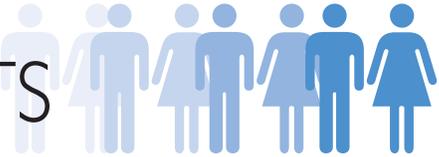


EXTREME PREMATURITY AND PARENTAL RIGHTS



AFTER *BABY DOE*

by JOHN A. ROBERTSON

The Child Abuse Amendments of 1984 established the norms for treating disabled newborns, but they did not address the treatment of premature babies. Parents and physicians need a framework for decisionmaking. A decision handed down recently by the Texas Supreme Court is a step forward.

Contemporary ethical and legal norms hold that all human beings born alive should be treated equally, regardless of disability. Yet there is a strong sense that some lives are so diminished in capacity for interaction or experience that little good is achieved by providing medical treatments necessary to keep them alive. In addition, many persons believe that the parents who have the chief responsibility to provide care should have a dominant say in whether their children are treated.¹

Before 1970, the question of whether to withhold treatment from such newborns was rarely contested. The ancient Spartan practice of exposing babies on hillsides and keeping those that survived had a contemporary counterpart in the common medical

practice of simply not treating those born with major handicaps. As late as 1972, some doctors and parents thought it appropriate to withhold from children with Down syndrome or spina bifida surgery necessary for their survival. Noted pediatricians published articles in major medical journals reporting the withholding of life-saving treatment from infants with many kinds of disabilities.² Surveys of doctors showed that these practices were not exceptions.³

In the mid-1970s, the emerging discipline of bioethics began to question the ethics and legality of these practices even as they were publicized. Courts became more willing to order treatment over parental wishes, though neither a uniform response nor clear guidelines emerged.⁴ It took the Baby Doe controversy of 1981 and the federal Child Abuse Amendments (CAA) of 1984 to produce a rough consensus about the norms and practices that would govern this area.⁵ Since passage of the CAA, ethical

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and legal controversy over parental authority to withhold treatment from handicapped or disabled newborns, although still featured in bioethics courses and texts, has largely ceased.

Yet one aspect of the controversy was never directly resolved. Because the Baby Doe controversy had focused on infants with genetic and chromosomal anomalies, the extent to which the CAA norms might require changes in practices with very premature and low birth weight infants remained open, even though it was occasionally mentioned in articles.⁶ As a result, physicians and hospitals that insisted on treating premature newborns over parental objections were vulnerable to tort actions by parents. In January 1998, a Houston jury awarded \$43 million in damages to parents whose daughter, born at twenty-three weeks and weighing 614 grams, was resuscitated and initially treated without their consent, leading to a life with severe mental and physical impairments. Texas appellate courts eventually reversed that decision, but in the five-year interim, hospitals and physicians faced the prospect of huge damage awards if they sought to treat cases of extreme prematurity in accordance with CAA standards against the parents' wishes. This article reviews the controversy and assesses the extent to which parents should have the right to decide not to treat severely premature newborns.

The Baby Doe Controversy

The Baby Doe controversy, which played such a key role in clarifying norms and practices in this area, arose in 1981 in Bloomington, Indiana. Parents of a newborn child with Down Syndrome and a tracheal-esophageal fistula refused to consent to a standard operation that would enable the child to take food and water by mouth. The hospital and doctors sought approval from a family court to perform surgery against the parents' wishes. A probate court denied the request on the ground that



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the parents had the right to make the decision. The child's guardian *ad litem* appealed the case unsuccessfully to the Indiana and then to the United States Supreme Court. While the case was pending, it drew wide media coverage and the attention of right-to-life and disability rights groups. Before the United States Supreme Court could rule on the guardian's appeal, Baby Doe died.

Groups opposed to the outcome in the Baby Doe case sought relief from federal officials in the Reagan administration sympathetic to right to life concerns. Soon after, the Department of Health and Human Services issued regulations that required newborn nurseries and neonatal intensive care units receiving federal funds to post notice of a hotline number to report cases of discrimination in treatment based on handicap. When reports came in, "Baby Doe squads" of doctors, nurses, and social workers were dispatched to hospitals, demanding medical records to determine whether treatment was inappropriately denied.⁷

Greatly disturbed by these interventions, the pediatric and hospital community sued to invalidate them on the ground that they were beyond federal regulatory authority. A federal district court enjoined enforcement because of the government's failure to follow legal requirements for new regulations.⁸ The administration then complied with those requirements and issued slightly less intrusive regulations. Further litigation ensued. The United States Supreme Court eventually ruled, in *Bowen v. American Hospital Association*, that Congress had not authorized federal agencies to regulate nontreatment decisions in hospitals and newborn nurseries.⁹

The battleground shifted to Congress. The resulting tussle among the administration, right to life, disability, hospital and physician groups produced a compromise bill, the Child Abuse Amendments of 1984. Under this legislation, direct federal intervention in newborn nurseries and neonatal intensive care units would cease. Instead, states, as a condition of receiving federal child abuse prevention funds, would agree to set up systems, including infant care review committees, to make sure that all newborn children were protected against discrimination on the basis of disability. The only exceptions recognized to equal treatment of children with handicaps were for children who were permanently comatose, near death, or for whom treatment would be inhumane because futile or virtually futile.

A Consensus of Sorts

The Child Abuse Amendments of 1984 ended the political controversy over the federal role in decisions to withhold treatment from handicapped newborns. In terms of substantive norms, right to life and disability groups could claim victory. The substantive provisions of the CAA were strongly protective of the rights and interests of those with disabilities and left little room for nontreatment decisions to be based on ex-

pected low quality of life or the interests of parents. All children, whatever the extent of their disabilities, were to be provided medical treatment unless they met the narrowly defined exceptions.

Procedurally, however, physician and hospital groups could also claim victory. As a legal matter, the CAA substantive provisions were not directly imposed on any individual or institution, nor did they directly amend federal or state substantive law. They did not, for example, make it a federal crime or a civil wrong for a doctor, parent, or hospital not to treat a child who did not meet the narrow exceptions. Nor did the CAA require hospitals to comply with its standards in order to receive Medicare and Medicaid funds. Instead, it obligated the states to set up protective procedures in order to receive child abuse funds. Any regulatory action would thus be the responsibility of individual states, which were less well equipped than the federal government for strong enforcement action. This was a far cry from federal hotlines and intrusive Baby Doe squads.

But while the CAA imposed no legal duties directly on doctors and hospitals, many doctors, hospital administrators, and even lawyers perceived its passage as creating a legal presumption in favor of treating children likely to have disabilities. Technically this was inaccurate, but it was not an unreasonable conclusion. At the very least, the CAA could be perceived as setting the standard of care to which hospitals and doctors would be held, both by accrediting bodies and by courts hearing challenges to nontreatment decisions. In addition, the ethical controversy over nontreatment decisions had convincingly shown the importance of respecting the life and interests of disabled children and recognizing limits on parental rights. The values incorporated in the CAA showed a deep ethical commitment to respecting human life regardless of disability.



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Whatever its actual legal reach, passage of the CAA awakened pediatricians, neonatologists, and hospitals to the problem of discrimination against handicapped newborns. The norms of practice shifted: most physicians and hospitals were now more reluctant to defer automatically to parental wishes. Parents could no longer deny needed surgery to children with Down syndrome or spina bifida, as had occurred in the much publicized Baby Jane Doe case at Stony Brook.¹⁰ If treatment were to be denied, a parent would have to show that the child was comatose, terminally ill, or that treatment would be futile or virtually futile. In borderline cases, some quality of life judgments might unavoidably occur, but overall a high degree of compliance followed passage of the CAA. Indeed, both the American Academy of Pediatrics and the American Medical Association, which had fought the Baby Doe rules, issued policies calling for equal treatment of newborns regardless of disability and low quality of life and recommended the

use of institutional ethics committees to review contested cases.¹¹

With further experience, however, some physicians, ethicists, and parents caught up in such situations came to question whether the CAA and medical reactions to them had gone too far in favoring treatment regardless of quality of life. Yet there was little overt controversy or litigation until the issue arose in the context of extreme prematurity.

The Problem of Prematurity and Very Low Birth Weight Infants

The area with the least consensus and the most uncertainty about the reach of the CAA was that of extreme prematurity. Due to a large investment of public resources, regionalization of perinatal intensive care units, and growing technical abilities, treatment of premature newborns had shown great success. The line for viability and successful survival has been continuously pushed back to earlier and earlier ages. Before 1980, few babies born in the 1000-1500 gram range before twenty-eight weeks would do well. Now they are routinely saved and restored to a relatively normal life. Great success is also occurring with smaller babies. It is now routine to save babies as young as twenty-five weeks and as little as 750 grams. Under twenty-five weeks, however, results are much more mixed. At the margins of viability, twenty-three to twenty-four weeks' gestation, mortality occurs in half or more of the cases, and survivors often have significant physical and mental handicaps, including blindness, hydrocephalus, cerebral palsy, limited use of language, and learning disabilities.

Newborns born under 750 grams and before twenty-five weeks pose a major problem under the CAA. On their face, the CAA standards leave no room for discretion. All conscious, viable premature newborns must be treated, even if they are likely to have severe physical and mental disabili-

ties. Not to treat them would be to discriminate against them on the ground of expected disability.

In effect, the CAA supplied an ethical and legal justification for the intense efforts of neonatologists to push back the limits of viability. Most hospitals and neonatal programs treated premature newborns in conformity with the CAA, with neonatologists present at all premature deliveries and likely to resuscitate newborns born alive, regardless of parental wishes.

Not all neonatal programs complied equally strictly with the CAA standards in cases of very low birth weight, however. In more marginal cases, under twenty-five weeks or where Grade IV intraventricular hemorrhaging or other major problems had occurred, some programs would provide “compassionate care” or non-treatment only if parents requested it (usually without ethics committee or legal review of the decision). A 1991 *New York Times* survey found that two programs in the same New York county had completely different attitudes toward treatment in marginal cases, one treating aggressively, the other deferring to parental wishes. A 1994 *Chicago Tribune Sunday Magazine* survey showed similar disparities.¹² In most cases the disparity in approach was due to the personal philosophy of the NICU director or perceptions of legal risk.

The aggressive approach to treatment of low birth weight infants in some programs has led to conflicts between parents and doctors and hospitals.¹³ Many parents reported being given little choice about treatment of their premature newborns, with the result that infants born at twenty-three to twenty-six weeks’ gestation were resuscitated and vigorously treated, in some cases over parental wishes. While half or more of these children survived, many survivors were likely to have serious disabilities, including cerebral palsy, blindness, mental retardation, and learning disabilities. Increasingly, parents have requested that no resuscitation or treatment occur in these cases, thus pitting parental wish-

es against the neonatology ethic of trying to save all premature newborns and the no-discrimination requirements of the CAA.¹⁴

Miller v. HCA as the Catalyst for Reexamination

In a litigation-oriented society, it is no surprise that this conflict is now played out in lawsuits brought by parents claiming violation of their rights to control the medical care provided to their children. Such suits shift the forum for defining treatment norms from Congress and the federal judiciary, which played a major role in the Baby Doe controversy, to state juries and trial and appellate judges. The jury award in the recent case of *Miller v. HCA* suggests that there is popular support for recognizing some parental right to have treatment withheld in low birth weight cases. Although the award was eventually overturned, the question remains whether parents should have a right to deny life-saving medical treatment to low birth weight newborns because of the high probability that they will have severe mental or physical disabilities.

The *Miller* case arose in Houston, Texas, when a twenty-eight-year-old woman twenty-three weeks into her first pregnancy in 1990 experienced contractions and possible rupture of membranes.¹⁵ The medical team attempted to stop her contractions with tocolytic therapy, but she developed chorionamnionitis, and prompt delivery appeared necessary. After discussing the child’s prospects with the couple’s obstetrician and a neonatology fellow, the father informed them that he and his wife did not want any “extraordinary, heroic” steps to be taken because of the child’s extreme prematurity. Their physician consulted the head of obstetrics and they concluded that a neonatologist should be present at birth and that the child should be resuscitated if it were born alive. A meeting was held with the father to discuss a treatment plan. The need to have a neonatologist present and initial treatment pro-

vided was explained. All parties present except the father thought there was a consensus that the child, if born alive and vigorous, would be resuscitated, and that later management decisions would be based on the child’s postbirth condition. The father denied that he had agreed to this plan.

Pitocin was started to induce labor, and the mother delivered a 614-gram girl, Sidney Miller, six hours later. The neonatologist present at delivery immediately treated the infant, first bagging and then intubating her. Her Apgar scores were three at one minute and six at five minutes. Some 90 minutes after birth, after central lines were inserted and surfactant administered, she was transferred to the NICU. The father, who was present at the birth, voiced no objections to the neonatologist’s presence or treatment. He signed consents for injections of Vitamin E, surfactant, and a blood transfusion within the first two hours after birth. On the fourth day after birth the child suffered a Grade III/IV intraventricular hemorrhage. Later he or his wife consented to surgical cutdowns to insert other lines, and at five weeks consented to insertion of a cerebroventricular shunt to relieve her hydrocephalus.

After two months in the NICU, the child was transferred to Texas Children’s Hospital, and six months after birth was released from the hospital. Her parents have cared for her since discharge at home. She has had numerous surgeries to repair or replace the shunt. She is now fourteen years old and has severe mental and physical disabilities: she has cerebral palsy, does not walk or talk, and is blind and incontinent. She smiles and appears to interact with parents to some minimal extent, although she seems to lack the capacity for symbolic interaction. With good care she could live to age seventy.

The parents sued the hospital and its corporate owners, but not the physicians, for treating the child at birth without their consent. After a two-week trial in January 1998, a jury awarded the family \$30 million in

compensatory and \$13 million in punitive damages. The compensatory damages were based in part on the cost of providing care to Sidney until age seventy.

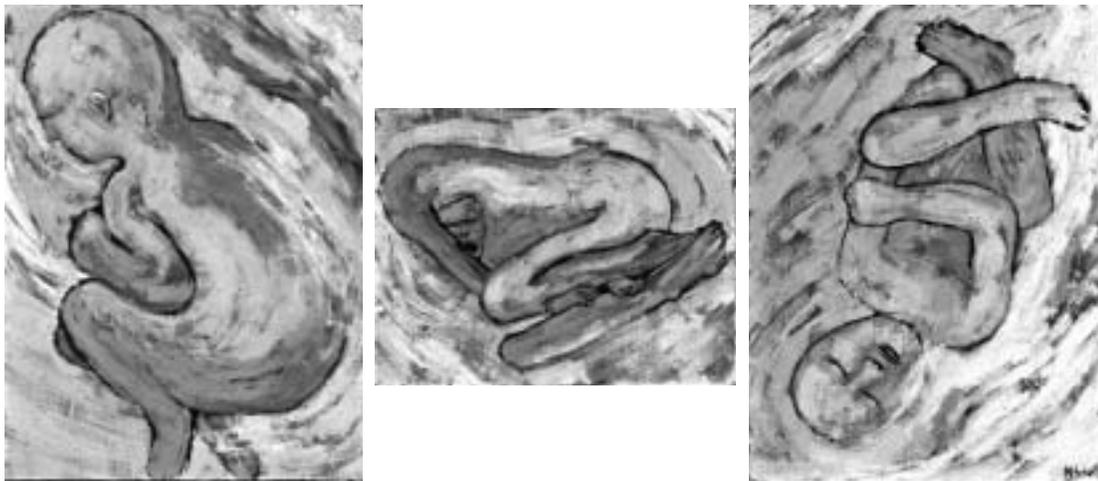
Even though it was reversed on appeal, *Miller* raised the question of whether parents have the right to have treatment withheld immediately at birth, prior to any resuscitation or evaluation of the child. The plaintiffs claimed that the hospital was aware of the parents' refusal of resuscitation and treatment at birth and knowingly chose to override their wishes, possibly to profit from the sale of expensive neonatal services. The hospital

Modifying the Substantive Standard

Some persons might argue that the jury verdict in *Miller* in favor of the parents was appropriate because of the great burdens that treatment against their wishes imposed on them. According to this view, the substantive norms for treatment reflected in the CAA and the law of many states (including Texas, as clarified on appeal) are too strict; they should be modified to privilege the parents' reluctance to take on those burdens. The parents' wishes should trump arguments that focus narrowly on the interests of a severely impaired child

impaired child's interest in treatment would deviate from the principle that all persons who are conscious and not imminently dying should have equal access to needed medical services.¹⁷

Given these competing concerns, the ethical and legal challenge is to uphold the general principle that all children born alive are to be treated equally regardless of disability while also recognizing the importance of parental decisional authority. The problem is that any modification of the equal treatment standards may be seen as opening the door to full-scale quality-of-life-based decisions, yet anything that clearly does not permit



Transcendent by Marilyn Mitchell, oil on canvas.

Courtesy of OATH, Organization for Artists Trained in Health Care, muze@erols.com.

defendant argued first that the parents had in fact consented to the treatment—or at least gave a reasonable person the impression that they had consented. Second, the hospital argued that it was following its duty under Texas and federal law and the applicable standard of care to treat all newborns alike regardless of expected disability. In finding for the parents, the jury was necessarily finding that they had not consented to treatment, and that their consent was essential to the treatment, thus squarely posing the question of whether they had a right to deny treatment to a viable newborn who was likely to have substantial disabilities.

with little chance of a normal life.¹⁶ Because parents (and other children) will bear the burdens of caring for the child with severe impairments, they should have the right to refuse resuscitation or treatment in such cases.

Few would not have deep sympathy for a family faced with an extremely premature child and the great burdens that rearing the child could impose. In addition, many would find that the CAA standards are too demanding, given the realities that families face in these situations and the importance of respecting family autonomy. Yet modifying the equal treatment standards of the CAA and the law of most states to allow parental choices to trump the severely

some quality-of-life decisions may still seem to improperly restrain the rightful sphere of parental choice.

One way to try to reconcile these competing concerns is to declare that treatment against the parents' wishes is required only if the child possesses some threshold level of cognitive ability. A second strategy would be to clarify the burden of proof so that parents are recognized as the primary decisionmakers, with the burden of proof on caregivers or others to establish that the child has the required level of cognitive ability. Finally, a decision is needed as to whether parental choices made *before* birth should have the same presumptive

weight as those made after birth (the issue in the *Miller* case).

How, then, to think about the threshold level of cognitive ability? One route would be to adopt a change that recognizes that some states of consciousness rest on such limited cognitive ability as to call into question whether the child's putative interest in continued life is substantial enough to warrant protection. In that case, denial of treatment could be justified under a patient-centered approach as not harming the child because the child simply lacks strong interests in continued life. Some threshold of cognitive ability beyond mere consciousness—such as the capacity for language or meaningful symbolic interaction—is needed to endow a person with interests in living and thus a duty to treat.

A standard based on relational ability is consistent with mainstream ethical writing on the subject. Father Richard McCormick, the highly regarded Catholic bioethicist, recognized in 1974 that treatment need not be provided if the child lacks the ability for interaction or human relationship.¹⁸ Professor Nancy Rhoden argued in 1986 that there should be an additional category for withholding treatment under the CAA when the infant or child “lacks potential for human interaction as a result of profound retardation.”¹⁹ The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research and many bioethicists also supported such a standard.²⁰ Indeed, even authors who have strongly supported the right of handicapped newborns to be treated at birth have recognized that an exception in cases of extreme prematurity or lack of meaningful interests should also exist.²¹

None of these commentators, however, has specified more precisely what lack of “interaction or relationship” means. Under such a standard, treatment would still be required for premature infants who have suffered or might suffer intraventricular hemorrhaging and severe brain damage



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because such infants are still capable of some interaction with others. Despite their severe physical and mental disabilities, such children do respond to stimuli and appear to experience pleasure when touched or rubbed—arguably a form of “interaction or relationship” because it leads to further touching or rubbing. In the *Miller* case, for example, there was evidence that Sidney smiled and responded favorably to physical contact.

If interaction or relationship is taken to mean the human capacity for meaningful symbolic interaction or communication, then some greater mental capacity would be required than such severely damaged children have. If one lacks altogether the capacity for meaningful symbolic interaction, then one lacks the characteristics that make humans the object of moral duties beyond that of not imposing gratuitous suffering on them. We value humans in large part because of the capacity to have conscious interests and experiences, including meaningful symbolic interaction with others.

A modification in the CAA's substantive standards and in similar state laws to permit non-treatment in extreme cases would necessarily rest on quality of life assessments based on disability. But the mental disability in such cases is so extreme, so far from those cases in which children may be

said to have valid interests in living, that they arguably do not threaten or harm the important values underlying the injunction against quality of life assessments in cases of disability. We could adopt such a standard without encouraging discrimination against disabled persons who have the capacity for symbolic thought and interaction. In contrast to nontreatment of a child with Down Syndrome or spina bifida, or indeed, children born at twenty-five weeks gestation and weighing over 750 grams, nontreatment in these cases does little damage to norms calling for respect for life and to equal treatment regardless of disability. If this modification of the CAA standards is too permissive, then no modification of those standards is likely to be acceptable.

Process Solutions and the Burden of Proof

Substantive norms are not easily separated in practice from the procedures by which they are implemented. Another way to give greater deference to parental interests while upholding the norm of equal treatment would be to devise a procedural approach that better balances the interests of each. Both the American Academy of Pediatrics and the President's Commission for the Study of Bioethical Problems in Medicine recommended that institutional ethics committees review such decisions, particularly when there was disagreement or uncertainty about whether the child's interests required treatment.²² Thomas Murray and Alan Fleischman have also supported this approach and even discussed the burden of proof to be followed in such cases.²³

Although the Baby Doe rules included review by “infant care review committees,” none was used in the *Miller* case. The hospital had not established such a committee, and even if it had, the rapidity with which events developed, and the fact that they all occurred on a Saturday, left

little room for using it. Furthermore, since the administrator, social worker, the head of obstetrics, and other hospital personnel who had met with Mr. Miller on the afternoon before Sydney was born to explain the hospital policy of treating all newborns at birth all had the impression that he had accepted the policy, no emergency ethics committee or probate court review would have been called. If emergency permission to treat at birth had been sought, it is likely that an ethics committee or judge would have erred on the side of keeping the child alive while a more thorough assessment of the child's condition was made.²⁴

In future cases, the burden of proof that must be met to have a child treated over the parents' wishes should be clarified. Parents should have a presumptive right to have their decisions about the child's welfare respected unless a clear need to protect the child is shown.²⁵ The burden would lie with physicians, hospitals, and other caregivers to challenge the parents' decision against treatment. If the "symbolic capacity" standard were employed, then the caregivers would have the burden of establishing, by at least a preponderance of the evidence, that the child is likely to have the minimum cognitive ability for symbolic interactions. In less certain cases, the parents' wishes would control.

An essential part of a burden-shifting approach is the effect it has on the rights and duties of the parties. Under the approach suggested here, neither the parents nor the physicians and hospitals would be liable if the parents made a good-faith judgment that treatment would not serve the child's interests and the physicians and hospital respected their choice. However, caregivers should also be free to challenge the parents' decision because of a good-faith belief that the child would possess the capacity for symbolic interactions. They should not be liable for questioning the parental decision or for seeking institutional ethics committee or judicial

review of the decision. An initial decision to err on the side of life, as Fleischman and Murray recommended in 1983, would limit parental discretion in the short run, but facilitate and protect its exercise at a later stage.

Deciding After Birth

Any modification of the CAA's non-treatment standard and clarification of the burden of proof should also specify the point at which increased deference to the parents is appropriate. Parental autonomy is important, but it is not so robust that parents have the right to deny a disabled child the medical resources necessary for life regardless of the child's interests in living or ability to interact with others.

Determining whether those conditions are met will be difficult enough when they occur after birth but before physicians can determine how the child will fare, particularly if intraventricular bleeds have occurred or are expected. It is even more difficult to make those determinations before birth on the basis of gestational age estimates and expected birth weight. Whether the child lacks the capacity for symbolic interaction and whether the parents are making a reasonable judgment about them will require full information about the child's conditions and prospects. That can be obtained only after birth, because assessments about gestational age and its effects are too prone to error.

The question presented in *Miller* and other cases is whether parents should be free to decide against treatment in advance of birth by, for example, issuing a prenatal do-not-resuscitate order that has legal effect once the child has been born, so that if the child were alive at birth, no resuscitation or other efforts would be made on its behalf. Recall that in *Miller* the parents never objected to treatment once the child was born. They based their suit solely on the hospital's refusal to honor their pre-birth rejection of treatment—on the

resuscitation by the neonatologist present at delivery.

To determine whether a particular infant lacks or is reasonably certain to lack the mental capacity for symbolic interaction or relationship one must first assess the child and its condition. But this can be known only after birth, when a full assessment of the child's situation and likely capacity is possible. Doing so will require immediate treatment to stabilize the situation and a full work-up by neonatologists to determine the child's condition and prospects.

As a result, parents' directions not to resuscitate at birth should not be given effect until a medical assessment of the child's condition and prognosis justifying nontreatment has been made. Doctors and hospitals should be legally free to have neonatologists resuscitate and treat for a limited period after birth to assess the child's capacity regardless of parental consent or orders not to resuscitate. Under this standard, the initial medical response in the *Miller* case—resuscitation at birth if the child is alive—was reasonable. If medical evaluation after resuscitation shows that the child is likely to develop the capacity for meaningful symbolic interaction and the parents continue to refuse life-sustaining treatment, then ethics committee and judicial review should be sought to determine whether to treat the child over the parents' wishes.

A rule that permits initial treatment pending assessment admittedly carries burdens for parents. It means that closure on a difficult and trying event in their lives may be postponed for a few days. Also, it is easier to say no to treatment for an abstract child than for one that has a personal presence for them. The parents may find themselves bonding with the child during the assessment period, making it harder for them to refuse treatment later, even if doing so would be justified. Unless resuscitation and initial treatment occurs, however, there will be no firm basis for finding that the child lacks the relevant capacity that

must be shown to justify denying treatment. Allowing parents to refuse resuscitation at birth based on pre-birth estimates of age and size risks denying infants who are unexpectedly large or vigorous the chance for life.

Based on this analysis, the Texas Supreme Court decision affirming the reversal of the jury's finding for the parents rests on sound ethical and legal grounds.²⁶ While recognizing that parents ordinarily have the right to consent to or refuse medical care for their children, the Court also recognized that an exception to the parental consent requirement arises when an emergent condition exists and treatment must occur immediately to prevent the death of the child. The Court found that the doctor's initial resuscitation in *Miller* was justified because the situation was an emergency and there was not enough time necessary to get consent from the parents or from a court. As the Court noted, a nontreatment decision made prior to birth and post-birth evaluation would be based on "speculation" that would not promote the child's best interests.

A ruling in favor of the parents would have meant that parents always have the right in advance of birth to refuse treatment for premature newborns. Unless physicians and hospitals were first able to get a court to rule otherwise, the threat of *Miller*-like damages would strongly incline them to follow the parents' wishes, depriving some newborns who could have meaningful lives of treatment they need to survive.

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