

Child Welfare Services for the Catastrophically Ill Newborn: Part I—A Confusion of Responsibility

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On October 17, 1991 a Superior Court Judge in Fulton County, GA, ruled that a hospital could not discontinue life support for a comatose child without her parents' permission. The judge ruled that the rights of the parents, not the child's best interests, were paramount in the case. The girl's mother testified that she could not decide what to do, but could not bear the thought of being held responsible for her daughter's death. Physicians had testified that the only sensation the young girl felt was pain, and that keeping her alive constituted child abuse [Columbus Dispatch 1991a].

What stance should a child protective services agency with jurisdiction in this case take? In passing the Child Abuse Amendments of 1985, Congress gave public child welfare agencies the responsibility to police bioethical decision-making for catastrophically ill neonates. The public child welfare system was thus made responsible for assuring that bioethical decisions regarding medical treatment are in a newborn's best interests and do not constitute abuse or neglect. Despite the 1985 amendments, however, public child welfare

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agencies have provided little or no protective services to developmentally disabled neonates with life-threatening medical complications [Barnett 1990; U.S. Commission on Civil Rights 1989]. This is not because clear and consistent decisions are routinely made for such children. In fact, hospital personnel, medical societies, and health professionals appear factious, and their decisions are not guided by a consistent, universally applied bioethical paradigm. Literature and research suggest that the majority of health care and child welfare professionals believe that the Child Abuse Amendments do not provide an adequate bioethical decision-making criterion. Most professionals either feel the Child Abuse Amendments are unclear, or they disagree with the Amendments' ethical premises [Chalnick 1989; Barnett 1990]. The fact that the child welfare profession does not have its own clear criteria for determining when "treat/no treat" decisions are "in the child's best interests" has likely contributed to the lack of protective service activity in these situations.

Since 1970, approximately 100 "wrongful life" lawsuits have been filed in the United States on behalf of children [Columbus Dispatch 1991b]. Typically, those bringing wrongful life lawsuits argue that for "a severely disabled child to have no life would have been preferable to one filled with pain and suffering" [Liu 1987]. Most lawsuits regarding treatment decisions for catastrophically ill children are, however, brought to continue treatment rather than discontinue it. These suits often contend that to discontinue treatment constitutes child abuse. Herein lies the dilemma for child welfare professionals. How do child protective service workers decide what constitutes child abuse in the milieu of treatment decision-making for developmentally disabled neonates with life-threatening medical complications? Do the "child's best interests" constitute the final criteria? If so, how can one determine if it is in a child's best interests to continue or discontinue medical treatment? How is it that the child welfare system in this country finds itself with the responsibility to assure that decisions in the medical setting do not result in neonatal abuse or neglect, yet does not have a consistent criterion to determine when treatment decisions are in a child's best interests? To answer these questions one must examine the bioethical issues involved.

Thousands of developmentally disabled children are born each year with life-threatening medical complications [Lyon 1985; Driscoll 1982; Todres 1977]. For each of these children, a decision must be made to provide or withhold vigorous medical treatment. For the vast majority of children, decisions are quickly and routinely reached to provide medical treatment [Shaw 1973; Duff and Campbell 1973; Lorber 1971]. But some of these children have such serious neurological problems; so limited a prognosis for social, emotional, and cognitive development; and so certain a prognosis for a short

and painful existence that a formal decision-making process to determine whether to treat or withhold treatment appears to be an ethical necessity. For some children, decisions are made to terminate, or not to begin, rigorous medical treatment. Reasons given for withholding or terminating treatment include (1) treatment would only prolong the dying process and thus would be inhuman [Kuhse and Singer 1987; Mahon 1988]; (2) the potential good achievable from treatment would not justify the certain and horrific consequences of treatment [Fleischman 1986; Brennan 1986; Mahon 1988]; (3) the prognosis for the infant's posttreatment quality of life in the best possible scenario suggests that the beneficent option is not to prolong the life [Keyserlingk 1987; Fleischman 1986; Kuhse and Singer 1987]; (4) the limited potential benefit to the child from treatment would not outweigh the potential harm to the integrity of the family brought about by the child's condition [Berkowitz 1986; Mason and Meyers 1986; Simms 1986; Battle 1987]; and (5) social justice or social utility would be better served if society's limited resources were used otherwise to more efficiently and effectively save and maintain life [Lister 1986; Taft 1987; Subramanian 1986].

These decisions can be complicated by a number of situational variables, including (1) the neonates are often in life-threatening distress and require immediate medical decisions [Battle 1987; Lyon 1985] (2) treatment prognoses are often inherently equivocal [Lyon 1985; Shelp 1986]; and (3) parents may be extremely emotionally distraught at a time that rational decisions are vitally needed [Simms 1986; Davis 1986; Mahon 1988].

But these decisions are difficult for other more fundamental reasons as well. Although the Child Abuse Amendments clearly assign responsibility to the child welfare system, there is no consensus within the social work profession or in our society regarding who should make these decisions, or what the criteria for decision-making should be [Lang 1985]. Before we look at the variously championed loci of decision-making authority in our pluralistic society, or the problems associated with our society's lack of a consensus-guiding ethical paradigm for decision-making, let us consider the history of treatment for catastrophically ill newborns.

A Historical Perspective

Until recently, decisions to provide or withhold treatment for developmentally disabled children with life-threatening medical problems were made by the newborn's parents within the guidelines and sanctions of their respective cultures and their own conscience. Literature provides us with details of such

bioethical decision-making through time and in diverse cultures. Most cultures appear to have adopted a utilitarian ethic. Decisions were often made after assessing a newborn's estimated future social utility—that is, after calculating the infant's net potential assets and deficits for the family unit or to society. Irrespective of the validity of the guiding ethical paradigm, these calculations were often characterized by ignorance and prejudice. Many children who were thought to be a net potential burden to their family or to society were allowed to die or were killed [Fraser 1976]. Plato, in the *Republic*, advocated the killing of children born with deformities in order to improve the state [Cornford 1945]. Toward this same goal, the laws of some Greek city-states called for infanticide of newborns with obvious physical deformities [Fraser 1976]. Several hundred years later, the Roman Seneca also argued for the routine killing of physically disabled newborns, a common practice in the Roman Empire [Lyon 1985]. Although Christianity generated some of the first sanctions against infanticide, malformed children were often exempted from protection. For example, while the Christian Emperor Justinian supported the church's sanction against infanticide in general, he declared that the fathers of malformed children could destroy them [Lyon 1985].

Although Christian theology in western cultures clearly evolved an ethic stressing the inviolability of life, the secular realities of poverty, disease, lack of birth control, and limited resources combined to support decisions based upon utility. Infanticide for developmentally disabled newborns was a common phenomenon in western Europe during the Middle Ages and continued up through the 18th and 19th centuries in England and France [Rosen 1976].

Selective infanticide of newborns was also a common and accepted practice in many non-Western and non-Christian societies. North American Eskimos, the aborigines of Australia, the Maori of Polynesia, the Yanomamo Indians of Venezuela and the Zhun-twasi Bushmen of Africa have all culturally sanctioned selective infanticide, especially of physically deformed infants [Lyon 1985]. It has also been a part of the cultural history of the Chinese and Japanese and of the city-states of India [Rice 1990].

Although selective infanticide and the calculated withholding of support for developmentally disabled newborns have historically been condoned, only recently has the decision-making process informing these decisions become a public issue. This can be attributed to changes in the newborn's milieu and to advances in the technologies of treatment. At the turn of the century in the United States, childbirth took place at home. Prevailing medical philosophy stressed nonintervention; the infant was protected from infection and otherwise provided with support with as little additional interference and handling as possible. Most developmentally disabled children with life-threatening medical complications died under this philosophy of benign neglect.

After World War II, significant technological developments combined to move childbirth from the home to the hospital and to change the treatment approach dramatically. Nonintervention was supplanted by increasingly sophisticated interventions, including indwelling feeding tubes and specialized neonatal surgical techniques. The 1960s saw the advent of electronic monitoring, respirators, sophisticated blood analysis, and the specialization of neonatology. Large numbers of catastrophically ill newborns who formerly would have died were sustained, although with varied prognoses. Whereas decisions to treat or withhold treatment had formerly been privately made at home by parents, they were now being made in public care facilities with a confusing convergence of shared authority and responsibility.

The mid-twentieth century also saw an explosion of sociomoral issues brought about by scientific and technological advances in the social, biological, and medical sciences. Bioethical dilemmas with respect to treatment decisions for catastrophically ill neonates became a public social issue as a result of these technological advances and the ensuing dilemmas of social justice. Bioethical review committees began to appear as a means of deciding moral issues. Sterilization review committees were established in the 1950s to protect the rights of persons with developmental disabilities. In the 1960s, dialysis committees were established to select the few among many who would benefit from scarce medical resources [Fox and Swazey 1978]. Federally mandated review boards were also established to standardize research involving human subjects and to protect human subjects from the potential abuses of dangerous and/or intrusive science. The 1970s saw a considerable social and legal impetus for the formation of formal ethics committees to review decisions regarding the withholding or termination of medical treatment. The Karen Ann Quinlan case in 1976 provided an important impetus in its recommendations that ethics committees be established to verify the validity of prognoses [*In Re Quinlan* 1976]. This trend continued through the 1980s. In 1983 the President's Commission for the Study of Ethical Problems recommended the establishment of ethics committees as means of resolving medical ethic dilemmas [The President's Commission for the Study of Ethical Problems 1983]. The Child Abuse Amendments of 1985 strongly encouraged the establishment of Infant Ethics Committees for all hospitals caring for newborns [Department of Health and Human Services 1985]; by 1985 the American Hospital Association reported that 60% of the respondents in a survey it conducted had institutional ethics committees [Hosford 1986].

The Baby Doe Case

It was within this social environment of increasing moral awareness that the case of "Baby Doe" focused this country's attention on the bioethical issues

associated with treatment decisions for developmentally disabled children with life-threatening medical complications. On the evening of April 9, 1982 a child was born in a Bloomington, IN, hospital, severely hypertonic, blue from lack of oxygen, not breathing, with an erratic heartbeat. It was immediately evident that the child had Down Syndrome. Further examination revealed that the child had a constricted aorta, esophageal atresia, and a tracheoesophageal fistula, a combination of disorders that would be lethal if left untreated. After consultation with the attending physicians, the parents decided it was in the child's best interest not to provide treatment, a decision that meant death within days for the newborn. Baby Doe died six days later.

Many similar scenarios have ended shortly thereafter, with the death of the child occurring in relative anonymity. The legal, theological, political, and medical machinations that followed Baby Doe's death, however, so focused attention on the medical and ethical dilemmas associated with treatment decisions for mortally ill developmentally disabled infants that henceforth the Baby Doe case would acquire historical significance and notoriety. From the very beginning, those involved with the case were divided with respect to who should make the case decisions and what constituted the proper treatment for the infant [Lyon 1985]. Three attending physicians consulted with the parents to facilitate their decision-making. Two of the physicians recommended immediate and extraordinary medical intervention. The other physician, after considering the child's and the parents' best interest, recommended no treatment of the infant as the best possible case outcome. Two physicians believed the local protective service agency and the local courts should make the treatment decision. The third physician believed the decision should remain entirely with the parents. The Baby Doe case represented in microcosm a society's confusion and disagreement about who should make such life and death decisions and what the decision-making criteria should be.

The Child Abuse Amendments of 1985

After the media attention given to the Baby Doe case, national politics began to play an increasingly important role in this bioethical issue. Both the executive and legislative branches of government became involved. Using civil rights legislation for its authority and with the regulatory initiative of the U.S. Department of Health and Human Services, the Reagan administration strongly endeavored to effect policy that approached medical treatment of infants from a strictly deontological, or sanctity of life, philosophical perspective [Victoroff 1986]. The courts repeatedly found these efforts unlawful and set them aside [Barnett 1990].

The Reagan Administration then tried to promulgate nearly identical pol-

icies in the form of child abuse legislation. From early 1982 through early 1984, Congress grappled with various versions of compromise legislation to regulate treatment decisions for catastrophically ill newborns with developmental disabilities. Senators from across the ideological spectrum encouraged representatives of the various interest groups involved in this issue to negotiate a compromise amendment, which was passed by Congress and was signed by the President into law on October 9, 1984. The Child Abuse Amendments of 1985 (P.L. 98-457) and their implementing regulations became effective one year later [U.S. Department of Health and Human Services 1985].

This compromise was not wholly successful due to the impracticality of trying to make two inherently dissonant ethical paradigms compatible, and due to the difficulty of enforcing regulations ideologically incompatible with the beliefs of the majority of the health care workers affected by them [Chalnick 1989]. The final law was one with which most of its ideologically divergent authors could agree, as long as they could disagree about the definition of key words and phrases within the amendment, such as "virtually futile," "imminent," "near future," and "merely prolonging dying." A final attempt by the Reagan Administration to insert clarifying definitions that were concordant with the deontological/sanctity of life ethical paradigm into the amendments ended as a compromise—the definitions were attached to the amendment as nonbinding interpretive guidelines.

Although the law's wording and instruction represent a degree of compromise and, in some instances, are open to interpretation [Murray 1985; Barnett 1990], its content represents a significant success by those committee members who wanted to produce legislation whose content removed both "quality of life" and "social utility" considerations from the treatment decision-making for catastrophically ill newborns. In practice, however, the results have been equivocal [Barnett 1990]. A great many physicians, nurses, and other professionals working with catastrophically ill neonates with developmental disabilities disagree with the deontological/sanctity of life ideology that informs the final language of the Child Abuse Amendments. And, whether from differing interpretation, calculated noncompliance, or lack of enforcement, the law has not resulted in consistent treatment decision-making [Barnett 1990]. In a report issued by the United States Commission on Civil Rights in 1989, Commissioner Robert Destro suggested that most states still were "not certain which children are covered by the law and which aren't," and that inappropriate decisions to withhold treatment for these children continued with tacit approval of federal, state, and local government agencies, and had resulted in potentially hundreds of "Baby Doe" cases since the passage of the Child Abuse Amendments in 1984 [U.S. Commission on Civil Rights 1989].

In contrast to the continuing uproar regarding applicability and enforcement of the Child Abuse Amendments, the fiscal consequences of noncompliance are almost insignificant. States that do not comply with the amendments can lose funds under the Child Abuse Prevention and Treatment Act. These funds are relatively meager and, as a result, the financial incentive for compliance is not great.

Although the amendments do not provide clear and effective guidance, they do clearly enjoin states to assign regulatory authority to their respective child protective service systems. Thus, state and local departments of child welfare and individual workers find themselves with legal authority and responsibility, but without clear and effective guidelines or the operational decision-making criteria they need to do their jobs.

The Locus of Decision-Making Authority: Who Should Decide?

Although the amendments assign final authority for policing neonatal bioethics to the child welfare system, society remains divided regarding the proper locus of decision-making authority. Many loci of decision-making authority have been suggested as appropriate—the parents of the child, the attending physicians and other medical staff, infant bioethics committees, structures of the state such as child welfare agencies and the courts, and theological institutions.

The Parents

Parents are considered by many to be the proper locus of final decision-making authority. Broad parental rights are a fundamental and established legal and cultural tradition within our society. Parents have considerable latitude in making decisions for their children in such areas as education, religion, and discipline. The legal and cultural traditions of parental rights, prerogatives, and responsibilities are based upon the presumed emotional bond and commitment of parents to their children [Battle 1987; Kuhse and Singer 1987; Cranford and Doudera 1984; Taft 1987]. It is often believed that this intrinsic bond and commitment will ensure that parents, more than others, will advocate for the neonate's best interests.

Although few would argue against the basic right of parents to direct medical treatment of their children, many do argue that parents should not have unconditional decision-making authority. Many believe that because of potential conflicts of interest, parental decisions cannot be assumed or assured to always be in the seriously ill infant's best interests. The parents' own interests and the interests of other family members can impinge upon their

decisions. In a universe of limited resources, some parents may conclude that the time, money, and emotional energy needed to meet the often considerable needs of a seriously ill newborn may be at the expense of other family members. Some would argue that in spite of these potential conflicts of interest, parents should still retain final decision-making authority, even though the self-interests of the parents or the family unit may potentially conflict with the neonate's interests. Proponents contend that parents have special rights and responsibilities that supersede societal goals when family goals are threatened, and therefore, parents may have the right and responsibility to subordinate a developmentally disabled neonate's interests to the countervailing interests of the family [Schoeman 1985]. The assignment of final decision-making authority to parents is often questioned and challenged by various factions of the medical establishment, by theologians and theological institutions, in a plethora of political arenas, and in the courts, which clearly assert their responsibility to intervene in situations of abuse or neglect.

The Medical Community

The medical community is often considered to be the proper locus of authority for treat/no treat decisions for critically ill neonates. Physicians have historically assumed responsibility for many such decisions, both because they believed they had the responsibility and because others had abdicated responsibility. There is considerable support in recent literature for a medically based locus of decision-making authority. Siegler [1986] writes that bioethical deliberation and decision-making for newborns should be the responsibility of physicians and nurses in the neonatal environment, because this is where the "anguish of the moral dilemma" is played out. He believes experiencing this anguish is an essential element of the moral deliberation; therefore, attending physicians and nurses are the proper locus of decision-making authority. Many physicians contend that the bioethical principle of "do no harm," derived from the physicians' Hippocratic Oath, requires that physicians make these treatment decisions and advocate for the patient's best interests when conflicts arise between those interests and the interests of other involved parties, such as the parents [Gustaitis 1988; Young and Stevenson 1990]. Brennan [1986] agrees, stating that neither parents nor ethicists nor jurists are familiar with the medical and emotional nuances associated with the care of acutely ill and dying patients, and therefore, the treatment decisions should be left to physicians.

Mahon [1988] contends that nurses have no choice but to assume a shared responsibility for making treatment decisions. Although physicians often write the treat/no treat orders, the nurses usually carry them out. These circumstances conspire to assign nurses moral culpability. Mahon contends that

nurses should ultimately act in the child's best interests, even if such actions are in conflict with a physician's or parent's dictate.

By contrast, there are those who feel that final moral decision-making authority should not rest with physicians and nurses. The medical director of a large pediatric hospital reported that some children are "salvaged" because of the "professional challenge" such activities afford the physicians [Battle 1987]. Some physicians believe that while it was an assumed responsibility in the past, physicians should no longer be the arbiters of life-and-death decisions concerning developmentally disabled infants [Weil 1986].

Some feel that physicians, because of their positions of authority, have undue influence over parents in the decision-making process and should not be making the decisions [Lister 1986]. Cranford and Roberts [1986] state that a physician's training affords little skill outside of medicine, and therefore, a physician should not be construed as possessing special abilities in moral decision-making. Asch et al. [1987] cite the lack of consensus among physicians regarding treatment policies and the possibility of conflict of interest as justifications for not assigning exclusive authority to medical professionals in bioethical decision-making for seriously ill newborns.

The Ethics Committee

Many authors have recently suggested that some form of an ethics committee on infants would be the best locus of decision-making authority [Asch et al. 1987; Cranford and Doudera 1984; Weil 1986; Lyon 1985; Ross et al. 1986; Hosford 1986; Cranford and Roberts 1986; Doudera 1986; Bioethics Committee of the Canadian Paediatric Society 1986; Victoroff 1986; Fleishman 1986; Taft 1987]. Although the suggested makeup of infant care review committees varies somewhat from author to author, and the makeup of existing committees also varies somewhat, most hospitals use similar guidelines for establishing committee membership. The aim is to include members representing the service providers (physicians, nurses, hospital social workers, and psychologists), representatives of the community being served (local community lay members), professional moralists (clergy, ethicist-philosophers), representatives of the state (child protective service workers), and legal experts. The rationale for using bioethics committees is that discourse among representatives of the various interests in a milieu of guided ethical decision-making can best bring about consistent and just ethical decisions. This common-sense rationale would appear to have some intrinsic validity. In practice, however, the consistency and logical validity of various committees' recommendations is being questioned. The literature has little supporting documentation and no supporting research for the conclusion that by assembling such a group, one is more likely to achieve consistent and logical bioethical

decisions than could be achieved with other more homogeneous groups or by individuals.

Lyon [1985] states that infant care review boards were founded to standardize treatment decision-making, but in fact, have not done so. Many reasons are suggested for the contended lack of standardization and potential inconsistency, including the lack of philosophical sophistication of members of infant ethics committees [Wolf 1986; Siegler 1986], the lack of medical sophistication of members of infant ethics committees [Brennan 1986], and the utilization of different philosophical paradigms by different committees as guiding principles for decision-making [Wolf 1986; Hughes 1989]. Wolf [1986] suggests that ethics committee members generally have no formal training in ethics and are not experts in moral reasoning. She believes their decisions are suspect as a result. In research concerning the dynamics of decision-making by an ethics committee on infants, Hughes [1989] concluded that intercommittee reliability can be significantly compromised because ethics committees lack a standardized guiding ethical paradigm. Thus, the neonate could receive differing treat/no treat decisions depending upon which hospital, which ethics committee, and which guiding ethical paradigm was used to make the decision. Siegler [1986] states that the usual ethics committee is an unmanageable collection of uninvolved professionals who have no special expertise in moral reasoning; he believes that the role of interdisciplinary ethics committees should be education only, and the resolution of bioethical dilemmas should be left to committees of specialized nurses and physicians. Brennan [1986] argues for physicians retaining responsibility since "ethicists . . . are not familiar with the medical and emotional nuances associated with the care of acutely ill and dying patients." Despite suggested problems of taking away physician authority and responsibility, and suggested problems associated with uninformed lay committee members, others warn against physician-dominated bioethical decision-making committees and testify to the utility of more diverse committee membership. Victoroff [1986] warns that, in his experience, bioethics committees dominated by physicians are usually much less effective than those whose membership consists of a majority of other professionals.

The Theological Community

The theological community is an often championed locus of bioethical decision-making authority. Given the nation's secular government, a theological locus may never be a legally compelling authority; however, theological institutions may have ascribed authority and are often freely sought and chosen for ethical guidance by individuals within our society. Parents who find themselves thrust by circumstance into situations where they must make pro-

found and conflicting moral decisions often look to theological authority for guidance. Submitting to the traditional and absolute authority of theological imperatives in situations replete with ethical and emotional dilemmas can often be psychologically compelling and comforting. In addition, various voices within the theological community, representing various religious traditions, often do not accept a secular moral decision-making authority. Many theological traditions consider the ethical imperatives regarding matters of life and death to be transcendent, and therefore, feel that all involved parties have a moral responsibility to follow the tradition's guidelines for conduct and behavior [Ashley and O'Rourke 1978; Francoeur 1983]. These guidelines are often believed to be absolute and categorical, communicated by God or other transcendent sources [Rosner 1983; Beauchamp and Childress 1983]. Problems arise, however, as a result of the inconsistencies that can result from attempts to interpret and utilize absolute moral principles as practical guidelines in situations replete with relativistic contingency. For example, while all Judeo-Christian traditions place a high value on life, practical differences exist among denominations in their normative rules of conduct. The sanctity of life is a common fundamental presupposition for many denominations of the Judeo-Christian tradition [Rosner 1983]. For many, adherence to this principle requires that an attempt to sustain life must be made, regardless of how heroic and extraordinary the effort, and without consideration of expenditure of resources or the quality of the life that is perpetuated [Veatch 1981; Lyon 1985]. Yet the *Declaration of Euthanasia* of the Catholic Church uses the premise of sanctity of life as a justification for sometimes withholding treatment. The rationale is that one must protect life's sacredness from the potential dangers of the humanistic excesses of medical technology [McCormick 1978]; when there is neither hope nor benefit for the patient, treatment may be withheld or withdrawn. Thus, nearly dichotomous interpretations can be derived from the same absolute principle.

With our societal tradition of strict separation of church and state, it is extremely improbable that any theological locus of decision-making authority could be legally assigned. The moral authority of theological institutions notwithstanding, any legal authority for a theological locus of decision-making authority will be derived from parental rights arguments pertaining to religious freedom prerogatives.

The State

Structures of the state, including juvenile courts and child protective service agencies, are viewed by many as the appropriate final authority for treatment decision-making. Arguments for or against these structures of the state as loci of decision-making authority usually take the form of arguments for competing

rights, compelling responsibility, or prescribed authority. Those who champion parents as the appropriate locus of decision-making authority argue the relevance of individual privacy rights pertaining to medical treatment, the confidentiality of the physician-patient relationship, and the supereminence of parental rights [Crossley 1987]. Physicians may claim moral responsibility and legal authority derived from historical professional guidelines such as the Hippocratic Oath, requirements and responsibilities related to the fiduciary relationship between physician and patient, and medical legislation. Religious institutions may claim a "higher authority," or an authority derived from individual rights of religious freedom.

The state conditionally recognizes and sanctions these legal rights and jurisdictional claims through its various legislative and legal canons. Individuals may choose what they believe is medically in their own best interests when those interests are the only compelling interests affected by such choice, even if the choice is obviously a lethal one. Legislation and common law also generally support and protect parental rights and the integrity of the family unit [Garibaldi 1987]. There is also strong legal precedent supporting the rights of privacy and confidentiality in the physician-patient relationship [Gustaitis 1988]. Federal and state legislation prescribing professional medical authority, responsibility, and privilege is a significant part of our legal and social culture. Laws protecting religious freedom and supporting religious institutions encourage religious fellowship.

Yet in addition to all of the above, our government has clearly retained authority to intervene to protect children from harm. There is a long-standing legal tradition of formal state interest in protecting children from harm, expressed in the doctrine of *parens patriae*—the parental role of the state. Countervailing interests of the state begin at the point of viability of the fetus and newborn [Victoroff 1986; Crossley 1987]. The infant is generally protected by child welfare law from being put at risk of harm by intentional acts of the parent or caregiver, by inaction, or by the parent's or caregiver's inability to protect the child. The courts have consistently ruled that privacy rights or parental rights cannot supersede the state's compelling interest to protect a child from serious harm [Sassaman 1983; Avery et al. 1978; Curran 1978; Damme 1978]. Historically, the public child welfare system, as the delegated agent of the state, has been given protective service responsibility.

The Child Welfare System

In a very real sense, the Child Abuse Amendments reaffirmed and precisely delineated what was almost certainly an already existing but neglected area of child welfare responsibility. The child welfare system's mission is to protect children from abuse and neglect and in doing so, to always be guided by the

child's best interests. This responsibility is not contingent upon the setting in which the harm occurs. Even though the milieu of potential abuse may be the strange land of a hospital neonatal nursery, and even though an assessment of risk may involve unfamiliar medically related variables, the responsibility for determining whether abuse or neglect exists remains a categorical responsibility of the child welfare system. In addition, local child welfare agencies are more and more finding themselves with primary legal responsibility for medical treatment decision-making for catastrophically ill and developmentally disabled neonates and young children. In the last several years, the number of children born with catastrophic illness as the result of HIV infection has increased dramatically. Many of these children are abandoned at birth or otherwise become the legal responsibility of local child welfare agencies. The agencies then have guardian responsibility for life-and-death treatment decisions. Discussion and disagreement regarding the proper locus of decision-making authority will continue. The Child Abuse Amendments of 1985, however, invest the public child welfare system with the responsibility and authority to police bioethical decision-making for catastrophically ill newborns. This may be a well-placed responsibility, but it would require the child welfare field, at a minimum, to be able to employ a consensus-guiding ethical paradigm for decision-making.

The Lack of Consensus on an Ethical Paradigm for Decision-Making

Assigning responsibility for decision-making must be accompanied by an adequate, workable, and acceptable criterion to guide these decisions. The Child Abuse Amendments do not provide such a criterion, in spite of attempts to do so. The "best interests of the child" criterion, which is used as the decision-making criterion in other child protective service interventions, has not been operationalized for catastrophically ill neonates. There is no consensus regarding what would be in the best interests of children in these situations. This lack of consensus is not unique to the child welfare system. Our society has still not made the difficult but necessary choice of a consistent ethical paradigm to guide bioethical decision-making for all developmentally disabled neonates with life-threatening medical complications, and catastrophically ill children are subjected to inconsistent treatment decisions that vary depending upon where they are born, who their parents are, and who attends their birth. Until consensus-guiding principles are adopted, neither the child welfare system, nor infant ethics committees, nor any other potential locus of decision-making authority will be able to consistently and justly discharge this responsibility. The absence of a consistent decision-making criterion for

the child welfare profession also makes it extremely difficult to challenge a hospital's treat/no treat decision for a severely ill newborn. Since the inception of the Child Abuse Amendments, few child welfare agencies have done so [U.S. Commission on Civil Rights 1989].

Treatment decisions for catastrophically ill newborns are critical decisions. They often require choices between life or death—choices that can involve pain and suffering. If one is involved, one cannot abdicate responsibilities. Doing nothing can be anything but benign, leading to the most dire consequences. Inaction *is* an ethical choice with moral consequences. If we conclude that child protective service workers have a moral and legal responsibility to act, we must have a guiding ethical paradigm to inform our decisions if we are to meet our responsibilities validly and consistently. A standardized ethical paradigm to guide our profession's activities is more than just a practical necessity. It is an ethical necessity. It is imperative that we develop a consensus bioethical paradigm to guide child protective service activities for catastrophically ill newborns.

Summary

The majority of these difficult bioethical decisions should properly be made by parents with input from physician and health care workers, utilizing the resources and guidance of infant ethics committees within the involved hospitals. The child protective service system should have the final authority, however, to assure that the decisions of the "caregivers" do not constitute abuse or neglect. This will require that the child welfare system sometimes walk the razor's edge between protecting the child's best interests and preserving, facilitating, and empowering families in these difficult circumstances. But this is an ethical dilemma the child welfare system negotiates daily, and is perhaps the reason used to justify assigning the child welfare system this responsibility. It will also require that the child welfare field have a consensus bioethical paradigm for treatment decision-making for children born with catastrophic illness. Consistent treatment decisions in the best interests of our most vulnerable children cannot be assured, or even expected, without such standardized guidelines. ◆

References

- Asch, Adrienne; Cohen, Cynthia B.; Edgar, Harold; and Weisbard, Alan J. "Who Should Decide?" In *Imperiled Newborns*. Hastings Center Report 17, 6 (1987).

- Ashley, B. M., and O'Rourke, K. D. *Health Care Ethics: A Theological Analysis*. St. Louis, MO: The Catholic Health Care Association of the United States, 1978.
- Avery, M. E.; Janeway, C. A.; Berenberg, W.; and Medearis, D.N. "The Saikewicz Decision." *New England Journal of Medicine* (1978): 1208–1209.
- Barnett, Terry J. "Baby Doe: Nothing To Fear But Fear Itself." *Journal of Perinatology* 10, 3 (1990): 307–311.
- Battle, Constance U. "Beyond the Nursery Door: The Obligation to Survivors of Technology." *Clinics in Perinatology* 14, 2 (1987): 417–427.
- Beauchamp, T. L., and Childress, J. F. *Principles of Biomedical Ethics* (2nd ed.) New York: Oxford University Press, 1983.
- Berkowitz, S. T. "A Committee Consults: The Care of an Anencephalic Infant." *Hastings Center Report* 16, 3 (1986): 18–22.
- Brennan, Troyen A. "Do-Not-Resuscitate Orders for the Incompetent Patient in the Absence of Family Consent." *Law, Medicine and Health Care* 14, 1 (1986): 13–19.
- Canadian Paediatric Society, Bioethics Committee. "Treatment Decisions for Infants and Children." *Canadian Medical Association Journal* 135 (1986): 447–448.
- Chalnick, Marla Kappen. "Compromising Positions: Medical Treatment for Disabled Infants." *Maternal-Child Nursing Journal* 18, 2 (1989): 167–177.
- Columbus Dispatch. "Hospital Can't Remove Girl's Life Support." *Dispatch Publishing Company* (October 18, 1991).
- Columbus Dispatch. "Is No Life Better Than Life of Pain, Suffering?" *Dispatch Publishing Company* (November 30, 1991).
- Cornford, Francis MacDonald. *The Republic of Plato*. New York: Oxford University Press, 1945.
- Cranford, Ronald E., and Doudera, A. Edward. *Institutional Ethics Committees and Health Care Decision Making*. Ann Arbor, MI: Health Administration Press, 1984.
- Cranford, Ronald E., and Roberts, John C. "Biomedical Ethics Committees." *Primary Care* 13, 2 (1986): 327–341.
- Crossley, Mary A. "Selective Nontreatment of Handicapped Newborns: An Analysis," *Medicine and Law* 6 (1987): 499–524.
- Curran, W. J. "The Saikewicz Decision." *New England Journal of Medicine*, (1978): 1209(b).
- Damme, C. "Infanticide: The Worth of an Infant Under the Law." *Medical History* 22 (1978): 1–24.
- Davis, A. "Informed Dissent: The View of a Disabled Woman." *Journal of Medical Ethics* 12 (1986): 775–76.
- Doudera, A. Edward. "Developing Issues in Medical Decision Making: The Durable Power of Attorney and Institutional Ethics Committees." *Primary Care* 13, 2 (1986): 315–325.
- Driscoll, J. "Mortality and Morbidity in Infants Less Than 1001 Grams Birth Weight." *Pediatrics* 69 (1982): 21–26.
- Duff, R. S., and A. G. M. Campbell. "Moral and Ethical Dilemmas in the Special-Care Nursery." *New England Journal of Medicine* 289 (1973): 890–94.
- Fleischman, Alan R. "An Infant Bioethical Review Committee in an Urban Medical Center." *Hastings Center Report*, 16, 3 (1986): 16–18.
- Fox, R., and Swazey, J. *The Courage to Fail*. Chicago: University of Chicago Press, 1978.

- Francoeur, R. T. *Biomedical Ethics: A Guide to Decision Making*. New York: John Wiley and Sons, 1983.
- Fraser, Brian G. *The Child and His Parents: A Delicate Balance of Rights*. In *Child Abuse and Neglect: The Family and the Community*, edited by Ray E. Helfer and C. Henry Kempe. Cambridge, MA: Ballinger, 1976.
- Garibaldi. In the Matter of Kathleen Farrell (Case 108 N.J. 335). New Jersey Supreme Court Reporter 108 (187).
- Gustaitis, Rasa. "Right To Refuse Life-Sustaining Treatment." *Pediatrics* 81, 2 (1988): 317-321.
- Hosford, B. *Bioethics Committees: The Health Care Provider's Guide*. Rockville, MD: Aspen Publications, 1986.
- Hughes, R. C. *Ethical Paradigms Utilized By Health Care Workers in Decision Making for Developmentally Disabled Neonates With Life-Threatening Medical Conditions*. Unpublished Research, 1989.
- In Re Quinlan, 70 N.J. 10,355 A.2d 647 (New Jersey, 1976).
- Keyserlingk, E. W. "Against Infanticide." *Law, Medicine and Health Care* 14, 3-4 (1987): 154-157.
- Kuhse, Helga, and Singer, Peter. "For Sometimes Letting—and Helping—Die." *Law, Medicine and Health Care* 14, 3-4 (1987): 149-153.
- Kuhse, Helga, and Singer, Peter. "The Quality/Quantity-of-Life Distinction and Its Oral Importance for Nurses." *Int. J. Nurs. Stud.* 26, 3 (1989): 203-212.
- Lang, Gary C. "Baby Doe—A Medical Ethical Issue." *Western Journal of Medicine* 142, 6 (1985): 837-841.
- Lister, David. "Ethical Issues in Infanticide of Severely Defective Infants." *Canadian Medical Association Journal* 135 (1986): 1401-1404.
- Liu, Athena N. C. "Wrongful Life: Some of the Problems." *Journal of Medical Ethics* 13 (1987): 69-73.
- Lorber, John. "Results of Treatment of Myelomeningocele." *Developmental Medicine and Child Neurology* 13 (1971): 300.
- Lyon, Jeffrey. *Playing God in the Nursery*. New York: W.W. Norton, 1985.
- Mahon, Margaret M. "Nursing Involvement in Treatment Decisions Regarding Newborns with Congenital Anomalies." *Holistic Nursing Practice* 2, 2 (1988): 55-67.
- Mason, J. K., and Meyers, David W. "Parental Choice and Selective Non-Treatment of Deformed Newborns: A View From Mid-Atlantic." *Journal of Medical Ethics* 12 (1986): 66-71.
- McCormick, R. "The Quality of Life, The Sanctity of Life." *Hastings Center Report* 8, 1 (1978): 30-36.
- Murray, Thomas H. "The Final Anticlimactic Rule On Baby Doe." *Hastings Center Report* 15, 3 (1985): 5-9.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington, DC: U.S. Government Printing Office, 1983: 82-90.
- Rice, Edward. *Captain Sir Richard Francis Burton*. New York: Charles Scribner Sons, 1990.

- Rosner, Fred. "The Traditional Jewish Physician and Modern Biomedical Ethical Problems." *The Journal of Medicine and Philosophy* 8 (1983): 225–241.
- Ross, J. W.; Bayley, C.; Michel, V.; and Pugh, D. *Handbook for Hospital Ethics Committees*. Chicago: American Hospital Publishing, Inc., 1986.
- Sassaman, E. A. *Ethical Considerations in Medical Treatment*. In *Handbook of Mental Retardation*, edited by J. L. Matson and J. A. Mulick. New York: Pergamon Press, 1983.
- Schoeman, Ferdinand. "Parental Discretion and Children's Rights: Background and Implications for Medical Decision-Making." *The Journal of Medicine and Philosophy* 10 (1985): 45–61.
- Shaw, A. "Dilemmas of 'Informed Consent' in Children." *New England Journal of Medicine* 17, 289 (1973): 885–90.
- Shelp, E. E. *Born To Die? Deciding the Fate of Critically Ill Newborns*. New York: Free Press, 1986.
- Siegler, Mark. "Ethics Committees: Decisions By Bureaucracy." *Hastings Center Report* 16, 3 (1986): 22–24.
- Simms, M. "Informed Dissent: The Views of Some Mothers of Severely Mentally Handicapped Young Adults." *Journal of Medical Ethics* 12 (1986): 72–74.
- Subramanian, K. N. S. "In India, Nepal, and Sri Lanka, Quality of Life Weighs Heavily." *Hastings Center Report* 16, 4 (1986): 20–22.
- Taft, Cynthia. "Baby Doe Decision: A Hospital Manager's Perspective." *Health Care Management Review* 12, 2 (1987): 61–68.
- Todres, I. "Pediatricians' Attitudes Affecting Decision Making in Defective Newborns." *Pediatrics* 60 (1977): 197–201.
- U.S. Commission on Civil Rights. *Medical Discrimination Against Children with Disabilities* (September 1989).
- U.S. Department of Health and Human Services, Offices of Human Development Services. *Child Abuse Amendments*. (45 CFR Part 1340). *Federal Register*, 50(72), (April 1985: L4878, L4880, L4889, L4893–L4901).
- Veatch, R. M. *A Theory of Medical Ethics*. New York: Basic Books, 1981.
- Victoroff, Michael S. "The Ballad of Baby Doe: Parental Discretion or Medical Neglect?" *Primary Care* 13, 2 (1986): 271–283.
- Weil, W. B. "The Baby Doe Regulations: Another View of Change." *Hastings Center Report* 16, 2 (1986): 12–14.
- Wolf, S. M. "Ethics Committees in the Courts." *Hastings Center Report* 16, 3 (1986): 12–15.
- Young, Ernie W. D., and Stevenson, David K. "Limiting Treatment for Extremely Premature, Low-Birth-Weight Infants (500-750 G)." *American Journal of Diseases of Children* 144, 5 (1990): 549–552.

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