

9-28-2009

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From Mueller to Miller:
Determining Standards for Decisions Regarding Critically Ill Newborns

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by

Tanaz Farzan Danialifar

2009

FROM MUELLER TO MILLER: DETERMINING STANDARDS FOR DECISIONS REGARDING CRITICALLY ILL NEWBORNS. Tanaz Farzan Danialifar (Sponsored by Geoffrey Miller). Section of Neurology, Department of Pediatrics, Yale University, School of Medicine, New Haven, CT.

The controversy surrounding selective nontreatment of critically ill newborns has been ongoing for over three decades. Since ancient times ill, premature, or deformed infants have been treated discriminatorily, and infanticide has been a historically acceptable practice. With medical, moral, and legal progress, infanticide has disappeared and been replaced with selective nontreatment. This raises new ethical concerns such as best interests, quality of life, wrongful life, and parental autonomy; and legal questions regarding medical neglect, privacy, discrimination, and the limits of the Federal Government. Through an examination of relevant medical and legal literature, mass media publications, and both state and federal court decisions, this paper will provide a historical overview of the development of the ethical and legal principles guiding neonatal decision-making. In addition to a review of the historical contexts for treatment decisions regarding vulnerable infants, a discussion of several landmark medical-legal cases will establish the current standards for neonatal decision-making. This historical overview reveals the shortcomings of past and current legislation and the dissonance between current practice, public opinion, and the law.

Acknowledgements

This work would not have been possible without the endless support and guidance of Dr. Geoffrey Miller. Thank you for guiding me through failed projects, for sharing with me the breadth of your expertise and knowledge, for supporting new ideas, and for your endless patience through long distance phone calls and emails. Thank you to my family, especially my parents Jilla and Fred, for supporting me in every way possible throughout my journey in medicine. Special thanks to my husband, Arash, for three years of patience, for living in a sea of books and papers, and for listening even when you had no idea what I was talking about.

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Introduction

In 1978 Maria Piers wrote, “Nowadays we universally condemn practices such as infanticide, incidental and specific abuse, and the torture of infanticidal mothers; and most importantly, today there is universal agreement that every child born has the right to live. This is a new idea. A true achievement of this century,”(1). Piers highlights the drastic changes in treatment of infants since historic times; however, what is perhaps more significant are the developments in attitudes and legislation that affect current neonatology practice. With continued medical advancements and the ability to save the youngest and sickest newborns, come new bioethical and legal questions concerning best interests, quality of life, parental autonomy, and the role of the government in medical decision-making. In this thesis I will discuss the development of pediatric medical ethics with regards to selective nontreatment of critically ill and premature infants. The approach will include a brief historical overview of approaches towards imperiled newborns and a review of the development of modern neonatology. This will be followed by a discussion of landmark cases that have shaped the field in the United States and corresponding legislature. This presentation of the history, law and ethics related to the management of the vulnerable neonate in the United States continues to demonstrate a dissonance between clinical practice, fashioned mainly by physicians, and the law which continues to eschew a best interests standard. What remains unresolved is a standard method of determining such interests and protecting them.

Infanticide, abandonment, and overlaying

While the medical, ethical, and social grounds for abandonment of critically ill newborns have changed drastically, the practice in the West has spanned from antiquity to the present day. Societies as different as ancient Greece, classical Rome, Renaissance Italy, and Western Europe have had infanticide as part of their moral landscape and have displayed inconsistent legal patterns in dealing with the problem of child destruction or abandonment. In ancient Athens the major issue determining whether an infant lived or died was normalcy, and many philosophers advocated infanticidal practices. In *The Republic* Plato even promoted killing apparently normal products of “inferior” parents, writing:

The proper officers will take the offspring of the good parents to the pen or fold, and there they will deposit them with certain nurses who dwell in a separate quarter; but the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be (2).

Aristotle reaffirmed the notion of normalcy and created an explicit distinction between infanticide on the grounds of normalcy versus excess:

As to the exposure and rearing of children, let there be a law that no *deformed* child shall live, but that on the ground of an *excess* in the number of children, if the established customs of the state forbid this (for in our state population has a limit), no child is to be exposed, but when couples have children in excess, let abortion be procured before sense and life have begun...(3)

The insertion of a proposed threshold for abortion is interesting as it suggests that taking the life of a human after “sense and life have begun” would be morally unacceptable. However, there is no hesitation with the killing of “deformed” infants, implying their innate inhumanness and lack of value.

Such attitudes towards impaired newborns persisted in classical Rome, where while Roman law provided awesome punishment for anyone who hastened the death of a relative, the murder of a child by the father was exempted. Such exemptions often applied to the murders of girls or deformed newborns. In fact, killing “defective” newborns was such common practice it became a common feature of medical works. For example, Soranus of Ephesus had a section in his gynecological manual entitled “How to Recognize the Newborn that Is Worth Rearing.” He cited such conditions as the health of the mother, pregnancy carried to term, proper cry, and perfection “in all its parts, members, and senses,”(4).

For the Romans such infanticidal practices were supported by two fundamental reasons. Firstly, *patria potestas*, the father’s absolute legal authority over members of his family, as exemplified by the exception to the criminal code. Secondly, it was considered the most reasonable course of action in the case of deformed or weak infants. This was compared to the slaying of a diseased animal as defended by Seneca in the first century:

Mad dogs we knock on the head; the fierce and savage ox we slay; sickly sheep we put to the knife to keep them from infecting the flock; unnatural progeny we destroy; we drown even children who at birth are weak and abnormal. Yet it is not anger, but reason that separates the harmful from the sound (5).

With the coming of Christianity and the belief that all human life is sacred, came a backlash against infanticide. The *Didache*, which established a code of Christian conduct in the early second century, specifically opposed both abortion and infanticide and early Christian writers including Tertullian, Lactantius, and Philo vehemently opposed infanticide. With this fervent opposition against the killing of an infant came gradual revision of Roman law. Ultimately in 374 the direct killing of an infant for any

reason was declared an act of homicide punishable by death (6). Despite strict enforcement of the law, the disparity between religious and legal proclamations and parental practices persisted. It was in this new moral and legal landscape that there developed a new distinction between active and passive measures. Accidental “overlying” of the infant by the parents or suffocation by bedclothes became a common occurrence incurring a penance of at least one year . Furthermore, while intentional infanticide was a crime punishable by violent death, abandonment was acceptable, as it was perceived a less serious action given the remote possibility that the child would be saved. Notably, in rare circumstances when exposed children were rescued, they were often reared for slavery or prostitution (6). In the Middle Ages infant abandonment “was practiced on a gigantic scale with absolute impunity, noticed by writers with the most frigid indifference and, at least in the case of destitute parents, considered a very venial offense,”(7).

Widespread acts of infanticide directed toward illegitimate, unwanted, or defective children lead to the institutionalization of abandonment in Renaissance Italy. This occurred in two forms: foundling hospitals mainly for illegitimate males and care by a *balia* (lethal wet nurse) in the case of defective or female infants. The foundling hospitals, often run by religious officials, were meant to be a haven for unwanted children. However, they eventually became so overcrowded that children commonly died of neglect or inadequate medical care. As William Silverman wrote, “This merely changed the time and the site of child deaths,” (8). The *balie* on the other hand, took infants into the countryside and while apparently feeding them, killed them by either poisoning or suffocation. In return for payment by the parents, the *balie* helped rid them

of all legal and ecclesiastical problems associated with the death of their unwanted infants (9).

Such practices continued on throughout Europe during most of the seventeenth and eighteenth centuries. Infanticide became especially common in England, where separation from the Church of Rome provided even more leniency, and eventually reached America. While “killer nurses” continued to quietly poison unwanted children; neonates, bastards, and anomalous children were regarded as “changelings” and their deaths were necessary to protect parents from being labeled as accomplices of the devil.

As Robert Weir describes:

Physically deformed and mentally retarded infants were also regarded as subhuman parasites who, if fed, sucked “whitened blood” (milk) from the mother’s breast at every feeding. In addition, illegitimate infants and seriously deformed infants fell outside the category of “freemen” in medieval England, as evidenced by legal commentary of the time (10).

Infanticide continued to be rampant and a survey of British press in the 1860’s revealed frequent reports of dead infants found under bridges, in parks, culverts, ditches, and cesspools (11). As the crime became increasingly visible and troublesome, physicians including William Ryan and John Curgeven took a more active role and founded the Infant Protection Society. Their efforts led to the passage of the first Infant Life Protection Act in 1872. Public opinion, however, was more forgiving and English juries were reluctant to convict mothers. The attitudes of the British may be best evidenced in the statement of one witness, “You cannot estimate the loss to the child itself, you know nothing about it at all. With regard to the public it causes no alarm, because it is a crime which can be committed only by mothers upon their newly born children,” (12).

In America accidental “overlying” was most the most prominent form of infanticide and over time became increasingly uncommon for two reasons. Initially, the Puritan concept of sin significantly influenced attitudes, as child destruction was perceived a violation of “God’s law.” Furthermore, in the United States the law has never distinguished between infanticide and homicide, treating them both as equal under individual state penal codes. As a result infanticide and exposure became increasingly rare; however, medical advances created a new issue: selective nontreatment.

New technologies, new dilemmas

The development of the modern neonatal intensive care unit (NICU) can be attributed partly to the Franco-Prussian War between 1870-71. The immense loss of life both from violence as well as months of famine following the war created a new interest in more “feeble” neonates. French obstetricians and nurses applied miniature versions of technologies such as feeding tubes and ventilators, previously used for comatose patients, to premature infants. Additionally, the development of incubators helped prevent what were previously regarded as “expectant losses.” Around this same time English physicians began adopting the new French methods in an effort to combat the steady fall of the birthrate. In an article published in *The Lancet* in 1902, one physician argued to conserve the lives of all infants, “even the prematurely born... for economic as well as sentimental reasons,” (13).

As more critically ill newborns were sustained, new problems arose including recurrent waves of infection. To lower this risk, glass-enclosed hospital units were created to isolate the susceptible babies. Highly skilled nurses maintained nearly sterile

environments, even limiting physical contact between parents and their fragile babies. While such measures preserved the life of these previously nonviable infants, they also served to socially and emotionally isolate them from their families. This echoed the historic sentiments of parental detachment and perception of premature or defective neonates as aliens. Such attitudes allowed for the spread of Incubator Baby Exhibits at fairs and amusement areas such as Coney Island. The “changelings” of the eighteenth and nineteenth centuries had become the sideshows of the twentieth. As late as the 1939 World’s Fair in New York premature and deformed infants were displayed for the curious and paying public. Parents often willingly accepted such arrangements and as William Silverman, often considered the father of neonatal intensive care, observed, “They were often too accepting, for many quickly lost interest in their children, and there was some difficulty in convincing them to assume parental responsibilities when the time came to send the fattened babies home,” (14).

The initial premature infant nurseries proliferating in large American hospitals around this time maintained similar boundaries. Parents observed their babies from a distance through glass, physicians were discouraged from touching their patients too frequently, and often skilled and scrubbed nurses were the only caretakers growing attached to the survivors. As life-support techniques for neonates became more effective and pediatric surgery more successful throughout the 1960’s, the premature infant nurseries developed into the new neonatal intensive care units. The NICUs fostered physical and emotional bonding between parents and previously nonviable babies; however, many parents remained frightened and apprehensive. This was especially true in the case of very small or less-than-perfect babies. As Silverman describes:

The smaller the infant and the more serious the imperfection, the more common were the mixed feelings about survival. I was painfully aware that parental reactions were strongly influenced by my words and those of the nurses, and that nonverbal communication – not only from the caretakers but from the impressive physical setting and the awesome life-support machinery – played a significant role in determining how the parents expressed their feelings about this crisis in their lives (15).

It was in this manner that the NICU became the preeminent setting for life-and-death decisions about premature and congenitally anomalous infants. While parents made the majority of these decisions, it was the physicians' perspectives that served as the grounds for decisions regarding selective nontreatment. The literature produced by pediatricians and pediatric surgeons during that period demonstrates disagreement not only on standard medical practice in caring for critically ill newborns, but also on the ethical and clinical criteria for selective nontreatment.

In 1973 Duff and Campbell, two Yale pediatricians, were among the first to publish their experiences with foregoing treatment for 43 impaired infants. Over a period of two and half years they described 299 deaths in the special-care nursery, 43 attributable to withholding treatment from children with conditions such as trisomy 21, meningomyelocele, short-bowel syndrome, and other cardiopulmonary and central nervous system disorders. In support of these decisions Duff and Campbell draw upon the notions of "right to die" and "wrongful life," writing:

...Individuals should have a right to die in some circumstances such as anencephaly, hydranencephaly, and some severely deforming and incapacitating conditions. Such very defective individuals were considered to have little or no hope of achieving meaningful "humanhood." For example, they have little or no capacity to love or be loved. They are often cared for in facilities that have been characterized as 'hardly more than dying bins,' an assessment with which, in our experience, knowledgeable parents

(those who visited chronic-care facilities for placement of their children) agreed (16).

Duff and Campbell restrained from proposing rigid criteria for treatment and nontreatment decisions, concluding that decisions should be made “instance by instance” by the responsible parties involved.

Anthony Shaw, a pediatric surgeon and proponent of selective nontreatment, proposed mental retardation and/or severe physical malformation as important criteria in decision-making. He drew upon the quality-of-life argument in support of his criteria and even proposed a quantitative formula: $QL = NE \times (H+S)$, quality of life equals an individual’s natural physical and intellectual endowment times the contributions made to the individual by family and society. Applying this formula to certain clinical situations would indicate that an anencephalic infant has no quality of life because it lacks natural endowment. In the case of an infant with Down’s syndrome however, the child’s limited natural endowments would be modified by home life and society. Shaw acknowledged limitations of this criterion in borderline cases, yet maintained such predictions are necessary in decision-making (17).

John Lorber proposed another set of criteria for selective nontreatment: clinical criteria applying specifically to infants with spina bifida cystica. Lorber based his criteria on a study of 524 infants and used them to distinguish between infants with milder forms who had the prospect of meaningful life, as he defined it, and those whose severe forms would cause unnecessary suffering. He set forth six valuable prognostic criteria including the degree of paralysis, head circumference, the presence of kyphosis or scoliosis, associated gross congenital anomalies, intracerebral birth injury, and

thoracolumbar lesions. Lorber justified his criteria on the basis of nonmaleficence, stating:

In spite of the most energetic treatment over half of such infants [those with severe cases of spina bifida] died, often after years and a long succession of operations. The survivors continue with an unending succession of operations; most will remain incontinent with chronic pyelonephritis or hydronephritis and severely paralyzed, many will develop severe kyphosis, scoliosis and lordosis, and pathological fractures, more than a few will ultimately present the sequelae of hydrocephalus, especially fits (18).

Given the technical nature of Lorber's criteria, physicians would be primarily responsible for decisions not to treat, as parents rarely disagreed with physicians' advice against treatment. Applying these criteria to his own practice, Lorber reported that over a 21-month period 25 of 37 infants with spina bifida were not treated. All of the untreated infants died within 9 months, only one treated infant died, and the rest were reported to be normal or only moderately handicapped. Based on these results he concluded that selective nontreatment is "the best but not a good solution to an insoluble problem," (19).

Despite Lorber's apparent "success," John Freeman, a pediatric neurologist at Johns Hopkins School of Medicine, publicly opposed Lorber's policy of selective nontreatment. Freeman argued that while untreated cases of spina bifida do not survive beyond the first year, they do not die quickly and "euthanasia might be the most humane course...but it is illegal." Given the dilemma between legal but inhumane nontreatment and humane but illegal euthanasia, he stated, "in an *ambivalent* fashion, I feel that *virtually* every child should be given optimal, vigorous therapy," (20). He included the qualifier "virtually" to allow for exceptional cases such as that of a paraplegic child with multiple anomalies from whom he elected to withhold treatment. Clearly, what both

these approaches lack is what constitutes a meaningful life for a disabled child who has known no other life, and who can decide this, morally or legally, without oversight or accountability?

These obvious points were recognized by pediatrician Norman Fost and lawyer John Robertson. They added a new legal perspective to the discussion of selective nontreatment. In 1976 (prior to any formal legislation on the care of infants) they authored an article that suggested that parents and physicians engaging in selective nontreatment are potentially liable for charges of murder, manslaughter, child abuse, neglect, and conspiracy. Given the legal ramifications of such crimes they suggest establishment of clear universal decision-making criteria and a standard procedural mechanism. Fost also questioned pediatricians' prognostic capabilities as well as their criteria for judgment. He suggests that in recommending treatment decisions to families, physicians often project their own views about life and suffering:

The author would certainly not *choose* to spend his life in a wheelchair or with an ileal loop, but that does not mean that an infant or child, who never knew another life, need necessarily be psychologically overwhelmed by the experience (21).

Fost also challenged the inconsistencies in decision-making under the current lack of standards in which individual physicians choose to forego treatment for treatable conditions. In addition to his legal arguments, Fost opened a new discussion on the extent to which physicians may justifiably interfere with parental discretion. He suggested that in the situation of a child "whose prospects for a happy life are blocked only by a parental wish or preference," physicians must intervene (22). Despite his outspokenness on the issue of passive euthanasia, Fost still reserved the option for children with conditions such as anencephaly or trisomy 18.

C. Everret Koop, however, was steadfast about his belief in “the sanctity of all life, born or unborn.” Prior to his appointment as Surgeon General of the United States and his work towards The Baby Doe Rules, which will be discussed later, Koop was a distinguished pediatric surgeon committed to preserving the sanctity of life. Koop accused pediatricians such as Duff and Campbell of infanticide and questioned both their ethical and medical judgment. Like Fost, he questioned accuracy of diagnosis of lethal lesions and advocated for surgical correction except in terminal cases. He also criticized the notion of protecting parents from having burdens they are unable to bear by ending the life of a handicapped infant. He furthers this argument by suggesting that if factors justifying selective nontreatment include family stability, socioeconomic status, and social standing, then it is “clear that there has been introduced a discrimination just as deplorable as those of race, creed, or color,” (23). It would be ten years before Koop’s argument eventually became the basis for legislation.

The NICU makes it to Primetime

In 1971 the ethical issues surrounding critically ill newborns reached the public with the production of the film “Who Should Die?” by the Joseph P. Kennedy, Jr. Foundation. The film was a dramatization of the death of an infant with Down syndrome as a result of the parents’ decision to forgo surgical correction for duodenal atresia. The production was the driven by two cases of infants with Down syndrome and duodenal atresia that took place at Johns Hopkins Hospital during the preceding years. While surgical correction for duodenal atresia had been well accepted since the 1950’s, children with Down syndrome were still viewed as having very poor outcomes both medically and

socially. The first baby was born to Roman Catholic parents who already had two older children. In an interview with the infant's pediatrician, the parents' feelings were summarized:

...I remember very well the mother saying, I can't remember the words but the implication was that there was no way that she would take the baby home. That it would be so traumatizing to her personally and the whole family and so disruptive that she simply didn't want to sign the operative permit. She would rather have the baby die and end it all than to undertake caretaking of a severely handicapped baby (24).

Robert Cooke, Chairman of the Department of Pediatrics at the time, was disturbed by the parents' and physicians' decisions but was limited in his ability to intervene. Cooke even informally consulted Emory Niles, retired Chief Judge of the Supreme Bench of Baltimore City, who told Cooke that the court would not intervene if this case were brought before it (25).

The second case involved the Jewish parents of an infant with Down syndrome: a nurse at the hospital where the child was delivered and a lawyer. At first the parents were uncertain about the surgery and it was postponed. Upon formal diagnosis of Down syndrome the parents decided against surgery and all feedings were held until the child died at 13 days of age. J. Alex Haller, Jr., the attending surgeon, recalled that, "the parents believed that their child's condition was God's will and that they would not interfere with His plan," (26).

Cooke was again constrained in his ability to intervene as the baby was under the surgical service. Consequently, when the Kennedy Foundation began preparing for an international Symposium on Human Rights, Retardation, and Research, Cooke was eager to bring the case into the public forum. The result was the production of "Who Should

Survive?: Choices on Our Conscience,” dramatizing the events surrounding the second Hopkins case from the perspective of the second year resident involved. In the film the parents’ faces are never shown and they never speak. Following the screening of the film at the symposium, it was previewed for the media and quickly became the subject of national media coverage. Readers from across the country responded in letters to the editor and directly to some of the physicians involved. While a small number of responders sympathized with the parents, the majority were critical of the parents’ decision, some even made general appeals to the law. As a result, a debate that had been taking place in NICU’s for years finally entered living rooms across America and everyone had an opinion.

The Right to life itself: The case of Baby Houle

The battle over treatment of imperiled newborns finally reached courtrooms in 1974 concerning the case of Baby Boy Houle. Born at the Maine Medical Center, Baby Houle had multiple deformities: an absent left eye, a rudimentary left ear with no ear canal, a malformed left thumb, unfused vertebrae, and a tracheoesophageal fistula. The infant also suffered seizures and was suspected to have an unknown measure of brain damage. The Houles refused to consent to surgical repair of the fistula that would allow for proper feeding and respirations. Several physicians involved in the case, together with hospital administration disagreed with the parents’ decision to withhold treatment. The hospital initiated a medical neglect case and petitioned the court for permission to perform the surgery. Judge David Roberts did not hesitate in issuing an order for treatment. In his judgment he stated:

...At the moment of live birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself... The issue before the court is not the prospective quality of life to be preserved, but the medical feasibility of the proposed treatment compared with the almost certain risk of death should treatment be withheld. Being satisfied that corrective surgery is medically necessary and medically feasible, the court finds that the defendants herein have no right to withhold such treatment and that to do so constitutes neglect in the legal sense (27).

Judge Roberts disregarded the arguments concerning quality of life, given that it was beyond the scope of a doctor's expertise to make such judgments. Baby Houle underwent surgical repair for his fistula with consent by a court appointed guardian. He died the following day.

Conspiracy to commit murder: The Mueller conjoined twins

On May 6, 1981, conjoined twins Jeff and Scott Mueller were born sharing a single trunk below the waist and three legs. Their parents, Pam, a registered nurse, and Robert, an emergency room physician agreed with their family physician not to resuscitate the twins. Although the twins began to breathe spontaneously following birth, the attending physician and parents still believed the prognosis remained severe. They decided to withhold care and a note was entered into the chart, "Do not feed in accordance with the parents' wishes." The decision was met with skepticism by several staff members at the hospital and some nurses surreptitiously fed the boys small amounts of sugar and water.

When the twins were eight days old, an anonymous caller told the Illinois Department of Children and Family Services (DCFS) that they were being neglected. Within hours a social worker investigated the case and concluded there was reasonable

evidence of neglect reporting, "I saw their ribs sticking out - which indicated to me that they had not been fed," (28). The twins were transferred to Lakeview Medical Center under temporary court custody and DCFS filed a petition of neglect against the parents. Several nurses testified at the hearing both for and against the Muellers. Notably, they only agreed to testify after being granted a waiver of immunity from any possible criminal charges. At the June 5 custody hearing, Judge John P. Meyer upheld the state's contentions that the twins had been denied food, water, and medical care and granted temporary custody to the state. Judge Meyer did not comment on the issue of neglect on the part of the parents and even sympathized with them. In an interview with *The New York Times* in which he was frequently choking back tears, he said, "There's no doubt in my mind that all the parties involved thought they were doing the right thing. But when we put ourselves above the law, we cause nothing but heartache for our friends and for ourselves," (29). Nevertheless, against the wishes of the parents, Jeff and Scott were moved again to Children's Memorial Hospital in Chicago for evaluation and treatment.

On June 11 Danville prosecutor Edward Litak brought criminal charges against the parents and Dr. Warren. All three pleaded not guilty to the charges of conspiracy to commit murder and endangering the life and health of infants. This was the first time in US history that criminal charges had ever been brought against parents or doctors for withholding food or treatment from an infant. During the preliminary hearing nurses who had previously come forth were unwilling to testify and implicate the parents. As a result, Judge Richard Schott dismissed the criminal charges secondary to insufficient evidence to establish probable cause. Prosecutor Edward Litak continued his case against the Muellers until April of 1982 when a Vermilion County grand jury refused to indict

the parents and their doctor. All criminal records were subsequently ordered closed; however, Jeff and Scott remained in state custody.

After four months in DCFS custody, the twins were returned to their parents' home, but DCFS maintained legal guardianship. At the time of discharge, surgeons felt separation of the twins was nearly impossible and they were expected to live only a few weeks longer. The twins, however, did not cooperate with this prognosis, which may not have been evidence based, and after one year they were steadily gaining weight and healthier than ever. Everybody covering the case attributed the twins' success to the love and dedication of their parents rather than questioning the validity of the original prognosis. One author wrote:

The devotion Bob and Pam Mueller gave their sons, at great financial and emotional cost to themselves, unmasks [the myth that parents who opt for nontreatment are selfish]. To characterize them as abusive parents is both false and cruel (30).

In May of 1982 full custody of the twins was re-granted to their parents who just one year earlier had been facing criminal charges. Given the twins remarkable progress, surgeons decided it was safe to separate Jeff and Scott in a grueling nine-hour operation. Scott, who had congenital heart disease, died in 1985 at the age of 3. Jeff continued to do well and later entered regular school. Whether such sacrifice surgery was reasonable has been questioned by authors such as Dreger and Miller (31).

Families regain control: The case of Baby Doe

The infant known only as "Baby Doe" lived only six days, however his life and death changed the face of American neonatology. He was born on April 9, 1982 in Bloomington, Indiana and was immediately diagnosed with Down syndrome and a

tracheoesophageal fistula. By this time, surgical repair had a 90 percent success rate and mortality rates associated with all types of esophageal atresia had dropped from 100 percent in 1945 to nearly 10 percent in 1982 (32). The referring obstetrician, Walter Owens, consulted with the parents and emphasized the poor prognosis for a child with Down syndrome. He suggested that “some people with Down syndrome are ‘mere blobs’ and that the ‘lifetime cost’ of caring for a child with Down syndrome would ‘almost surely be close to \$1 million’,” (33). It is uncertain where the obstetrician obtained these figures, how they compared with the cost of raising a child with life long disability but normal cognition, or even the cost of raising any child. The parents decided against the surgery and chose to keep the child in Bloomington where he would eventually die. Hospital administration and pediatricians involved in the case disagreed with this decision and immediately consulted Monroe County judge, John Baker. At an unrecorded hearing that took place late at night in the hospital Owens ruled in favor of the parents and allowed Baby Doe to remain in Bloomington without surgery.

Three days later Monroe County Prosecutors Barry Brown and Philip Hill filed an emergency petition for custody of the child. The appeal was denied by the county circuit court and again the following day by the Indiana Supreme Court. In a final effort, the prosecutors traveled to Washington DC to appeal to US Supreme Court Justice Paul Stevens on April 15. Infant Doe died that day before the district attorney even arrived in Washington. The events surrounding the case were so highly publicized that three couples initiated attempts to adopt Infant Doe and the prosecutors were encouraged to consider bringing criminal charges against the parents and Dr. Owen. In explaining his decision not to pursue criminal charges Brown stated:

The parents and physician were proceeding under a ruling of the Monroe Circuit Court, and therefore, under the color of law. None of the traditional purposes for invoking the criminal sanction – deterrence, punishment, rehabilitation – are applicable in this case. We can find no theory of criminal law, which would justify placing the parents or the physician in criminal jeopardy. We also believe that the pursuit of criminal action in this case would only compound the tragedy (34).

Ultimately, during his short life Infant Doe reversed the precedent set by the previous cases of Baby Houle and the Mueller twins; however, his true impact on legislation was yet to come.

Baby Doe on Capitol Hill

The Reagan Administration responded to the events surrounding the Baby Doe case almost immediately. Surgeon General C. Everett Koop, a strong opponent of both selective nontreatment and abortion, encouraged President Reagan to take strong action. In a memo dated April 30, 1982, the President instructed Richard Schweiker, Secretary of the Department of Health and Human Services (HHS), to notify health care providers that section 504 of the Rehabilitation Act “forbids recipients of federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or services that would ordinarily be provided to persons without handicaps,” (35). Passed in 1973, the Rehabilitation Act protected handicapped adults and children from discrimination. This new interpretation by the Justice Department identified impaired newborns as handicapped citizens and as recipients of federal funds such as Medicare and Medicaid, hospitals were forbidden from denying treatment on the basis of handicap.

On May 18, 1982, HHS issued a “Notice to Health Care Providers” regarding “Discriminating Against the Handicapped by Withholding Treatment or Nourishment.”

Written by the director of the HHS Office for Civil Rights, the notice referred to the Infant Doe case and stated:

It is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

1. the withholding is based on the fact that the infant is handicapped; and
2. the handicap does not render the treatment or nutritional sustenance medically contraindicated.

While the notice recognized the limitations of its application to parental decision making, it warned hospital administrators to follow guidelines to avoid “facilitating discriminatory conduct,” (36). In response to the notice the American Hospital Association issued a formal statement denying that “hospitals have in any way been guilty of discrimination” and promising to “make every effort to assure that such simplistic solutions to complex situations involving health care delivery are avoided,” (37). The American Academy of Pediatrics also issued an official opinion opposing strict universal requirements:

The effort of the executive branch to solve this complex problem through strict interpretation and enforcement of the letter of section 504 may have the unintended effect of requiring treatment that is *not* in the best interest of handicapped children... It will frequently be the case that the use of a specific technology or procedures will *not* be in the best interest of the handicapped person. Withholding a medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients (38).

Despite resistance from hospitals and physicians, on March 2, 1983, the Reagan administration added an “interim rule” in efforts to follow-up on the prior regulation with more force. Coincidentally, this was issued the same week the film “Who Should Survive?” was aired for public audiences as a television series. The new notice mandated posting of warning signs in delivery wards, pediatric wards, nurseries, and NICUs. It

read, “Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law... Failure to feed and care for infants may also violate the criminal and civil laws of your state.” (Image 1) Anyone witnessing such “abuse” was encouraged to report it through the toll-free hotline and HHS officials were given authority to take “immediate remedial action.” Furthermore, hospitals were required to provide access to the hospital and its records to agency investigators, also known as “Baby Doe squads.” Composed of lawyers, government administrators, and physicians, the squads were designed to access all hospital information in an effort to investigate complaints. While publication of proposed rules must normally be followed by a thirty-day comment period, HHS argued that the requirement was unnecessary in this case. They maintained that the access and medical records requirements were “minor technical changes necessary to meet emergency situations.” Furthermore they argued that “any delay would leave lives at risk and for even a single infant to die due to lack of adequate notice and complaint procedure is unacceptable.” The regulations were to become effective March 22, 1983 (39).

In response to the proposed regulations the American Academy of Pediatrics, the National Association of Children’s Hospitals, and Children’s Hospital National Medical Center filed a lawsuit against HHS and new Secretary, Margaret Heckler, to enjoin the interim final rule. US District Court Judge Gerhard Gesell denied a temporary restraining order, but granted expedited review and agreed to hear the case on April 8. Judge Gesell ruled that the HHS interim rule was invalid on procedural grounds because affected parties were denied the normal length of time to comment on it. He took his judgment further, questioning the utility of the anonymous hotline:

...The sudden descent of Baby Doe squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.

He also criticized the failure to explore alternative means of preventing discriminatory denial of food or treatment as well as the absence of definition of “customary medical care.” Without such a definition he found the regulation to be “virtually without meaning beyond its intrinsic *in terrorem* effect.” Furthermore, he questioned the constitutionality of the rule stating, “To the extent the regulation is read to eliminate the role of the infant’s parents in choosing an appropriate course of medical treatment, its application may in some cases infringe upon [right to privacy interests]. Judge Gesell concluded that the regulation was “arbitrary and capricious” and the hotline rule was “hasty” and “ill-considered.” (40).

On July 5 1983, after losing an appeal to keep the regulations in effect, HHS proposed a new rule, similar to the one issued in March, but explaining that federal law does not require the imposition of futile therapies to prolong the dying of a baby who is "born terminally ill." Of the approximately 17,000 comments received during the ninety-day comment period, 97.5% favored the rule. The Baby Doe Rules would see several more revisions and another landmark case before realizing their final form. In the meantime, the efficacy of the regulations remained questionable. From March 17 to April 14 1983, the hotline received 600 calls. While the majority were requests for posters or information, twenty percent were wrong numbers or hung up. Of the sixteen calls making specific allegations, only five merited investigation without any further action (41). Another study discovered that Baby Doe squads forced additional treatment

for six infants, however in none of these cases were they able to *prove* a violation of the regulations (42).

On January 12, 1984, the Department of Health and Human Services published the final rule on procedures and guidelines relating to nondiscrimination of handicapped newborns. Effective February 13, 1984, it included four main provisions:

1. Hospitals are encouraged to establish infant care review committees.
2. Informational notices regarding the legal rights of handicapped infants are to be posted.
3. Child protective service agencies are required to establish procedures for applying their own State laws protecting children from medical neglect.
4. Hospitals are to provide expedited access to records and expedited action to affect compliance when HHS officials determine that immediate access is necessary to protect the life or health of handicapped infant. (43)

No access for the Federal Government: Baby Jane Doe

As the Baby Doe Rules continued to be revised, a child known as Baby Jane Doe was born in Long Island on October 11, 1983. She was born to middle-class parents, Linda and Dan, who had been married less than one year. She suffered from spina bifida with meningomyelocele, hydrocephalus, a damaged kidney, and microcephaly, and was immediately transferred to the NICU at University Hospital at the State University of New York at Stony Brook. The attending surgeon, Arjen Kenscamp, recommended emergency spinal closure and shunt placement to drain the hydrocephalus in an attempt to minimize developmental retardation. George Newman, the pediatric neurologist, advised the parents against surgery given Baby Jane's inevitably poor outcome. As he later stated, Newman felt that, "the child was not likely ever to achieve any meaningful

interaction with her environment, nor ever achieve any interpersonal relationships, the very qualities which we consider human,” (44). The parents, wanting to avoid “extraordinary” measures chose to forgo surgery and they requested comfort care including food, fluids, and antibiotics.

Despite the expectation that Baby Jane would soon die with her spinal cord open and increasing intracranial pressure, four days later she was still alive. The story quickly made it to the news and *Newsday* reporter Kathleen Kerr published an exclusive interview with the parents. Dan and Linda’s distress was clear:

Each time he began a sentence, Mr. A. let out a deep sigh, as though seeking strength to answer. Mrs. A continually touched her husband’s arm and rubbed it soothingly. Mr. A. shed his tears openly...Mr. A. said, “We feel the conservative method of treatment is going to do her as much good as if surgery were to be performed. It’s not a case of our not caring. We very much want this baby.”... “We’re not being neglectful, and we’re not relying on our religion [Catholicism] to give us the answer to what we’re doing here.”(45)

Physicians, nurses, and other staff at the hospital also sympathized with the parents and supported their decision. A hospital social worker noted that Linda was determined to give Baby Jane “as much love as possible.” In the era of the Baby Doe regulations, however, proponents of the right-to-life were eager to pursue the issue of handicapped newborns. In this case Lawrence Washburn, a municipal-bonds lawyer from Vermont who promoted right-to-life organizations, received a confidential tip about Baby Jane Doe and filed suit in New York to obtain an order to have the surgery performed. Given the death of Baby Doe during appeals, the case of Baby Jane Doe passed through the courts with unprecedented speed.

Judge Melvyn Tanenbaum, who had accepted the Right-to-Life party nomination in November of 1982, presided over the case in an emergency hearing on October 20. As Washburn had no legal standing in the case, attorney William Weber was appointed as Baby Jane's guardian *ad litem*. Upon first speaking with the parents and Dr. Newman, Weber fully supported their decision; however upon reviewing the medical record, he reversed himself. Two facts contradicted what Weber had previously been told. First, Newman had written that after the surgery, Baby Jane would be able to walk with braces. Second, her chart said that the initial measurement of her skull was 31 centimeters, a value within normal limits and indicative of possible normal brain function (46). Weber concluded that regarding the microcephaly, Newman had lied both during discussion with the parents and in his court testimony. In court he argued for immediate surgery and Judge Tanenbaum authorized Weber to consent to the surgery.

The parents appealed the decision and the following day the county Appellate Division reversed judge Tanenbaum's decision. The court reasoned that the parents had chosen between two medically reasonable options as the proposed surgery carried significant risk as well. Subsequently the New York Court of Appeals ruled that Judge Tanenbaum had abused his discretion in even hearing the case, as Washburn had "no disclosed relationship with the child, her parents, her family, or those treating her illness," (47). Furthermore the court dismissed the suit on procedural grounds because the allegation of child abuse and neglect had not been made to the state's Department of Social Services for appropriate investigation. While her case was making history in the courts, Baby Jane's wound naturally closed and she continued to survive. This was not necessarily and unexpected occurrence in untreated babies with open spina bifida.

The government, however, had already begun to act following an anonymous complaint to the HHS hotline that Baby Jane Doe was being discriminatorily denied treatment. HHS began a review of the medical record through October 19, which had become available during the state proceedings and Surgeon General Koop personally reviewed the case. He concluded that he could not determine the basis for denial of treatment without “immediate access to, and careful review of, current medical records.” Despite a thorough investigation by the New York State Child Protective Services, which on November 7 concluded that there was no cause for state intervention, HHS initiated action to obtain the remainder of the medical record. In response, Baby Jane’s parents said:

They’re not doctors, they’re not the parents, and they have no business in our lives right now... I just want [all this] to end. Just to have a baby like this and deal with it is so much to go through right now. Just let us be with our daughter and leave us alone... If there’s hell, we’ve been through it. (48)

Despite resistance from the hospital and the parents, HHS brought suit in US District Court to obtain the child’s medical records in an effort to conclude the section 504 investigation. Judge Leonard Wexler ruled that the hospital was not in violation of section 504 as the parents’ decision and not discrimination was the basis for forgoing surgery. In support of the parents Wexler found their decision “reasonable” based on “the medical options available and on a genuine concern for the best interests of the child,” (49). HHS appealed the decision, this time introducing a new argument questioning the responsibility of the hospital to intervene with the parents’ decision. HHS claimed that, “the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents’ decision and

compelling surgery was itself a violation of the nondiscrimination requirements of section 504.” Furthermore, they argued that while the state court had already ruled that no discrimination had occurred, that was only on the basis of chart review through October 19 and as “medical decision-making is a dynamic process” there remained the possibility of discrimination at a later date.

The defendants, including the parents and University Hospital, argued against the application of section 504 to this case for two reasons. First they questioned whether Medicare and Medicaid constitute “Federal financial assistance” as referred to by 504. Secondly they argued “congress did not intend that section 504 serve as the basis for federal intervention in medical decision-making.” Primarily the three-judge panel of the Court of Appeals determined that as a recipient of Medicare and Medicaid the hospital does fall under the statute of section 504. They next addressed the central question in the case: “Did congress intend section 504 to reach the conduct HHS seeks to investigate?” To answer this question the court first reviewed the history of HHS and its predecessor the US Department of Health, Education, and Welfare (HEW). They noted that in 1976 HEW adopted the position that 504 did not give it authority to regulate regarding patients’ rights to “receive or refuse treatment.” The court found HHS’s current position on the scope of section 504 to be “flatly at odds with the position originally taken by HEW.”

The court was left to focus on the statutory language of section 504, which states:

No otherwise qualified handicapped individual in the United States, as defined in section 706(7) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

After determining that Baby Jane Doe does indeed fit the definition of a “handicapped individual” the court turned its attention to the application of the phrase “otherwise qualified” which they interpreted:

... Refers to a person who is qualified in spite of her handicap and that an institution is not required to disregard the disabilities of a handicapped applicant, provided the handicap is relevant to reasonable qualifications for acceptance, or to make substantial modifications in its reasonable standards or program to accommodate handicapped individuals but may take an applicant's handicap into consideration, along with all other relevant factors, in determining whether she is qualified for admission.

They concluded that when the handicap itself is the subject of the service, as in the case of Baby Jane, section 504 does not apply. Furthermore the Court of Appeals reinforced Congress’s consistent policy “against the involvement of federal personnel in medical treatment decisions” and found no difference in “the field of child care... which has traditionally been occupied by the states.” On February 23, 1984, upon concluding that Section 504 of the Rehabilitation Act did not give HHS authority to interfere with “treatment decisions involving defective newborn infants” the Court of Appeals decided 2-1 to deny HHS’s request to obtain access to the medical record and continue its investigation (50). The Justice Department subsequently filed and was denied a request with the Court of Appeals asking the entire twelve-member court to rehear the governments case.

In 1986, the case reached the United States Supreme Court with new HHS Secretary Otis Ray Bowen as the petitioner. This time the defendants including the American Hospital Association challenged the validity of the Final Rules, which had been published after Baby Jane’s birth. While there was disagreement among the Justices as to Baby Jane’s designation as an “other wise qualified handicapped individual, the

judgment held that “There is nothing in the administrative record documenting the Secretary’s belief that there exists ‘discriminatory withholding of medical care’ in violation of section 504 which would justify federal regulation.” They went on to criticize the proposed complaint-handling process, stating “...state child protective service agencies are not field offices of HHS bureaucracy and they may not be conscripted against their will as foot soldiers in a federal crusade.” While HHS can require state agencies to document their *own* compliance with section 504, the Supreme Court found no authorization for HHS to force state agencies to enforce compliance by other recipients of federal funds. Finally, the decision invalidated the Final Rules on the grounds that HHS could not provide any evidence that discrimination against handicapped infants occurs:

Section 504 does not authorize the Secretary to give unsolicited advice either to parents, to hospitals, or to state officials who are faced with difficult treatment decisions concerning handicapped children. The administrative record demonstrates that the Secretary has asserted the authority to conduct on-site investigations, to inspect hospital records, and to participate in the decisional process in emergency cases in which there was no colorable basis for believing that a violation of section 504 had occurred or was about to occur. These investigative actions are not authorized by section 504, and the regulations that purport to authorize a continuation of them are invalid. (51)

Essentially, the Supreme Court decision protected state law, which places qualified consent and decision-making responsibility for the medical care of their children in the hands of parents. The States also carry legislative responsibility for cases of child neglect.

Amidst the continuing legal battle, Linda and Dan eventually changed their minds and permitted surgery to shunt and drain the hydrocephalus. This decision was unknown

until months later. Baby Jane was taken home by her parents on April 7, 1984, at age 5 ½ months. The case continued to receive extensive media coverage, even becoming the focus of broadcasts by *60 Minutes* and *Face the Nation*. For the most part the media and the public supported the parents and the hospital and C. Everett Koop was villainized as a fundamentalist Big Brother. Baby Jane continued to do well and in a 1994 interview, the child known to the public only as Jane Doe was described:

Now a 10 year-old...Jane Doe is not only a self-aware little girl, who experiences and returns the love of her parents; she also attends a school for developmentally disabled children – once again proving that medicine is an art, not a science, and clinical decision making is best left in the clinic, to those who will have to live with the decision being made (52).

Let's compromise: The Child Abuse Amendments

As the battle over Baby Jane Doe continued in courtrooms, Congress began an effort to end the political controversy over the federal role in decisions to withhold treatment from handicapped newborns. New rules were developed as a result of negotiations among physicians' organizations, hospital associations, right-to-life groups, and advocates for people with disabilities. These came in the form of Child Abuse Amendments (CAA) of 1984 to the Child Abuse Protection Act of 1974. The new category of medical neglect was added and stated:

1. All such disabled infants must under all circumstances receive appropriate nutrition, hydration, and medication.
2. All such disabled infants must be given medically indicated treatment.
3. There are three exceptions to the requirement that all disabled infants must receive treatment, or stated in other terms, three circumstances in which treatment is not considered "medically indicated." These circumstances are:
 - a. If the infant is chronically and irreversibly comatose.
 - b. If the provision of such treatment would merely prolong

dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant.

c. If the provision of such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.

4. The physician's "reasonable medical judgment" concerning the medically indicated treatment must be one that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. It is not to be based on subjective "quality of life" or other abstract concepts.

The guidelines came with a commentary providing definitions and further interpretation of ambiguous terms such as "virtually futile," defined as "highly unlikely to prevent death in the near future on the basis of reasonable medical judgment." The CAA restricted the involvement of the federal government in individual cases of medical neglect and obligated states to set up procedures for responding to cases of medical neglect in order to continue receiving child abuse funds. Regulatory and legislative action became the responsibility of the states. (53)

Right-to-life and disability groups were appeased because the provisions prohibited nontreatment decisions based on expected low quality of life or the interests of parents. Physicians and hospitals, on the other hand, were protected because CAA imposed no legal duties on doctors. For example, it would not be a federal crime for a doctor, parent, or hospital not to treat a child who did not meet the narrow expectations. Nevertheless, the CAA were perceived as creating a legal presumption in favor of more aggressive treatment. Physicians and hospitals became more reluctant to defer to parental wishes. As a result, multiple studies over the next few years demonstrated what many perceived as overtreatment by physicians due to the rules (54). Both the American Academy of Pediatrics (AAP) and the American Medical Association, which had both

fought the previous Baby Doe rules, issued policies in support of equal treatment of newborns regardless of disability and low quality of life. They also recommended the establishment of “infant care review committees,” the predecessors to ethics committees now found in many institutions. In 1996 the AAP published a policy statement on “Ethics and the Care of Critically Ill Infants and Children.” Their recommendations were:

1. Decisions about critical care for newborns, infants, and children should be made similarly and with informed parental permission.
2. Physicians should recommend the provision or forgoing of critical care services based on the projected benefits and burdens of treatment, recognizing that parents may perceive and value these benefits and burdens differently from medical professionals.
3. Decisions to forgo critical care services on the grounds of resource limitations, generally speaking, are not clinical decisions, and physicians should avoid such “bedside rationing.” (55)

Since then, the states have played a passive role, intervening only under extreme circumstances or when hospital ethics committees cannot resolve conflicts between parents and care providers. In the twenty years since the passage of the Baby Doe regulations, the states’ reactions in these instances has been conflicting as will be demonstrated in the discussion of cases that follow.

Parents seize control: Sammy Linares and Baby Messenger

In 1998 a case in Illinois truly tested the law. Sammy Linares, a six-month-old boy was at a birthday party when his five-year-old sister handed him a rubber balloon, which he inhaled, causing asphyxiation and cardiac arrest. By the time he arrived at the emergency room Sammy had been without oxygen for nearly twenty minutes. There he

was resuscitated and maintained on a ventilator prior to transfer to the PICU at Rush-Presbyterian-St. Luke's Medical Center. Despite the doctors' predictions that Sammy would survive no longer than 24 hours, four days later he remained alive in what his doctors described as a "persistent vegetative state." His father, Rodolfo, requested termination of life sustaining interventions; however, the hospital, unsure of the legal ramifications, resisted. As his physician, Gilbert Goldman later stated, "There was no ethical difference of opinion here. The physicians agreed that the child was in an irreversible coma and would not recover. There was no medical opposition to removing the ventilator. What we faced was a legal obstacle." At the time, Illinois law did permit withdrawal of life support mechanisms from patients with absent brain activity; however, there was no precedent governing those with minimal brain activity, even in the absence of any prospect of regaining consciousness. Chief hospital attorney Max Brown advised the medical staff not to remove the life support for the Linares child. Brown supported his decision stating, "There is an absence in the law. I told the medical staff there was a possibility they would face criminal charges. I can't speculate with the careers of doctors and nurses," (56). Sammy remained on life support and eventually the hospital initiated transfer to an extended care facility.

The hospital had advised Mr. Linares and his wife, Tammy, to seek a court order authorizing the removal of the respirator. However, the Linareses, a family living on welfare, felt limited by their financial constraints. After four months Mr. Linares, desperate to end the saga, attempted to disconnect Sammy's ventilator but was restrained by hospital staff as it was reconnected. Four months later Mr. Linares tried again, this time keeping hospital staff at bay with a handgun, and succeeded. After holding his son

and sobbing for twenty minutes, Mr. Linares turned himself over to the police. He was charged with murder, but the grand jury refused to issue an indictment for homicide. Sympathy for Mr. Linares was universal. Robert Stein, the medical examiner ruled that the death was “accidental” and declared the primary cause of death asphyxiation by balloon (57).

In response to the Linares case, the Illinois Governor signed the Health Care Surrogate Act into law in 1991. The act allowed surrogate decision makers to withdraw life sustaining treatment from any patient lacking “decisional capacity” as long as the patient met one of the following “qualifying conditions”:

1. Terminal condition in which, “there is no reasonable prospect of cure or recovery, death is imminent, and the application of life-sustaining treatment would only prolong the dying process.”
2. Permanent unconsciousness “for which initiating or continuing life-sustaining treatment, in light of the patient's medical condition, provides only minimal medical benefit.”
3. Incurable or irreversible condition “ that ultimately will cause the patient's death even if life-sustaining treatment is initiated or continued.”

The act required certification in writing in the patient's medical record by the attending physician and by at least one other qualified physician. The law remained mindful of the CAA and in the case of neonates specified “Nothing in this Act supersedes the provisions of 45 C.F.R. 1340.15 concerning the provision of ‘appropriate’ nutrition, hydration, and medication for neonates.” (58)

Another case in Michigan demonstrated a similar outcome. In 1994 Baby

Messenger was born at 25 weeks and weighing 750 grams. In consultation with the attending neonatologist, the parents had been told there was a 50-75% chance of mortality and a 20-40% chance of severe intraventricular hemorrhage and subsequently requested that no “extraordinary” measures be taken during the resuscitation. The neonatologist was not present at the birth and a physician assistant resuscitated the infant who was later admitted to the NICU in poor condition. The parents requested withdrawal of treatment and refused to consent to surfactant administration. The physician assistant responded that she was unable to terminate care and by the time the neonatologist arrived, the baby had somewhat stabilized and the physician wanted to continue care. Once the parents were alone with the baby, the father disconnected the ventilator as the mother held the dying baby. The father was charged with manslaughter, but the jury believed that parental choice was in the child’s best interest and found him not guilty (59).

These cases demonstrate a clear shift in attitudes since the days of Baby Doe just ten years earlier. Baby Doe’s parents who had merely refused to consent to surgery were criticized across the country. However, these two fathers, who in essence committed infanticide, received sympathy and support from the public. The general consensus once again became that parents have a child’s best interest at heart and should retain all decision-making authority. Actual practice among NICU’s in America became incongruous. 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 (60). Similar disparities were found in many other studies as well.

The price of a wrongful life: Sidney Miller

On August 17, 1990 Karla Miller was admitted to the Woman's Hospital of Texas with chorionamionitis and preterm labor. The baby was estimated to be at 23 weeks gestational age and weigh approximately 630 grams. Both the attending obstetrician and neonatologist informed the Millers that "the infant had little chance of being born alive," and even if it were, it would suffer "severe impairments, including cerebral palsy, brain hemorrhage, blindness, lung disease, and mental retardation." The Millers requested that "no heroic measures" be performed and their requests were documented in the medical chart. Later that day, the obstetrician convened with hospital administrators and other physicians and determined that, according to unwritten hospital policy, if the fetus was born alive and weighed over 500 grams, the hospital was obligated to resuscitate. Mark Miller, the father, refused to consent to immediate resuscitation and it was decided that a neonatologist would be present at the birth to evaluate the infant and decide to resuscitate based on her condition at birth. Mark later denied that he had agreed to this plan (61).

Sidney Miller was born later that night at 23 weeks and one day, weighing 615 grams and with Apgar scores of three and six and one and five minutes respectively. She was resuscitated, intubated, received surfactant, and was transferred to the NICU with central lines in place. According to hospital records, Mark Miller signed consents for administration of Vitamin E, surfactant, and a blood transfusion within the first two hours of life. Four days after birth Sidney suffered a Grade III/IV intraventricular hemorrhage. The Millers later consented to surgical cutdowns to replace ruptured access vessels as well as surgical placement of a ventricular shunt to relieve her hydrocephalus. After two

months in the NICU, Sidney was transferred to Texas Children's Hospital, and at age six-months she was released to her parents' home.

At the age of seven, Sidney could not walk, talk, feed herself, or sit up on her own. She was legally blind, had mental retardation, cerebral palsy, seizures, and spastic quadriparesis in her limbs. She could not be toilet trained and required several shunt revisions to relieve her hydrocephalus. She needed care twenty-four hours a day. Around this time the parents sued the Hospital Corporation of America (HCA), but not the physicians, for battery and negligence in treating Sidney without consent and seeking compensation for her "wrongful life." The parents alleged "vicarious liability for the actions of the hospital in... treating Sidney without consent [and] having a policy which mandated the resuscitation of newborn infants weighing over 500 grams even in the absence of parental consent." Furthermore, they asserted that HCA was directly liable for "failing to have policies to prevent such treatment," (62). In January 1998 a jury under the 189th District Court In Harris County found HCA liable, and awarded the Millers \$29,400,000 in past and future medical expenses, \$13,500,000 in exemplary damages, and \$17,503,066 in prejudgment interest.

However, on appeal in December 2000 a two-to-one- split reversed the decision and rendered a take-nothing judgment against the Millers. The district court had based its judgment on the Texas Natural Death Act, which allowed parents to forego life-sustaining treatment in children with terminal or irreversible conditions. The appellate court referred to the application of The Act, stating:

The Legislature has expressly given parents a right to withhold medical treatment, urgently needed or not, for a child whose medical condition is certifiably terminal, but it has not extended that right to the parents of children with non-terminal impairments,

deformities, or disabilities, regardless of their severity.

The court held that because Sidney's condition was not certified as terminal, the Millers did not have the statutory right to refuse life-sustaining treatment. The judgment also focused on the state's interest in preserving life, referring to Texas Family Code section 151.002, "a child born alive after a premature birth . . . is entitled to the same rights as are granted by the State to any other child born alive after normal gestation." The appellate court acknowledged that a compelling argument can be made that the law should make an exception for a baby who is "born so prematurely and in such poor condition that sustaining [the baby's] life, even if medically possible, cannot be justified." However, as no present legislature indicated which nonterminal conditions would qualify, the court could not classify Sidney's case as an exception. The appellate court held that as long as a baby's medical condition is not certified as terminal, medical professionals have no duty to follow a parent's directive "to withhold urgently needed life sustaining medical treatment" from a baby. Furthermore, the appellate court found that no court order was necessary to override the Millers' refusal of life-sustaining treatment because the need for life-sustaining treatment actually became urgent while the nonterminally ill baby was under the care of the medical providers. (63)

The Millers appealed to the Texas Supreme Court, asserting battery and negligence claims for the medical treatment provided to Sidney without parental consent. In 2003 the court issued an opinion affirming the appellate court decision that Sidney did not meet the conditions of the Natural Death Act. Furthermore, they agreed that treatment without parental consent in this case did not constitute battery and that given the urgency, no court order was necessary. The court found that Sidney's medical treatment was

provided “under emergent circumstances as a matter of law” and that “those circumstances provide[d] an exception to the general rule imposing liability on a physician for providing treatment to a minor child without first obtaining parental consent,” (64). HCA was accordingly absolved of all liability. Perhaps what was more notable about the Supreme Court’s decision was what it did not say. They denied the wrongful life cause of action (which have all other courts), and did not address quality of life concerns or best interest standards. But it is important to note that although the child’s eventual neurological status was poor, such severity is not the rule for surviving extremely preterm infants.

Epilogue

Some might argue that the outcomes of the Miller case highlight the inadequacy of current legislation and the impracticality of rigid legislation. While the right to life and the autonomy of the family have become widely accepted into current practice neither is an absolute. The roles of wrongful life and quality of life remain unclear. Discerning a wrongful life is a legal imponderable as it requires comparing an undesirable life against no life. This is a reason why a wrongful life suit is yet to be successful. Requiring the courts to balance the benefits and burdens of a condition when these are uncertain is also difficult. Accordingly, US courts have favored preserving life except when the outcome is clear and well delineated. The legal and legislative history of neonatal decision-making establishes and protects the role of parents as primary decision-makers. In doing so, we place the responsibility of protecting a child’s best interests into the hands of the parents. This does not however give families the unregulated right to determine which children

are preferable and which are simply a burden. As Geoffrey Miller suggests, “Society has to trust parents and physicians to provide care for children, up to a point. Where to draw the boundary is open to discussion, but not that there should be a boundary,” (65).

Current Federal law protects physicians and hospitals from criminal consequences, but does not clarify boundaries, beyond the CAA. State laws are explicit in cases of terminal and incurable infants, but fail to establish guidelines in more ambiguous cases. The failure of most of the previous legislation on this matter is likely attributable to the attempt to address all situations with a single set of rules. Perhaps the best approach may be one proposed by Duff and Campbell: instance by instance. However, such a model risks the dangers of ignorance, hubris, and prejudice. Ethics committees can be the foundation for such decision-making as this might prevent the individual beliefs of physicians from obscuring the interests of the family and the child. However, given their variable composition and nature and their susceptibility to “group think,” ethics committees cannot replace statutory legal boundaries. Morality and law remain related, but they are not the same. Both can evolve or regress, and not necessarily in the same directions, depending on times and circumstance.

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Images

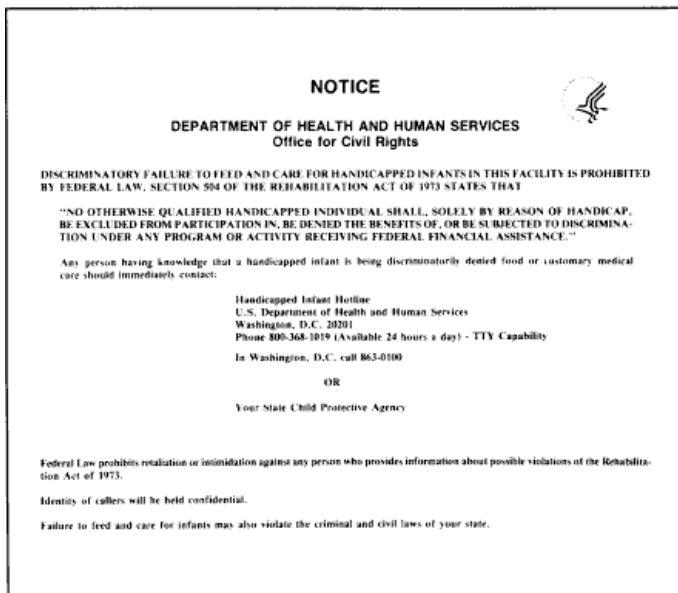


Image 1: Sample of notice posted in all US hospitals receiving federal funds.