it were successful and the child survived, that this still would not be a normal child. That it would still be a mongoloid, a Down's syndrome child with all the problems that even the best of them have. That they did have another alternative which was to do nothing. In which case the child would probably live only a matter of several days and would die of pneumonia probably. . . . Some of these children, as I indicated in my testimony to Judge Baker are mere blobs. Some of them, most of them, eventually learn to walk and most of them eventually learn to talk. . . . [T]his talk consists of a single word or something of this sort at best. I have never personally known the true Down's Syndrome child that was able to be gainfully employed in anything other than a sheltered workshop, with constant supervision, in other words, a child that could be self-supporting. I've never heard of such a Down's Syndrome child. I've never heard of a Down's Syndrome child that could live alone. They require at best constant attention. . . . These children are quite incapable of telling us what they feel, and what they sense, and so on.³⁸

On April 12, 1982, the court issued a declaratory judgment ordering Bloomington Hospital to allow Mr. and Mrs. Doe to choose a course of "treatment" for Infant Doe that was certain to result in his death.³⁹

Two orders were issued by trial courts in these cases. The first was the declaratory judgment issued April 12, 1982. The second was an order dismissing the companion case entered on April 14, 1982. Both orders are included in their entirety in the Appendix following the references for this article.

Baby Jane Doe

On Oct. 11, 1983, Baby Jane Doe was born in a small hospital in Port Jefferson, N.Y.⁴⁰ She had spina bifida, involving the failure of the spinal column to seal in the spinal cord completely, and hydro-

cephalus, or excessive fluid surrounding her brain. The standard treatment for this condition is surgery to close the spine and shunt the fluid from the brain. Although they received an initial recommendation for surgery and transferred her to the state university hospital at Stony Brook, Long Island, because it had the proper surgical facilities, her parents, on the advice of Dr. George Newman, soon decided to deny consent for these measures. Someone inside the hospital contacted attorney Lawrence Washburn, who applied to the New York Supreme Court (a low level court of general jurisdiction) for the appointment of a guardian ad litem to argue on behalf of surgery for the child.⁴¹ Justice Tannenbaum appointed William Weber to that post, and a hearing was held on Oct. 19 and 20, at the conclusion of which the court ordered the surgery to be performed.⁴² The ruling was immediately appealed to the appellate division, which stayed the order and, after hearing arguments, on Oct. 21 reversed the lower court's ruling. In a narrowly drawn and fact-based opinion, the unanimous court affirmed the authority of the lower court to entertain the question, but reread the record as indicating that the parents simply chose one among two courses of risky medical treatment.

[T]his is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. Rather, it is a situation where the parents have chosen one course of appropriate medical treatment over another.⁴³

Guardian ad litem Weber then appealed to the state's highest court, the Court of Appeals. In an opinion that can be described as caustic, the court dismissed the case, holding that the interveners on behalf of the child, whose actions it called "offensive,"⁴⁴ had no standing to challenge the parents' private decision. Since New York's child protection agency concurred with the parents' decision, the high court essentially ruled that intervention to save the child's life was impossible.⁴⁵

That ruling prompted the United States Justice Department to bring suit in federal District Court on Nov. 17 to obtain Baby Jane's medical records under Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap in federally funded hospitals. Long Island's Stony Brook Hospital had refused to give government civil rights investigators the child's medical records subsequent to the Oct. 19-20 lower court hearings. The district court ruled against the Justice Department, and that ruling was affirmed by the Second Circuit of Appeals.⁴⁶ We shall return to these rulings after considering the litigation surrounding the federal "Baby Doe" regulations.

First, however, it will be useful to examine more carefully the facts of the Baby Jane Doe case. The contrast between the public perception of those facts, as a result of inaccuracies spread by press reports and by the courts themselves, and the true condition of the child provides a classic case study of the way in which dehumanizing fal-

lacies about the disabled color our judgment and foster our prejudice.

In March of 1984, after winning on every level in their fight to avoid surgery for their daughter, Baby Jane Doe's parents changed their minds. They agreed to permit surgery to install a shunt for the hydrocephaly.⁴⁷ Her spinal lesion, having healed (a rare, but not unprecedented, happenstance in the absence of spinal closure surgery), she left the hospital for her parents' home on April 4. At the time of greatest public attention to her plight, amidst the flurry of litigation in October and November, 1983, the universal public expectation was not nearly so rosy.

Statements by Press

Press reports, columns, editorials, and court opinions stated almost without equivocation that Baby Jane Doe would be severely retarded, bedridden, and live only to age 20 if given the surgery.⁴⁸ Yet an examination of the testimony at the lower court hearing led one of the nation's leading experts on the treatment of spina bifida, Dr. David McLone, chief of pediatric neurosurgery at Chicago's Children's Memorial Hospital and associate professor of surgery at Northwestern University Medical School, to conclude, "If you take our experience of a child [in Baby Jane Doe's described medical condition] I would predict that the child in our hands would have a normal intelligence and would be a community ambulator . . . [walking] probably with some bracing."⁴⁹

Testifying at the lower court hearings, which are still the only detailed source of information on the child's medical condition, Dr. Newman, a neurologist at Stony Brook Hospital, said that the child's head at birth "was abnormally small," which gave her "virtually a 100 percent chance of being retarded."⁵⁰ But Dr. Albert Butler, chief of neurological surgery at the hospital, Newman's superior, and the only other physician to testify in the case, agreed with a statement that the baby's 31-centimeter head circumference was "within normal measurements for a baby of that size."⁵¹

Dr. McLone, who has treated over 1,000 children with spina bifida, agrees with Butler: "Approximately 15 to 20 percent of the children born with spina bifida have a head circumference in that [31 centimeter] range, and that is perfectly compatible with normal intellectual development." In fact, said McLone, some children in that range of head size are among the "very brightest" of individuals with spina bifida. "It's the child who has the extremely large head who is at risk for having decreased intellectual development. It's actually backwards," he said of the prognosis.⁵²

Newman testified that the parents decided it would be unkind to allow the child to undergo surgery, because "[o]n the basis of the combinations of the malformations that are present in this child she is

not likely to ever achieve any meaningful interaction with her environment, nor ever to achieve any interpersonal relationships, the very qualities that we consider human. . . ." ⁵³ Newman also asserted, "It's unlikely that she is going to develop any cognitive skills," ⁵⁴ and that the child would have positive experience of "nothing whatsoever" on the cognitive scale.⁵⁵ But Dr. Butler asserted, "I think we have to reasonably expect that this child might be able to sit up, look around, be aware of parents or good friends. . . ." ⁵⁶ Butler, who with Newman, favored the parents' decision, also contradicted Newman by affirming that the child would, at least to a limited extent, be able to experience emotions such as sadness and joy, if she lived long enough. ⁵⁷

In cases similar to Baby Jane Doe's, Dr. Butler stated in the Nov. 9 issue of *Newsday*, that it is possible that the child "with special education could be able to feed himself, talk some, have fun in a very rudimentary kindergarten-type class but not necessarily go home with much information."⁵⁸

The Arnold-Chiari brain malformation to which Dr. Newman's grim prognosis referred involves a compression of the brain stem.⁵⁹ This, as well as a dilation of the brain's ventricles, were measured by an ultrasound sonogram test. Dr. Butler testified that the test classified the dilation of the child's ventricles as "a moderate effect."⁶⁰

"Would it be a fair statement to say that at this very moment we really don't know the full extent if any of brain damage?" Butler was asked. "Precisely, no," he responded.⁶¹

"All of these children," says McLone, "have a brain malformation. The spina bifida child, virtually 100% of those children have the Chiari tube brain malformation, which is a profound brain malformation. However, it is a brain malformation which is compatible with normal development function." McLone said, "Virtually 98 percent of these kids at birth will have a dilated ventricular system and 15 to 20 percent of those kids will have a small head, and still it's perfectly compatible with normal intelligence."⁶²

Press accounts have repeatedly stated that Baby Jane, if she received the necessary surgery, was destined to be "bedridden." Testifying on Baby Jane's probable daily routine after the proposed surgery, Dr. Newman said, "It would likely consist of lying in bed, being fed probably by bottle. . . ." ⁶³ Later in the hearing, however, Newman's own written prognosis for the child was quoted by Dr. Butler from the medical records: "The prognosis offered with appropriate reservation was for probable . . . walking with bracing. . . ." ⁶⁴

McLone agrees with the more optimistic of Newman's dual prognoses. "If you take our experience of a child with a head circumference of 31 centimeters with a slightly dilated ventricular system, L-3 motor level in the lower extremities [all ascribed to Baby Jane in the medical testimony] I would predict that that child in our hands would have a normal intelligence and would be a community ambulator . . .

[walking] probably with some bracing." Wheelchair confinement for such a child whose spina bifida condition was aggressively treated within the first hours after birth, says McLone, would not even be anticipated.⁶⁵

Media reports similarly appear to have distorted Baby Jane Doe's life expectancy. Although New York trial court Justice Melvyn Tanenbaum in his oral opinion summarized the testimony as predicting a maximum lifespan of 20 years even with surgery, Newman's testimony, upon which the recollection was based, reads somewhat differently. "How long might the child live after surgery?" Newman was asked. "There is really no way of placing a limit on it if the surgery is performed," he answered.⁶⁶ "Could it conceivably be twenty years?" asked the cross examiner. "Yes," Newman answered, ". . . 20 years is possible."⁶⁷ No physician ever claimed, however, that 20 years were the *outside limit* of Baby Jane's life expectancy.

Media assertions that the child would be in constant pain all of her life apparently derive from Newman's testimony that, as with other children, "she is capable of experiencing pain."⁶⁸ Speculating on the possible infections, commonly contracted and overcome by people with spina bifida, that Baby Jane might develop, Newman then said that to perform the lifesaving surgery for the child "would increase the total pain that the child would experience."⁶⁹

This is obvious in the sense that a longer life includes more of all life's experiences, including pain. But the evidence is that children with Baby Jane Doe's handicap do not experience significantly more pain than normal children. Contrary to editorial versions of the child's story, Dr. Butler in *Newsday* stated that for a child similarly situated to Baby Jane, "certainly there would be little expectation of pain."⁷⁰

In another apparent contradiction, Dr. Newman claimed that the child's arms were spastic.⁷¹ Butler, however, agreed with the statement that the child's upper extremities had "good reflexes in relation to nervous system testing."⁷² He testified that "the child can move [her arms] around, at least to the extent that would be expected of a nonaffected baby."⁷³

Custodial care which involved failure to drain the excess fluid in the child's head and to close the lesion, or meningomyelocele, on the child's spine was described in the hearings as "conservative treatment" by the parents' lawyer, Paul Gianelli.⁷⁴ McLone, however, considers this care to leave the spina bifida condition "untreated." Writing in the recent anthology *Infanticide and the Handicapped Newborn*, McLone said "If by 'untreated' one means providing only supportive care for the child in the form of proper nourishment and appropriate medications but withholding surgical therapy, then the mortality rate [in the first two years of life is] 60-80 percent."⁷⁵ The decision not to treat was made on the basis of the Lorber criteria, named for a British neurosurgeon who, Newman said, promulgated "certain criteria

which . . . would predict a virtually invariable poor outcome" for certain infants with spina bifida.⁷⁶ But Dr. McLone asserts, "I think that that criteria has been proven over and over in institutions in this country to be completely invalid."⁷⁷

Did the decision to deny the corrective measures place Baby Jane "in eminent [sic] danger, or in risk of eminent [sic] danger?" "No," Newman responded.⁷⁸ Questioning Butler, however, the judge noted, "You have said that there is an imminent danger of infection, with the onset of infection the child will be lost, is that a fair statement?" Butler answered, "That's correct."⁷⁹ Earlier Butler was asked, "Would the operation . . . remove the danger of infection or the risk of infection?" "[S]ignificantly," Butler responded.⁸⁰ Dr. Keuscamp, the first neurosurgeon in charge of the infant's care, recommended immediate transfer to Stony Brook Hospital, where the surgery could be performed. The parents originally consented to transfer for the surgery,⁸¹ but, under Dr. Newman's advice, changed their minds. Keuscamp thereafter withdrew from the case "in light of his feeling that the surgery should be performed."⁸²

Did the requested corrective procedures constitute ordinary medical care for a child in Baby Jane's condition? Yes, answered Dr. Butler, again contradicting Newman. "In the sense that what we do most commonly or how we most commonly treat an infant who presents with these groups of problems. . . . In that sense, in most instances the surgical procedure is performed to repair the myelomeningocele and then either at the same operation or shortly thereafter to perform the shunting procedure."⁸³ The *Newsday* interview with Butler, moreover, described him as one who "favors surgery in cases medically identical to those of Baby Jane because he believes such infants have far more potential than other Stony Brook physicians have predicted for the patient."⁸⁴

The picture which emerges of Baby Jane Doe is that, far from being a "hard case," she is really one of the better cases in terms of prognosis for a high "quality of life." Her saga illustrates the profound unreason that an openness to discrimination fosters: a willingness, even an eagerness, to believe the worst about a minority in order consciously or subconsciously to justify a denial of equal protection. History has taught over and over again how this willingness systematically leads to distortion in the view the majority holds of the minority, the acceptance of inaccuracies and stereotypes which in turn, reinforce the discriminatory attitude. This cycle, in which discrimination and failure of perception reinforce and feed each other, step by step leads to an ever expanding class of victims and a gradually increasing degree of gravity of the wrongs the majority is led to perpetrate upon the minority. This ignoble tradition is carried out fully in the Baby Jane Doe case. For in the space of five months, different levels of the courts progressed from opinions which simply got the

facts wrong while asserting the right and duty of society to intervene to save the lives of the disabled, through opinions virulent in their denunciation of any who sought to intervene, to an opinion that disclaimed any authority to intervene at all. An understanding of these opinions, however, requires that we first examine Section 504 and the "Baby Doe Rule."

The Baby Doe Rule and the President's Commission Report

The well-publicized April, 1982 denial of food and surgery to Bloomington, Indiana's "Infant Doe" prompted President Reagan to issue a statement on April 30, 1982, in which he directed HHS to notify health care providers of the applicability of Section 504 of the Rehabilitation Act of 1973 to discriminatory denial of food or medical treatment to disabled infants.⁸⁵ On May 18, 1982, HHS issued such a notice to the country's 7,000 hospitals, an act denounced by hospital and medical associations.⁸⁶

It was not until March 7, 1983, however, that HHS issued regulations dealing with the problem.⁸⁷ This first version of the rules required posting of a notice in each hospital ward likely to treat disabled newborns. The notice stated that "Discriminatory Failure to Feed and Care for Handicapped Infants in This Facility is Prohibited by Federal Law." It gave 800-368-1019 as the number of a toll free 24-hour hotline through which confidentially to report suspected denial of "food or customary medical treatment" to the HHS Office of Civil Rights (OCR). The regulations also allowed federal investigators to visit the hospital at any time, not just during "normal business hours," and to act to enforce compliance without the 10-day waiting period required in other civil rights investigations.

Also in March, 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research released its report, *Deciding to Forego Life-Sustaining Treatment*, with a chapter on "Seriously Ill Newborns."⁸⁸

The President's Commission divided the problem into three categories:

- 1) where treatment is available which would clearly benefit the child;
- 2) where all treatment is futile;
- 3) where the probable benefits to an infant from different choices are quite uncertain.

Concluding that in all cases the standard or norm for treatment is the best interests of the child as seen from the child's own perspective (*not* that of the parents), the Commission concluded that as to category one, a very strict standard is appropriate: "Such permanent handicaps justify a decision not to provide life sustaining treatment only when they are so severe that continued existence would not be a net

benefit to the infant. . . . [The standard] *excludes* consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society."⁸⁹

As to category two, where all treatment is clearly futile, omission of "treatment" is clearly legally and ethically justifiable.

A physician is not mandated by law to render useless treatment. By "useless" is meant that continuation of the therapy cannot and does not improve the prognosis for recovery. Even if the therapy is necessary to maintain stability, such therapy should not be mandatory where the ultimate prognosis is hopeless. This does not mean that ordinary means of life-support, such as food and drink, can be discontinued merely because the ultimate prognosis is hopeless. It does mean, however, that physicians can exercise sound medical judgment and common sense in determining whether treatment is efficacious and, if it is not, then to cease the treatment. When the patient's illness is terminal and the end is near, society, through the physician, should be concerned with easing the difficult burden of death with loving care and concern. This goal is not achieved through officious death-bed burdens such as sustained heroic treatment, flawed living wills, or mandatory court approval for decisions that are best guided by medical judgment.

The physician who withdraws treatment from the terminally ill patient whose death is imminent should not be held criminally or civilly liable for such conduct when this care unduly prolongs life of the dying patient without holding out any reasonable hope of benefit. The withdrawal of treatment that only briefly forestalls imminent and inevitable death does not legally cause the death of the patient, since such conduct merely allows the underlying disease or illness to run its inevitable course.

We speak here of a limited class of cases, however. When referring to "treatment," we mean a regimen of medical care, as distinguished from ordinary care such as food and drink. Nourishment and palliative care should be given to all patients, even to those terminally-ill and from whom treatment has been withdrawn. When referring to "useless" treatment or "hopeless" cases, we mean those situations in which the decision to withdraw treatment is in essence a recognition that nothing more can be done for the patient, that the only sensible course is to withdraw treatment. The physician cannot be held liable for death here because he has not caused the patient to die. Rather, he simply has recognized, in exercise of sound medical judgment, that death from this disease or condition is inevitable *and* imminent.

As to the third category — ambiguous cases — the Commission properly acknowledges that the difficulty in these cases arises from factual uncertainties. It looks to the creation of objective medical standards learned after the new medical area of neonatology has had the opportunity to grapple with such difficult issues. It also proposes procedural

recommendations such as Infant Care Committees so that decisions concerning the treatment of severely handicapped newborns are made after consultation, with prospects for retrospective review.⁹⁰ In the context of this, it criticizes the "Baby Doe" regulations as unwarrantedly "adversarial."⁹¹

However, the important observation here is that the Commission is of the opinion that most cases involving treatment choices for the severely handicapped newborn will fall in category one. This is so since, the Commission says, the parents may not "reject treatment that is reliably expected to benefit a seriously ill newborn substantially *as is usually true if life can be saved*" (emphasis added).⁹² Down's syndrome is specifically excluded by the Commission as grounds for refusing treatment.⁹³

Meanwhile, the first "Baby Doe" regulation was challenged in District of Columbia federal district court by the American Academy of Pediatrics and other medical groups. On April 14, 1983, Judge Gerhard Gesell enjoined the rules, calling them "arbitrary and capricious" and ruling that there was insufficient evidence of an emergency adequate to waive the 60-day comment period normally required by the Administrative Procedure Act before proposed federal regulations can take effect.⁹⁴

In response, on July 5, 1983, HHS published as a proposal a second version of the regulations.⁹⁵ They reduced the size of the notice to 8½" x 11" (from 8½" x 14" in the original rules), and required that it be posted only in nurses' stations, not wards. (A principal criticism of the original regulation had been that janitors, visitors, or other medically untrained persons might be induced by a public notice to make frivolous and harassing complaints.) They added a set of requirements for state child protection agencies receiving federal financial assistance: the agencies would have to develop written procedures for dealing with treatment denial reports on a timely basis, including, "where appropriate," on-site investigation, and make provision for seeking timely court orders "to compel the provision of necessary nourishment and medical treatment."⁹⁶ They required state agencies to notify the Office for Civil Rights of each report received and of the steps taken to investigate and dispose of the report. They also added an appendix describing, with examples, the distinction between an acceptable decision not to attempt futile treatment and an unacceptable decision "for those handicapped infants . . . who could live if given treatment for a life-threatening congenital anomaly . . . to withhold treatment which is based on the infant's handicap rather than on a medical judgment . . ."⁹⁷

During the 60-day comment period, 97.5% of the 16,331 comments received supported the proposed regulation.⁹⁸ However, hospital and physician groups vehemently denounced them and the American Academy of Pediatrics proposed a detailed alternative which would

provide for no applicability of Section 504 but, based on Medicaid and Medicare regulatory authority, would require each hospital (or groups of nearby hospitals) to create an "Infant Bioethical Review Board." Such boards would be vested with authority to decide contested cases of denial of food or treatment. The American Medical Association, however, opposed the notion of any government intervention, including government mandated hospital review boards.⁹⁹

In November, 1983, according to Felicity Barringer of the *Washington Post*, "Surgeon General C. Everett Koop, on a trip with Health and Human Services Secretary Margaret M. Heckler, told her that it would be easier to take the heat for the controversial rule if he had some part in writing it. 'It's all yours,' Heckler responded, according to someone familiar with the conversation."¹⁰⁰ Koop then sponsored negotiations which included medical organizations and disability rights organizations.

The compromise result of those negotiations was publicly announced on Jan. 9 as the third and final set of regulations.¹⁰¹

The final rule is far more elaborate than its predecessors. The requirement that notice be posted is retained, although its size is reduced to 5" x 7" and it now need not be posted either in wards or in nurses' stations; it may be posted someplace "where nurses and other medical professionals can see it," such as a cafeteria or locker room, yet which is not "in area(s) where parents of infant patients will see it."¹⁰² However, there are two alternative notices, both changed in wording from that used in the previously published version of the regulations. Each is now headed "Principles of Treatment of Disabled Infants." "Notice B" states "Federal law prohibits discrimination on the basis of handicap. Under this law, nourishment and medically beneficial treatment (as determined with respect for reasonable medical judgments) should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairment." It lists the telephone numbers of the state child protective service and of the HHS OCR toll-free 24-hour number, pledges that the identity of callers will be kept confidential, and notes that retaliation against callers is prohibited.¹⁰³

"Notice A" is similar, but it begins, "It is the policy of this hospital, consistent with federal law" and then states the same standard of care. Above the number of the state and federal agencies, it lists the number of a "hospital contact point," either "for further information, or to report suspected noncompliance."¹⁰⁴ Hospitals may use "Notice B" if they 1) officially adopt the standard of care described in the notice, 2) agree to maintain confidentiality of those who make reports and not to retaliate against them (although a "hospital need not . . . forego management prerogatives with respect to anyone who might abuse the hospital's procedures by, for example, willfully making false or malicious calls," and 3) implement "a procedure for review of treat-

ment deliberations and decisions to which the notice applies, such as (but not limited to) an Infant Care Review Committee.”¹⁰⁵

A model committee is outlined in the regulations, following basically the format proposed by the American Academy of Pediatrics, but everything suggested about the committee by the regulations is purely advisory. Its composition and procedures — and even whether there is to be a committee at all, so long as there is some procedure for review of treatment deliberations — are left entirely to the discretion of each hospital.¹⁰⁶

Appended to the final rule is a set of guidelines for HHS investigations. “Unless impracticable,” if a hospital has an Infant Care Review Committee, federal investigators will wait 24 hours after receipt of any report of denial of treatment to allow that committee to consider the case and make its analysis and recommendations. An HHS medical consultant will contact the Committee. After receiving the Committee’s report, and with input from the medical consultant, the investigators will determine whether an on-site visit is necessary. The supplementary information published with the recommendation emphasizes that the Office of Civil Rights “undertakes a careful screening of complaints in an effort to avoid unnecessary on-site investigations.”¹⁰⁷ Should such an investigation be authorized, the first step of the investigators will be to meet with the Infant Care Review Committee.

Before promulgation of the final rule, disability rights groups had emphasized the importance of securing a physical examination of the child by the medical consultant. For example, in its comment letter, the Spina Bifida Association of America had emphasized, “The key to effective enforcement is securing an independent medical examination of children allegedly being denied treatment, by a physician or medical team both skilled in modern treatment techniques *and* committed to the equal treatment principle. . . . The only way to ensure effective enforcement is to give disability rights groups like SBAA the ability to recommend *which* expertise centers and expert consultants are used by the regional OCR offices to conduct the independent medical examinations.”¹⁰⁸ The Department firmly rebuffed this concept of the role of the medical consultant. “It is important that all interested groups understand the precise and limited role of the OCR medical consultants. Their function is *not* . . . to conduct a personal, independent examination of the infant. . . .”¹⁰⁹ Instead, the Department said, it is only to examine the medical records, in some cases discuss the matter with the attending physician, and then give investigators “an opinion as to whether medically beneficial treatment was provided.”¹¹⁰

The standard of care to be enforced is set forth in “Interpretative guidelines relating to the applicability of this part to health care for handicapped infants: . . . [H]ealth care providers may not, solely on the basis of present or anticipated physical or mental impairments of

an infant, withhold treatment or nourishment from the infant who, in spite of such impairments, will medically benefit from the treatment or nourishment.”¹¹¹ The guidelines emphasize that “treatment that will do no more than temporarily prolong the act of dying of a terminally ill infant is not considered treatment that will medically benefit the infant,”¹¹² and that “[i]n determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgments in selecting among alternative courses of treatment will be respected.”¹¹³

Much of the effectiveness of Section 504’s enforcement will, of course, depend on how “medically beneficial treatment” is construed, and on precisely how wide a variance is tolerated as “reasonable medical judgment.” The supplementary information keyed to these guidelines places considerable emphasis on the “principle of respecting reasonable medical judgments;” the Department will not “seek to engage in second-guessing of reasonable medical judgments regarding medically beneficial care.”¹¹⁴ However, it is stated that “the Department also recognizes that not every opinion expressed by a doctor automatically qualifies as a reasonable medical judgment,” and gives the example of “a doctor’s opinion that available corrective surgery to save the life of a Down’s syndrome infant should be withheld.”¹¹⁵ The section of the supplementary information purporting to deal with “Medically Beneficial Treatment” does not explain that term;¹¹⁶ however, another section is quite helpful and positive.

[I]f . . . surgery would be medically beneficial, in that it would be likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding . . . fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is *because* of the handicap and *in spite of* the infant’s being qualified to receive the surgery.¹¹⁷

There is one significant and troubling omission from the interpretative guidelines. The corresponding appendix in the proposed rules contained a paragraph which read:

[T]he basic provision of nourishment, fluids, and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment. Even if a handicapped infant faced imminent and unavoidable death, no health care provider should take upon itself to cause death by starvation or dehydration. Routine nursing care to provide comfort and cleanliness is required to respect the dignity of such an infant. To deny these forms of basic care to handicapped individuals would constitute discrimination contrary to section 504.¹¹⁸

No trace of such a view appears in the final regulations. The supplementary information notes that “The American Society for Parenteral and Enteral Nutrition stated that although there are no circumstances justifying ‘withholding oral feeding through a working digestive tract in any patient capable of digesting food, in whole or in part,’ there may be ‘limited circumstances’ in which not providing nourishment

through intravenous means 'may be appropriate.'" ¹¹⁹ Without directly replying to that comment, the Department's "Response" states, "The imprudence of seeking to speculate on the outcome of applying Section 504 in a wide variety of specific factual circumstances was underscored by some of the comments received," and goes on to say that, in balancing "the utility of providing some examples to assist in understanding the analytical framework of the statute" and "the need to allow individual attention to specific factual circumstances," it was decided to list only "examples dealing with Down's syndrome, spina bifida, anencephaly, and extreme prematurity."¹²⁰ The unfortunate implication is that, in contrast with its emphatic assertion of a universal duty to provide nutrition enunciated in the proposed rules, HHS now regards at least some denial of intravenous feeding to be within the gray area to be decided case by case.

United States of America v. University Hospital

The "Baby Doe" regulations are based on Section 504 of the Rehabilitation Act of 1973. ¹²¹ Section 504 reads:

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

The government has a responsibility under Section 504 to investigate all claims of discrimination on account of handicap in federally assisted programs. Congress has similarly charged the executive branch in companion civil rights laws to pursue complaints of discriminatory conduct based on race, sex, or national origin in programs receiving federal funding.

Section 504 was enacted by Congress to ensure that recipients of federal financial assistance, including providers of "health services" operate their federally assisted programs without discrimination against handicapped individuals. ¹²² Health care services must be provided to handicapped patients "on a basis of equality with those not handicapped."¹²³ Handicapped patients, therefore, must be given "full and unquestioned access to the same type and duration of inpatient treatment" as is provided nonhandicapped patients. ¹²⁴ Thus, just as Title VI provides that patients in federally assisted health care programs cannot be treated differently on the basis of their race, color, or national origin, Section 504 provides similar protection against discrimination on the basis of handicap.

Section 504 is, in essence, an equal treatment, nondiscrimination standard. Programs or activities receiving federal financial assistance may not deny a benefit, service or treatment solely on grounds of a person's handicap just as they may not deny a benefit or service on grounds of a person's race.

At the time of the New York State court rules on the Baby Jane Doe case, there was no version of the "Baby Doe" regulations then in force. The first set was under injunction, the comment period on the second (proposed) version had only recently ended, and the third, final version was yet to be issued. Thus, when the HHS Office for Civil Rights sought Baby Jane's records from University Hospital (S.U.N.Y. Stony Brook), it did so, not under the authority of the "Baby Doe" regulations, but under that of the statutory provision itself, and of pre-existing regulations which require federal financial assistance recipients to "permit access . . . to such of its books, records, accounts, and other sources of information . . . as may be pertinent to ascertain compliance" ¹²⁵

When the hospital refused to turn over the requested records, the Justice Department instituted suit. On Nov. 17, 1983, District Judge Leonard Wexler granted the hospital's motion for summary judgment, denying the federal government access to the records. ¹²⁶ Like the New York intermediate appellate court, the federal district court rendered a fairly narrow, fact-based ruling. Judge Wexler rejected the hospital's reliance on the doctor-patient evidentiary privilege and on the constitutional right of privacy. ¹²⁷ He characterized the latter argument as "extremely weak."

In the instant action, plaintiff is, at least implicitly, alleging the possibility that the parents of Baby Jane Doe, in refusing their consent to surgical procedures, were not acting in the best interests of the child. It would be highly paradoxical if an individual's right to privacy could be asserted by that individual's parent or guardian, purportedly acting in that individual's own best interests, for the purpose of precluding an inquiry into the question of whether the parent or guardian was in fact acting in the individual's best interests. . . . Under different facts, . . . it is quite possible that an assertion by a parent on behalf of a handicapped child of the child's right to privacy made to preclude the release of the child's medical records to officials would not be sustained as a valid invocation of the constitutional right to privacy.

. . . [T]he Court need not discuss the extent to which the statute authorizes challenges [sic] by the federal government to *unreasonable* choices of medical treatment for handicapped children. We may note, however, that it is quite possible that the statute does authorize such challenges. If so, this would appear to be a constitutional exercise of federal legislative power, given the federal interest in preventing discrimination against the handicapped in hospitals receiving federal financial assistance ¹²⁸

However, Judge Wexler held that, since the regulation at issue allowed federal access to institutional records only "to ascertain compliance," if the institution was "clearly not violating" Section 504, the government could not obtain access. ¹²⁹ This was the situation in the Baby Jane Doe case, he held, for two reasons: first, because the hospital was denying surgery, not on the basis of the child's handicap, but because the parents had refused consent and it had no legal right to provide the surgery without that consent; second, because "the papers

submitted to the Court demonstrate conclusively that the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child."¹³⁰

Judge Wexler's decision was unfortunate, not only because, as this article has earlier demonstrated,¹³¹ he misapprehended the facts about Baby Jane Doe's medical condition and prospects, but also because he seemed to hold that a medical institution could shelter itself behind a parental refusal to consent to treatment as an absolute bar to enforcement of the anti-discrimination statute. It is true that a physician or medical institution cannot ordinarily perform surgery or provide other treatment to a minor when the minor's parents or guardian refuse to consent. However, that refusal does not vitiate the hospital and the physician's obligation to render clearly necessary (especially life saving) treatment to its patient: the child. Medical personnel have the ability to seek a court order (or, as in the case of New York, at least the involvement of the state Child Abuse and Neglect Agency) to overcome the refusal to consent in order to protect the life of the child. Indeed, such governmental intervention is routinely sought when parental religious objections prevent lifesaving treatment. If it is the practice of a physician or hospital to employ these mechanisms to secure treatment for a nonhandicapped child whose parents refuse consent to treatment, then failure to do so when a child is handicapped, solely because of the handicap, is prohibited discrimination.

The Justice Department appealed from Judge Wexler's decision to the Second Circuit Court of Appeals. On Feb. 23, 1984, a panel of that court affirmed the district court's decision by a 2-1 majority, but on far more troubling grounds than those employed by the lower court.

The Court of Appeals rejected the view "that the government was required to establish some evidence of unlawful discrimination as a condition to obtaining the requested records."¹³² Instead, it concentrated on whether denial of lifesaving treatment to a disabled newborn could be regarded as "unlawful discrimination" at all under Section 504.

The court's answer was no. It said that Congress had never discussed or anticipated the application of Section 504 to medical treatment decisions concerning disabled newborns while enacting the provision. It said that Congress, in other contexts, had expressed a disinclination to regulate health care decisions. It expressed skepticism that a disabled infant could be seen as "otherwise qualified" for medical treatment:

As the mainstream of cases under Section 504 exemplifies, the phrase "otherwise qualified" is geared toward relatively-static programs or activities such as education, . . . employment, . . . and transportation systems. . . . As a result, the phrase cannot be applied in the comparatively fluid context of

medical treatment decisions without distorting its plain meaning. In common parlance, one would not ordinarily think of a newborn infant suffering from multiple birth defects as being "otherwise qualified" to have corrective surgery performed or to have a hospital initiate litigation seeking to override a decision against surgery by the infant's parents.¹³³

The court relied heavily on the "complexity" of medical decisions. "[T]he government has taken an oversimplified view of the medical decisionmaking process. Where the handicapped condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory.'"¹³⁴

These concerns are groundless. A conclusive response appears in the "Supplemental Information" accompanying the final "Baby Doe" rule:

[W]here the handicapping condition and the condition to be treated are the same . . . the "handicap" is the physical or mental impairment the infant has or will have (or "is regarded as having") after completion of the treatment under consideration. In the case of an infant born with myelomeningocele, for example, the treatment which must be considered is surgery to close the protruding sac to prevent infection and other potentially fatal consequences. The "handicap" is the physical and/or mental impairment the infant is regarded as likely to have in future life. To the extent the myelomeningocele itself or other complications . . . present, in the exercise of reasonable medical judgment, contraindications to the surgery, the infant is not able to benefit, in spite of his or her handicap, from the surgery. However, if the surgery would be . . . likely, in the exercise of reasonable medical judgment, to bring about its intended result of avoiding infection or other fatal consequences, then failure to perform the surgery because of the anticipated impairments in future life offends section 504, as the withholding of surgery is because of the handicap and in spite of the infant's being qualified to receive the surgery.¹³⁵

As the dissent pointed out, the majority evaded the clear intent of Congress to analogize discrimination against the disabled to discrimination on the basis of race.

A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judgment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. . . .

The logic of the government's position on these aspects of the case is thus about as flawless as a legal argument can be.¹³⁶

As we write, a Justice Department motion for a rehearing *en banc* is pending before the full Second Circuit. Whatever happens to that motion, eventual recourse to the Supreme Court is likely.

The Constitutional Issue Is Ripe

Whatever may be the ultimate outcome of the statutory construction issue raised in *United States of America v. University Hospital of the State University of New York at Stony Brook*, it is virtually cer-

tain that sooner or later the constitutional issues raised by denial of treatment cases will have to be faced, ultimately by the Supreme Court. As we write, there is legislation pending in Congress (one version has been passed by the House of Representatives, while another has been reported out of committee in the Senate) which would specifically address the nontreatment issue in terms that could leave no judicial doubt about Congressional intent to face it squarely.¹³⁷

Should a law that passes regulate the area in some form, it is virtually certain that the American Medical Association or some other group of medical professionals will challenge it, relying on a form of the familial privacy doctrine. It is almost as certain that some day a child with a disability will be denied treatment in a state hospital or in some other circumstances constituting state action and someone with standing to raise the child's rights will contend that the Constitution is being violated by that denial.

In either case, the resulting litigation will undoubtedly see a clash of the contending constitutional theories: the parents' asserted right to privacy versus the child's asserted right to life and equal protection of the law. The Court will decide no more crucial case in our generation. It will test whether we, as a nation, still maintain, as Justice John Marshall Harlan wrote, that "In view of the Constitution, in the eye of the law, there is in this country no superior . . . class of citizens. . . . In respect of civil rights, all citizens are equal before the law. The humblest is the peer of the most powerful."¹³⁸

REFERENCES

1. A recent case attracting considerable public attention was that of Pamela Hamilton, the 12-year-old Tennessee cancer victim for whom treatment was ordered over the objections of her father. See, e.g., A. Press, N. Cooper, M. Hager and L. Howard, "The Case of Baby Jane Doe," *Newsweek*, Nov. 28, 1983, p. 45.
2. Ala. Code §26-14-1(2)(1977); Alaska Stat. §47.17.070(5)(Supp. 1981); Am. Samoa Code tit. 21, §2901(3)(Supp. 1979); Ariz. Rev. Stat. Ann. §36-2281 (Supp. 1975-1983); Ark. Stat. Ann. §42-807(c)(Supp. 1981); Cal. Penal Code §11165(c)(West Supp. 1982); Colo. Rev. Stat. §19-1-103(20)(d) (1978 & Supp. 1981); Conn. Gen. Stat. Ann. §46b-120(b)(Supp. 1980); Del. Code Ann. tit. 31, §301(3)(1974); C.C. Code Ann. §16-2301(9)(B)(1981); Fla. Stat. Ann. §39.01(27)(West Supp. 1981); Ga. Code Ann. §15-11-2(8)(A)(1981); Guam Gov't Code §9120.20(C)(3)(1983); Hawaii Rev. Stat. §350-1(a)(Supp. 1981); Idaho Code §16-1602(n)(1)(1979); Ill. Rev. Stat. ch. 37, §702-4(1)(1983); Ind. Code Ann. §31-6-4-3(a)(1) & (f)(West Supp. 1983-84); Iowa Code Ann. §232.2(5)(e)(West Supp. 1981); Kan. Stat. Ann. §38-802(g)(1)(1981); Ky. Rev. Stat. §199.01(6)(Repl. Vol. 1980); La. Rev. Stat. Ann. §1299.36.1(West Supp. 1983); Me. Rev. Stat. Ann. tit. 22, §4002(1)(Supp. 1981); Md. Ann. Code art. 72A, §4(d)(Repl. Vol. 1978); Mass. Gen. Laws Ann. ch. 119, §51A(West Supp. 1981); Mich. Comp. Laws Ann. §722.622(d)(Supp. 1981-1982); Minn. Stat. §626.556(Supp. 1983); Miss. Code Ann. §43-21-105(1)(1981); Mo. Rev. Stat. §210.110(1)(5)(Supp. 1982); Mont. Code Ann. §41-3-102(3)(c)(1981); Neb. Rev. Stat. §28-710(3)(a)(Supp. 1979); Nev. Rev. Stat. §128.014(2)(1983 Supp.);

- N.H. Rev. Stat. Ann. §169-C:3 xix(b)(Supp. 1981); N.J. Stat. Ann. §9:6-8.21(c)(4)(a)(West Supp. 1982); N.M. Stat. Ann. §30-6-1(A)(2)(Cum. Supp. 1981); N.Y. Soc. Serv. Law §371(4-a)(McKinney 1976&Supp. 1982); N.C. Gen. Stat. §7A-517(21)(Repl. Vol. 1981); N.D. Cent. Code §27-20-5(Supp. 1981); Ohio Rev. Code Ann. §2151.03(C)(Page Repl. Vol. 1976); Okla. Stat. Ann. tit. 21, §845(West Supp. 1982); Or. Rev. Stat. §418.740(1)(b)(Repl. Part 1979); Pa. Stat. Ann. tit. 42, §6302 (Purdon 1981 Pamph.); P. R. Laws Ann. tit. 3, §211m (Supp. 1979); R. I. Gen. Laws §40-11-3(Supp. 1983); S.C. Code Ann. §20-7-490(c)(3)(Law. Co-op. Supp. 1981); S.D. Comp. Laws Ann. §26-8-6(4)(1976); Tenn. Code Ann. §37-202(6)(iv)(Supp. 1981); Tex. Fam. Code Ann. §34.01(Vernon 1975); Utah Code Ann. §78-3a-2(17)(1977); Vt. Stat. Ann. tit. 33, §632(12)(B)(Repl. Vol. 1981); V.I. Code Ann. tit. 19, §172(Supp. 1981); Va. Code §16.1-228(A)(2)(Supp. 1981); Wash. Rev. Code Ann. §26.44.020(12)(Supp. 1983); W. Va. Code Ann. §49-1-3(Repl. Vol. 1980); Wisc. Stat. Ann. §48.981(1)(d)(West 1979); Wyo. Stat. §14-6-201(a)(xvi)(C)(1978).
3. 375 Mass. 733, 379 N.E.2d 1053 (1978).
 4. *Id.* at 755, 379 N.E.2d at 1066.
 5. *In re Storar*, 52 N.Y.2d 363, 380-81, 420 N.E.2d 664, 73, 438 N.Y.S.2d 266, 275 (1981). See also, *In re Wachlin*, 309 Minn. 370, 245 N.W.2d 183 (1976); *In re Simpson*, 65 Misc.2d 658, 317 N.Y.S.641 (Fam. Ct. Ulster Co. 1971), *aff'd*, 37 App.Div.2d 668, 323 N.Y.S.2d 253 (3d Dept. 1971), *aff'd* 29 N.Y.2d 900, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972); *In re Green*, 448 Pa. 338, 286 A.2d 681 (1971); *State v. Perricone*, 37 N.J. 463, 151 A.2d 751, *cert. den.* 371 U.S. 890 (1962); *People ex. rel. Wallace v. Labenz*, 411 Ill. 618, 104 N.E.2d 769, *cert. den.* 344 U.S. 824 (1952); *Power of Public Authorities to Order Medical Care for a Child Over Objection of Parent or Guardian*, Anno., 30 A.L.R.2d 1138 (1953).
 6. See, e.g., *Jehovah's Witnesses v. King County Hospital Unit*, 390 U.S. 598 (1968), *aff'g.* 278 F.Supp. 488 (W.D. Wash. 1967); *In re Ivey*, 319 So. 2d 53 (Fla. Dist. Ct. App. 1975); *In re Clark*, 21 Ohio Ops. 2d 86, 185 N.E.2d 128 (Ct. C.P., Dom. Rel. Div. 1962).
 7. 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct., Bronx Co. 1979).
 8. *Maine Medical Center v. Houle*, Civ. No. 74-145 (Super. Ct., Cumberland City, Me., Feb. 14, 1974).
 9. 238 App. Div. 128, 263 N.Y.S. 552 (2d Dep't 1933).
 10. See Annot., 10 A.L.R. 1137 (1921).
 11. Lafave and Scott, *Criminal Law*, §68, at 535 (1972).
 12. 1 Wharton *Criminal Law* 484 (14th ed. 1978).
 13. 77 Mich. App. 8, 208 N.W.2d 656 (1977).
 14. 77 Mich. App. at 17 n. 7, 208 N.W.2d at 660 n.7. See also *Harrington v. State*, 547 S.W.2d 621 (Tex. Crim. App. 1977) (parents convicted of homicide for starvation of son); *State v. Nicholson*, 585 P.2d 60 (Utah 1978) (mother convicted of homicide for starvation of infant); *Zessman v. State*, 94 Nev. 28, 573 P.2d 1174 (1978) (mother convicted of homicide for starvation of infant); *Commonwealth v. Hall*, 322 Mass. 523, 78 N.E.2d 614 (1948) (homicide conviction of a father who withheld food from his infant son affirmed); *People v. Burden*, 72 Cal. App. 3d 603, 140 Cal. Rptr. 282 (Cal. Ct. App. 1977) (homicide conviction affirmed for parent who starved child).
 15. Robertson, "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," 27 *Stan. L. Rev.*, 213, 216 (1975).
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34. *Id.* at 6-7.
35. *Id.* at 7.
36. *Id.*
37. *Id.* at 7-8.
38. *Id.* at 8-9.
39. *Id.* at 9.
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41. *Id.*
42. *Id.*
43. *Weber, Guardian Ad Litem for Baby Jane Doe v. Stony Brook Hospital*, No. 3467E (N.Y. App. Div. Oct. 21, 1983), slip op. at 3.
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68. *Id.* at 33.
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109. *Id.*
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112. *Id.* at Appendix C(a)(2).
113. *Id.* at Appendix C(a)(3).
114. 49 *Fed. Reg.* at 1630.
115. 49 *Fed. Reg.* at 1630.
116. *Id.*
117. *Id.* at 1637 (emphasis in original).
118. 48 *Fed. Reg.* at 30852.
119. 49 *Fed. Reg.* at 1631.
120. *Id.* at 1632.
121. 29 U.S.C. §794 (Supp. V 1981).
122. S. Rep. No. 93-1297, 93d Cong., 2d Sess. 37 (1974).
123. *Doe v. Colautti*, 592 F.2d 704, 709 (3d Cir. 1979).
124. *Jennings v. Alexander*, 518 F.Supp. 877, 885 (M.D. Tenn. 1981); *rev'd on other grounds*, 715 F.2d 1036 (6th Cir. 1983), *petition for cert. pending* (No. 83-727).
125. 45 C.F.R. §80.6(c)(1982).
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127. *Id.*, slip op. at 8-9
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132. *United States of America v. University Hospital, State University of New York at Stony Brook*, 729 F.2d at 150.
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135. 49 *Fed. Reg.* at 1637.
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137. S. 1003, 98th Cong., 2d Sess. (1984) and H.R. 1904, 98th Cong. 2d Sess. (1983).
138. *Plessy v. Ferguson*, 163 U.S. 537, 559 (1896) (Harlan, J., dissenting).

APPENDIX

**IN THE CIRCUIT COURT FOR
THE COUNTY OF MONROE**

STATE OF INDIANA

IN THE MATTER OF THE TREATMENT AND CARE OF INFANT DOE

CAUSE NO. GU 8204-004A

DECLARATORY JUDGMENT

This matter came to be heard by the Court under certain extraordinary condi-

tions concerning the emergency care and treatment of a minor child born at the Bloomington Hospital.

The Court was contacted at his residence by representatives of the Bloomington Hospital. On the basis of representations made by those representatives, the Court quickly determined that an extreme emergency existed.

The Court further determined that the Judge of the Monroe Circuit Court had been contacted concerning this matter and was unable to attend the emergency hearing, and the Court personally contacted the Judge of the Monroe Circuit Court who directed this Court to proceed with hearing. Thereafter, hearing was held on the Sixth Floor of the Bloomington Hospital at approximately 10:30 p.m., Saturday, the 10th day of April, 1982.

The following persons were present: John Doe, natural father of Infant Doe, with counsel, Andrew C. Mallor, Esquire; Maggie Keller, Gene Perry, Administrative Vice-Presidents of Bloomington Hospital; Len E. Bunger, counsel for Bloomington Hospital; Dr. Walter L. Owens, Dr. William R. Anderson, Dr. Brandt L. Ludlow, obstetricians admitted to practice in the State of Indiana with privileges at Bloomington Hospital, Doctor Owens being the obstetrician in attendance at delivery of Infant Doe; Dr. Paul J. Wenzler, family practitioner with pediatric privilege at Bloomington Hospital and who has attended to Mr. and Mrs. Doe's other two children after their birth; Dr. James J. Schaffer and Dr. James J. Laughlin, pediatricians holding pediatric privileges at Bloomington Hospital. (Mrs. Doe was physically unable to attend.)

The Court thereafter heard evidence. Doctor Owens spoke for and on behalf of the obstetric group that delivered the Infant Doe, advising the Court that at approximately 8:19 p.m. on the evening of April 9, Infant Doe was born to Mary Doe in an uneventful delivery, but that shortly thereafter it was very apparent that the child suffered from Down's Syndrome, with the further complication of tracheoesophageal fistula, meaning the passage from the mouth to the stomach had not appropriately developed and, in fact, were the child to be fed orally, substances would be taken into the lungs and the child most likely would suffocate.

Doctor Owens further stated that he had been previously advised that Doctor Wenzler would serve as practitioner for Infant Doe and that he was further advised that Doctor Wenzler, when faced with extraordinary cases, routinely consulted with Doctor Schaffer. Doctor Schaffer was at the Bloomington Hospital at that time and was called by Doctor Owens and was requested to examine the baby. Doctor Wenzler was notified. Doctors Owens, Schaffer and Wenzler consulted; Doctors Wenzler and Schaffer indicated that the proper treatment for Infant Doe was his immediate transfer to Riley Hospital for corrective surgery. Doctor Owens, representing the concurring opinions of himself, Drs. Anderson and Ludlow, recommended that the child remain at Bloomington Hospital with full knowledge that surgery to correct tracheoesophageal fistula was not possible at Bloomington Hospital and that within a short period of time the child would succumb due to inability to receive nutrients and/or pneumonia.

His recommended course of treatment consisted of basic techniques administered to aid in keeping the child comfortable and free of pain. Doctor Owens testified that, even if surgery were successful, the possibility of a minimally adequate quality of life was non-existent due to the child's severe and irreversible mental retardation.

Doctor Schaffer testified that Doctor Owens's prognosis regarding the child's mental retardation was correct, but that he believed the only acceptable course of medical treatment was transfer to Riley Hospital in Indianapolis for repair of tracheoesophageal fistula.

Doctor Wenzler concurred in Doctor Schaffer's proposed treatment. Doctor Laughlin testified that he concurred in the opinions of Doctors Schaffer and Wenzler, and he differed with Doctor Owens's opinion in that he knew of at least

three instances in his practice where a child suffering from Down's Syndrome had a reasonable quality of life. However, he related no knowledge of treatment of children with co-existent maladies of Down's Syndrome and tracheoesophageal fistula.

Doctor Owens testified that he presented Mr. and Mrs. Doe with the two recommended courses of treatment and requested that they come to a decision. Doctor Owens understood that Doctors Schaffer and Wenzler also discussed their recommendations with Mr. and Mrs. Doe.

Mr. Doe testified that he had been a licensed public school teacher for over seven years and had on occasion worked closely with handicapped children and children with Down's Syndrome and that he and his wife felt that a minimally acceptable quality of life was never present for a child suffering from such a condition. Mr. Doe was lucid and was able to make an intelligent, informed decision.

Mr. Doe further testified that, after consulting with Doctor Owens, Schaffer, Wenzler and Laughlin, he and his wife have determined that it is in the best interest of the Infant Doe and the two children who are at home and their family entity as a whole, that the course of treatment prescribed by Doctor Owens should be followed, and at approximately 2:45 p.m., he and his wife, in the presence of each other and witnesses, signed a statement directing Doctor Owens to proceed with treatment of the infant, the content of said statement, omitting names and dates, is as follows:

The undersigned being the parents of Infant _____ born _____ at Bloomington Hospital, have had explained to them and they acknowledge that they understand, the course of this treatment for Infant _____ as indicated appropriate for Infant _____ by Doctors Walter L. Owens, James J. Laughlin, James J. Schaffer and Paul J. Wenzler.

Acknowledging their understanding and the consequences of all of the above proposals made by all of the above four physicians, that they direct that the course of treatment shall proceed as directed by Dr. Walter Owens, M.D., who does not have privilege to practice pediatrics at Bloomington Hospital.

Mr. Len E. Bunger, on behalf of Bloomington Hospital made a statement that it was the hospital's primary function to reduce morbidity and mortality and that the hospital did not have the knowledge or the authority to make diagnoses or to prescribe treatment and, for that reason, had requested the Court to make a ruling in this matter.

The Court, having heard evidence, recesses and thereafter determines as follows:

1. All qualified persons available to present evidence in this matter were present and thus appointment of a guardian ad litem for Infant Doe was not required to proceed further in this hearing.

2. The Court appeared solely as a representative of the State of Indiana and the laws of the State of Indiana require that the parents be sufficiently informed, as they are in this instance, and any personal feelings of the Court should not intervene.

ISSUE

Do Mr. and Mrs. Doe, as the natural parents of Infant Doe have the right, after being fully informed of the consequences, to determine the appropriate course of treatment for their minor child?

CONCLUSION

It is the opinion of this Court that Mr. and Mrs. Doe, after having been fully

informed of the opinions of two sets of physicians, have the right to choose a medically recommended course of treatment for their child in the present circumstances.

ORDER

The Court, being sufficiently advised, now directs the Bloomington Hospital to allow treatment prescribed by Dr. Walter L. Owens, as directed by the natural parents, Mr. and Mrs. Doe, for the Infant Doe.

The Court further directs that the Clerk of this Court assign a cause number and enter this cause upon the guardianship docket and fee book of this Court.

The Court further appoints the Monroe County Department of Public Welfare as guardian ad litem for the Infant Doe to determine whether the judgment of this Court shall be appealed.

DATED this 12th day of April, 1982.

(s)

JOHN G. BAKER
Judge, Monroe Superior Court
Division III, and as
Special Judge, Monroe Circuit Court

cc: Len E. Bunger

Andrew C. Mallor

Betty K. Mintz, Counsel

Monroe County Department of Public Welfare

STATE OF INDIANA COUNTY OF MONROE

SS: In the Monroe Circuit Court Juvenile Division

IN RE: THE MATTER OF BABY DOE,
A CHILD IN NEED OF SERVICES UNDER THE AGE OF EIGHTEEN

CAUSE NUMBER: JV8204-038A

Transcript of Hearing Held on Petition for
Emergency Detention Held on April 13, 1982

THE HONORABLE C. THOMAS SPENCER, JUDGE PRO-TEMPORE

APPEARANCES:

Barry S. Brown, Prosecuting Attorney

Lawrence J. Brodeur, Deputy Prosecuting Attorney

Court House

Bloomington, Indiana

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226 South College Square
Bloomington, Indiana 47401
ATTORNEY FOR DR. JAMES LAUGHLIN, INTERESTED PARTY & WITNESS

BE IT FURTHER REMEMBERED, that on the 14th day of April, 1982, The Court having taken this matter under advisement and being duly advised now makes the following findings:

1. That Baby Doe is a four-day old child with Down's Syndrome and a further complication of tracheoesophageal fistula, meaning the esophagus is not properly connected to the stomach.

2. That without corrective surgery the child will die due to its inability to receive nourishment.

3. That this Court has previously determined that the parents have the right to choose a medically recommended course of treatment for their child at this time.

4. That two alternative treatment plans have been presented to the parents. The first is corrective surgery at Riley Hospital. The second would be to take no action knowing that the child will die as a result thereof.

5. That this Court previously determined that these are medically recommended treatment modes and no evidence was presented concerning this issue.

6. That the parents, after consultation with all physicians concerned, chose the second treatment mode of allowing the child to succumb.

7. That this decision was made knowingly, voluntarily, and with the advice of medical experts.

8. That the parents in accordance with their religious beliefs have had the child baptized and seen that it has received the last rites.

9. That the child has, at the expense of the parents, been placed in a private room at the Bloomington Hospital under the supervision of private duty nurses hired by the parents where it is receiving no nourishment and under doctors' orders will receive pain medications if they appear necessary.

10. That this Court has previously conducted a hearing concerning this matter and entered a declaratory judgment, a copy of which is attached to this order.

11. That the Monroe County Child Protection Team of the Monroe County Department of Public Welfare, which was previously appointed Guardian ad Litem for the Baby Doe, conducted a hearing concerning this matter and decided not to appeal this Court's previous decision.

12. That the State of Indiana has filed a Petition for Emergency Detention pursuant to I.C. 31-6-6-4 requesting that the Monroe County Department of Public Welfare take immediate custody of the Baby Doe and provide emergency treatment to said child.

13. That in order for the Court to issue such an order it must be shown that the child is a child in need of services as defined in I.C. 31-6-4-3.

14. That after considering the evidence the Court finds that the State has failed to show that this child's physical or mental condition is seriously impaired or seriously endangered as a result of the inability, refusal, or neglect of his parents to supply the child with necessary food, and medical care.

WHEREFORE, the Court now DENIES the State's Petition for Emergency Detention.

So ordered this 14th day of April, 1982.

C. Thomas Spencer, Judge Pro-Tempore.