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A Historical Perspective on Ethical Decision-Making in the Care of the Impaired Newborn

By

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THESIS

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Approved: ........................... 5/14/85

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DEDICATION

This Master's Thesis is dedicated

to my husband, Michael

for his constant support and belief in me
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CHAPTER ONE

INTRODUCTION TO THE ISSUES
Introduction

Our modern technology has afforded us great benefits in relation to health care but along with these benefits have come unprecedented dilemmas. Nowhere are these dilemmas more striking than in the treatment of the critically ill newborn. Although newly developed technology has helped improve mortality and morbidity statistics for the newborn overall, many infants born critically ill who would have died in the past now survive with great suffering and life-long disability, sometimes only to die an agonizing death months or years later.

In this paper, I will focus on the decision-making process that occurs when treatment options are considered in the care of the critically ill newborn. This process and the environment in which it has occurred has undergone two distinct changes over the past century. Up until the early 1940's, birth and the process of choosing treatment options when an infant was born ill was a private one between parents and their doctor. These decisions were based more on hope than substance, as there was little medicine could offer. In the 1940's, therapies were developed specifically for the premature and critically ill newborn and the process of decision-making moved from the private domain of parents and physician to an institutional, more public one, where several professionals were now involved. The advent in the 1960's of the neonatal intensive care unit concept, where specially trained professionals ready with the newest
technologies, were on hand to initiate treatment immediately after the birth of an infant in need of resuscitation or other means of support, gave hospital authorities, lay and medical personnel increasing power. Although the benefits from a medical system constantly on the alert were numerous, the inertia and momentum of a system where immediate action was taken as medical indications dictated, moved the decision making process from the parents into the hands of the professionals. The question became one of "could we", rather than, "should we"? Then, in 1982, after media attention and public interest was focused on several "Baby Doe" cases, where decisions not to treat critically ill newborns were made by parents and their doctors, the so called "Baby Doe" regulations were instituted. These regulations, which mandate maximum medical care for all newborns but those with the most severe problems, moved the decision even farther from the family and out of the hands of the professionals into the domain of the government.

In a pluralistic society such as ours, I have serious doubts that restrictive guidelines such as the "Baby Doe" regulations accurately reflect our beliefs and values as a society. We claim to respect individual autonomy except in situations where harms to society are believed to be so great that individual choice is not permissible. As we are a society of diverse ethnic and religious traditions and we place the family as our primary unit invested with the responsibility of protection and nurture of its members, I believe the family should be given wide latitude in
latitude in treatment decisions. The current legislative approach not only ignores the particularities of each family, it prevents their involvement in making choices concerning what may be the most difficult situation confronting them in life—the birth of a severely ill or defective newborn.

There are those who argue that the family should not have the power that I advocate, citing our social tradition of protecting the needy and handicapped, and the belief that family members lack appropriate knowledge. However, in reviewing the literature, I found numerous grounds for support of the contention that the family is the appropriate authority for treatment decisions of this type. Not only have courts consistently recognized the authority of families in almost all decisions regarding the upbringing and care of its children, but there was overwhelming evidence that families also bear the greatest burden when an infant is born prematurely or critically ill, as these infants have a tremendous impact on family integrity and draw heavily on the family's physical, emotional and financial resources. Another reason families should be allowed decision making authority is that the ability to predict the outcome for any specific infant is poor, whether treatment is applied or not. In fact, there is a growing awareness that much of the treatment used in the care of these infants is the actual cause of multiple developmental and physical problems, in itself.

Instead of gaining clarity from surveying the differing viewpoints of physicians, ethicists, social commentators and
others representing diverse sectors of our society, I have found that there is an extraordinary lack of guidance regarding the "appropriate" direction one should take when confronted with the complex issues involved when making treatment decisions in the care of the critically ill newborn. Not only between groups, but within each group, as well, the parameters of the problem are difficult to specify and criteria considered relevant, and the interpretation of them, varies. There is not even agreement over what characteristics define a 'human being'. It remains unclear to me what the rationale is for this current shift in boundary-setting between what is considered societal imperative vs family domain.

When the critically ill newborn is the subject of care, the goals of medicine—to sustain life and alleviate suffering—often conflict. By mandating treatment, I believe we are not dealing with this conflict head on but, instead, are being deluded into thinking that no conflict exists at all. I propose to illustrate in this paper, that the problems we face are magnified by this legislative approach rather than resolved by it. If we admit that our ability to predict the outcome of technological support is poor, the treatments themselves may leave the critically ill newborn infant severely damaged, and recognize that the family will live with the repercussions of these decisions regardless of outcome, then I strongly believe it follows that they should have ultimate authority in deciding the level of aggressiveness of treatment for their infants. Technology has given us the
opportunity to offer infants and their families, hope, but the rise in care of infants needs to be tempered by the realities of just how much these infants benefit and potentially suffer. The role of society should be one of support rather than that of dictating as families attempt to deal with one of the more tragic events of life.

The Changing Role of Children in Society

Our current situation does not accurately reflect our historical views of the role and value of children in our society. In fact, children have not always been held in such high esteem as they are today. The rise in care of children and the immense resources and effort in time we devote to them is rather new in history. In times past, there was little that parents or science could do for infants that would make a difference in their survival and, as a result, adults did not invest many emotional or material resources in children. Due to the high death rate of young children, they were often not considered part of the family until they had reached the age of six or seven.1 As healthy children were often not considered part of the family until proving their ability to survive, the malformed were not even considered human. In many cultures worldwide, the malformed newborn was left outside in the elements unprotected to die. Ancient myths and legends demonstrate the deep ambivalence we have always felt toward infants who are
disturbingly different, so much so that throughout history we have ritually killed or worshipped them.\(^2\)

Organized medicine began to actually care for newborns in the 18th century with the emergence of scientific medicine and the belief that birth was a scientific event. Believing that midwives relied on custom rather than science, a successful movement followed which eventually placed the birth process in the hands of physicians within the hospital setting.

Although the decrease in infant mortality that occurred at this time was more likely due to improved nutrition, it instilled in physicians and the public the belief that infant deaths were preventable. During the early 20th century in the U.S., childbirth moved "en masse" to the hospitals. This occurred so rapidly that by 1939, half of all pregnant women and 75% of urban women delivered in hospitals, whereas in 1900, only about 5% of women had delivered in hospitals.\(^3\)

The change in attitude toward children by society and the evolution of doctors' views of birth and early childhood, was also reflected in the development of medical procedures designed specifically for the care of the premature newborn in the 19th century. In 1835, the first human incubator was built, and by 1870, the first experiments were carried out using oxygen for respiratory distress, which was recognized early as a primary problem of the premature infant.\(^3\) In the early 1900's, the infant incubators were demonstrated at the World Exposition in Berlin where premature babies believed too small to save were
displayed in these "child hatcheries".\textsuperscript{3} This show went to London and then America, where they were popular with the public and inspired the medical community to consider the use of incubators in the care of premature infants. Despite the early commercialism of these "Incubator Baby Side-Shows", as they came to be called, they led to the establishment of premature nurseries in hospitals around the U.S., the first of which was at the Sarah Morris Hospital in Chicago in 1923.\textsuperscript{3}

Early Neonatal Intensive Care Units

The new treatments developed for the critically ill newborn have not always produced beneficial results. Although many of these therapies were life-sustaining, they also left some infants blind, deaf and disabled. During the 1940's and '50's, therapeutic techniques were rapidly introduced into the care of premature newborns, often without thorough evaluation. It was during this period that a new eye disease, retrolental fibroplasia, which results in visual impairment and blindness, was first noted in some babies who had been treated for prematurity.\textsuperscript{3} The use of certain types of antibiotics was found to cause hearing impairment and even some deaths.\textsuperscript{3} Although these new therapies were instituted with the best of intentions, questions began to arise over outcome as more adverse effects of treatment were being discovered. Follow-up studies carried out in the 1940's and '50's revealed that over 50% of prematures
weighing less than 1500 grams at birth survived with some form of handicap.³

With all the attendant problems and setbacks, progress in care of the ill newborn, especially the premature, has been tremendous in the past two decades. Between 1970 and 1980, the death rate in the neonatal period, (first 28 days), where the risk of death is greatest, was almost halved, which represents the greatest proportional decline in any decade since 1915, when the first national birth statistics were gathered.⁴ The mortality rate for respiratory distress syndrome is now 15% compared to the 70% rate of the past.³ In 1975, neonatology, the subspecialty of pediatrics which has primary responsibility for the care of these critically-ill newborns, is one of its fastest growing and largest subspecialties.

Infant Mortality

Infant mortality statistics demonstrate that between 1900 and 1950, when public health programs were directed toward maternal health through improved nutrition and prenatal care, infant deaths decreased dramatically. Conversely, the decrease since 1950 appears to be largely attributable to improved neonatal medicine. Few would dispute the claim that prematurity is the primary health problem faced by newborns, therefore, the fact that the percentage of premature births has not declined significantly since the 1950's is somewhat alarming and suggests
that preventing prematurity should be a primary goal.

In 1900, the infant mortality rate in the U.S. was over 100 per 1000 live births. By 1950, this number was halved, most likely as a result of improved nutrition and environmental sanitation, as there were few treatments available for these infants. The group most effected by this improved survival was the postneonatal group, (between 28 days and eleven months). As postneonatal moratality decreased, a shift in the timing of infant death was noted. By 1950, two-thirds of all infant deaths occurred in the neonatal period, reflecting birth injury, asphyxia, congenital malformations and "immaturity".

One indicator of immaturity is low birth weight, recognized as 2500 grams or less. In 1950, immature infants considered low birth weight accounted for 7.5% of all births, but two-thirds of all neonatal deaths. In 1980, they accounted for 7% of all live births, about 230,000 infants, and interestingly, still account for about two-thirds of all neonatal deaths. These small infants are estimated to be about 40 times more likely to die in the neonatal period and five times more likely to die in the postneonatal period accounting for 20% of all postneonatal deaths. From looking at these statistics a few points need reemphasizing. One is that prematurity is the major problem faced in the newborn period and the second is that even with the advent of the Neonatal Intensive Care Unit (NICU) and its attendant technologies, the percentage of live births that are premature have not significantly changed.
Very low birth weight infants, under 1500 grams, account for about 1% of all newborns, but almost half of all infant deaths. In industrialized populations like our own, the proportion of very low birth weight infants is a major predictor of neonatal mortality.5

In 1980, the mortality rate in the U.S. was 13.1 per 1000 live births, a 47% decrease from the 1965 rate. Unlike the situation in the first half of the century, this recent change is primarily the result of a decrease in neonatal mortality.5 Of babies born with life-threatening conditions, approximately 20% have potentially lethal birth defects, the remaining 80% are premature.4 These statistics again make the point that prematurity is the major problem faced by the newborn.

Question of Resources

These statistics are encouraging and contribute to the impetus for pushing the frontiers of care forward, but questions remain as to where the credit for these improvements belong. Some claim they are due to the sophisticated technology and care provided by the NICU environment, others believe it is the improved nutrition of mothers and emphasis on prenatal care, and still others credit our overall improvement in living conditions. Determining where the credit is most deserved has important implications for the future as we decide where to focus our ever-dimishing financial resources.
It is estimated that the typical medical bill to keep a very low birth weight child alive is $50,000 or more and these infants are the ones at greatest risk. We would, therefore, use our resources more effectively if we directed our efforts at preventing prematurity in the first place rather than focusing our attention on treating those born prematurely.

Current Infant Morbidity Statistics

Although the statistics demonstrate declining mortality rates since the advent of NICU's, the effects of the various treatments can lead to significant morbidity and death. For example, respirators routinely used to treat respiratory distress syndrome, so common in the premature, can lead to a permanent and sometimes progressive scarring of the lungs called bronchopulmonary dysplasia (BPD). In infants who survive with BPD, 85% are rehospitalized within the first year for pneumonia or bronchitis. The eye disease, retrolental fibroplasia (RLF), believed to be associated with the use of oxygen and other unknowns, is on the increase again after a period of apparent decline. It is now estimated that 22-42% of very low birth weight infants suffer visual impairment from RLF and 5-11% are blinded by it. Necrotizing enterocolitis, an intestinal disorder, can result in intestinal perforation and death.

Cerebral palsy, a catch-all phrase describing difficulty with coordination from brain injury secondary to anoxia, also seems to
be an increased risk for the premature. In one 13-year study of 153 very low birth weight premature survivors, the incidence of cerebral palsy increased from 2.6% in 1966-70 to 11.9% in 1977-78.\(^8\) It is estimated that "for every 100 hypothetical very low birth weight infants born in 1977-78, 31 more are surviving than did in 1966-70, at a cost of producing 9 additional children with cerebral palsy."\(^8\) Of newborns weighing 1500 grams or less, who would not have survived in 1960, it is estimated that intensive care at the 1978 level produced 350 severely handicapped individuals.\(^9\) It is quite evident that serious harm can be inflicted by the use of these various therapies and this fact should require that they be a major consideration when making treatment decisions. However, the current mandated approach does not allow treatment harms to be evaluated and included when treatment options are decided.

Follow-Up Study Evaluations

With the discovery that not all treatment results were positive, studies to assess the benefits and risks were undertaken. Although many of these studies have identified conditions associated with the treatment of prematurity, the actual risks remain unclear, as several limitations in study design existed. In most studies morbidity has been restricted to neurodevelopmental outcomes even though LBW infants are at increased risk for other substantial health problems.\(^{10}\)
Some hospitals do not indicate the number of infants excluded from the statistics, such as infants born in another facility but later transferred, making meaningless any comparisons between hospitals or within the same hospital over sequential periods.

Sample size is often small, duration of follow-up varies as people move or cease returning to follow-up appointments, and those failing to return may be the ones with the worst outcome. There are no generally accepted criteria for major handicaps and how studies choose to define normal and abnormal varies. \(^9\)

Another significant problem is that follow-up studies are often done for only a few years after birth and many of the developmental problems are not evident until the child is five or older. \(^8\) In one University of California study, close to 90% of children born weighing less than 1500 grams seemed problem free at age one, but by age eight only 24% could still be considered normal. \(^11\)

Besides the statistical and logistical problems, it is also important to look at who conducts these studies. Most studies are done by neonatologists who have an understandable interest in putting out positive information. A hospital conducting research into the under 500 gram infant would have a vested interest in resuscitating and treating such infants. A pediatric surgeon with an interest in esophageal reconstruction has a professional stake in advocating surgery for babies with this affliction.

My intention in making these comments is not to fault the physicians or institutions or claim that they approach their work
casually, but merely to point out that the momentum of medical science often proceeds with a kind of 'tunnel vision' such that treatment effects presented do not adequately reflect the range of positive and negative effects on infants.

The Issue of Experimentation

One argument used in favor of treatment of premature babies with many technologies without explicit parental consent is that the therapies are not experimental, rather they are considered "ordinary". But the question is, by whose standards? The concepts of ordinary vs extraordinary or experimental treatments should not relate to the state of the art of a particular medical intervention but to a relationship between the effect of treatment on the one hand and the benefit to the patient on the other. The following is an excerpt from a letter written by Peggy Stinson who, together with her husband, Robert, wrote The Long Dying of Baby Andrew, which chronicles the experience of their child through five months of treatment. This experience demonstrates quite well that treatments considered routine should not necessarily be excluded from being considered experimental, as well. It also expresses the frustration and anger felt by many parents when they are prevented from protecting their infants from what they see as overly aggressive treatment and are forced, instead, to be observers who suffer but lack control over the events responsible for their own, and their infant's, pain.
Andrew was born at a gestational age of 24 weeks, was placed on a respirator against our wishes and without our consent. He had a months-long unresolved case of bronchopulmonary dysplasia, endured countless episodes of bradycardia and cyanosis, suctionings, tube insertions, blood samplings and transfusions, was "saved" to develop retrolental fibroplasia, numerous infections, demineralized and fractured bones, an iatrogenic cleft palate, and finally, as his lungs became irreparably diseased, pulmonary artery hypertension and seizures of the brain. He also suffered from a heart defect and possible stress ulcers. A pulmonary hemorrhage and a possible intracranial hemorrhage, cortical atrophy, enlarged ventricles, chronic encephalopathy, microcephaly and "severe developmental delay". He was, in effect, "saved" by the respirator to die five long, painful, and expensive months later of the respirator's side effects.

That treatment effects exist is clear, but that there is benefit obtained by a premature who suffers with hydrocephalus, BPD, blindness, cerebral palsy, and severe retardation, is questionable. Adequate models do not exist for testing therapies for critically ill newborns, therefore, promising therapies are often quickly disseminated to NICU's before adequate evaluation of all benefits and risks have been carried out. Because many of these therapies cause great harm, I argue that they should be recognized as experimental procedures and these infants should be considered experimental research subjects as these determinations would require that explicit written sanction be given by them. By considering procedures routine or accepted medical practice, as they often are, parental consent is not required.
Protection for the neonate from potential harms is negligible since the law does not require that drugs be specifically tested in neonates, despite the fact that they metabolize drugs differently from adults. There are also no requirements to test very powerful non-drug therapies such as respirators, phototherapy or hyperalimentation.\textsuperscript{11} Yet, many therapies used without adequate testing have caused major handicap in prematures. For instance, it was found that thalidomide, DES, sulfa drugs, "-mycin" drugs, and chloramphenicol antibiotics, safe and effective in adults and children, killed or severely damaged many prematures in the 1950's.\textsuperscript{11}

The deaths of premature infants from intravenous Vitamin E, long thought to be a preventative for BPD and RLP, may also be involved in an increase in the occurrence of necrotizing enterocolitis. This drug was put into use without going through the FDA and at least 38 infants deaths have been associated with its use.\textsuperscript{11}

Phototherapy, used for decades to reduce the brain damage caused by bilirubin excess may destroy DNA. Neonatologists are still pushing for the use of the randomized clinical trial to test its efficacy, as to date, there is no conclusive evidence that it is effective.

Trying to unravel which therapy is responsible for specific deleterious effects can be quite difficult since many therapies have been introduced simultaneously without full knowledge of their positive or negative effects. The confusion faced when trying to decipher cause and effect after the introduction of
numerous poorly tested therapies is demonstrated by the RLF story of the 1940's and '50's.

In one medical center working to determine the causes of RLF, Adrenocorticotrophic hormone (ACTH) was used prophylactically, as it was believed that it inhibited the proliferation of retinal vessels that occurs early in the disease. Although promising, when subjected to rigorous randomized controlled trials, a disturbing association between ACTH treatment and infection-related deaths was uncovered.\(^8\)

Not all of the impetus to treat these premature infants is consciously motivated. The research and teaching interests of a physician or hospital also play a role in the momentum of aggressive treatment. Resuscitation and treatment of extremely premature neonates is sometimes done, not because the chance for survival of the neonate is good, but because the staff gains knowledge and skills that can be used to better advantage on bigger babies, with more hopeful outcomes.\(^11\)

Once an infant is admitted to a NICU the staff works with maximal use of available resources. Because of the intensity and immediacy of these situations, where life hangs in the balance, each person involved carries out his or her own very specific role with expediency and precision. This incremental approach continues as the initial aggressive efforts give way to uniform maintenance protocols of respiration and nutrition. A neonatologist might say that a baby is doing nicely and making progress when oxygen has been reduced from 80% to 70%, even
though the infant may have already suffered irreversible neurologic damage, without disturbing this perception of progress.\textsuperscript{13} The problem is, who is standing back to gain perspective, to see "the forest through the trees"? Who asks: "Should we continue?" Once the monumental commitment begins of using what intensive care offers, it is often difficult to stop and appraise the value of this treatment while considering the potential outcome for the infant.\textsuperscript{13}

When we begin to understand the conflicting obligations, perspectives, needs, and societal ramifications involved in the treatment decisions that must take place in the NICU, it becomes clear that the issues involved are ethical in nature as well as sociological and medical. For this reason, I have looked to the history of ethical thought and have tried to determine which criteria, moral codes and ethical principles guide our thinking on these types of issues to better understand how differing viewpoints are substantiated.
CHAPTER TWO

ETHICS, TRADITIONS, BELIEFS AND PRECEDEATS
Historical Perspective on Medical Ethics

The moral and ethical principles which guide our societal values are based on those of the Greeks and Romans, modified by our Judeo-Christian heritage. What becomes clear when studying the history of ethics is that moral concepts change as social life changes. As the concepts change, the questions asked about any moral rule or social practice is: Is it part of the essentially local realm of convention or custom, or of the essentially universal realm of nature? This distinction is important when deciding which principle should be primary when conflict arises between them. When discussing decision-making for the care of the newborn this is especially important since so many viewpoints exist and these views are justified and substantiated by invoking different moral and ethical principles.

Although moral judgments involve the application of general guidelines defining right and wrong actions to concrete situations, they often rely on factual beliefs about the world as well. It is, therefore, a mistake to assume that moral disputes involve only conflicts between moral principles or their application, and not also conflicting interpretations of fact. Broad scientific or religious beliefs often underlie our interpretation of a situation in which we must act.\(^{14}\)

The values of self-determination, freedom of religion and privacy are highly protected in our society. In the care of the
competent adult, decision-making is left up to the person involved, supporting the principle of autonomy or respect for the individual. This principle demands that regardless of the opinion of others, the person's individual decision is to be respected, and is derived from the deontological ethical theory, which proposes that the action of self-determination in medical treatment supercedes the end, or severity of consequences. An example is the case of an adult Jehovah's Witness, who refuses the administration of blood on religious grounds. Even if it is known that this person will exsanguinate and die, his wishes are to be honored.

When this same person is no longer considered competent to make informed decisions, this authority is granted to another who acts as this person's surrogate. The surrogates involved are usually limited to the physician and/or the patient's family, who are believed to know best what the preferences of the patient would be if he were able to decide independently. When this process is stymied because family members or physician and family disagree, the courts become involved. Two standards are then implemented, the substituted judgement standard and the best interest standard, both of which derive from the utilitarian ethical theory which gauges the worth of actions by their ends or consequences.

The substituted judgement standard is applied by determining what the subjective wants and needs of a particular patient might be and then asking how a reasonable person with these wants and
needs would decide. Two widely publicized and precedent setting cases involving life-sustaining therapies utilized this approach. Karen Ann Quinlan, in a permanent coma after a drug overdose, was removed from a respirator when the court determined that from what her family and friends knew of her and from previous statements she had made to them, she would not want to be kept alive in her current state. In the Saikewicz case, involving a 67-year old man institutionalized with an IQ of 10 and a diagnosis of leukemia, a decision was made to withhold treatment by examining how other people in similar circumstances had decided for themselves.

The best interest standard, on the other hand, is guided by the principle of beneficence, which requires preventing harm and conferring benefit and the principle of nonmaleficence, which derives from the maxim "above all—do no harm". This standard attempts to compare the benefits and burdens of treatment rather than the subjective wishes of the incompetent patient, since they may not be known. In this approach, the consequences of the action are more important than the actual means to get there. But quite often in life or death decision-making, the treatments are neither clearly beneficial nor futile. For example, is life on a respirator in a persistent coma of more benefit or burden to the patient than possible death without it?

In the care of the newborn the reliance on such principles as autonomy, substituted judgment, and best interests as
decision-making guides is not clearly applicable since the infant has never been competent and no preference can be known. Although taken separately these basic principles appear straightforward, when actually applying them serious conflict among them can arise when one can appeal to moral considerations for taking each of two opposing courses of action. In the care of the premature newborn, in keeping with the principles of prolonging life and justice, we may be increasing suffering and pain, which is in conflict with the principles of nonmaleficence and beneficence. Since the principles of nonmaleficence and beneficence direct us to remove harms and confer benefit, we must question our confidence that we are always right when prolonging life.

Traditionally, parents have been designated as surrogates as it was assumed that they, above all, would have their infant's best interests at heart. Only when parental decision-making has been viewed by the courts as having consequences so severe for the child, such as when parents refuse permission for the administration of chemotherapeutic drugs for treatable leukemia, have the courts become involved, appointing temporary guardianship to another person. Along this same vein, child abuse laws exist to protect children when decisions made by their parents are viewed to be so detrimental that the risks clearly outweigh the benefits for the child. In all other situations, family autonomy has been respected. The primary dilemma inherent in decision-making in the care of the critically ill newborn
relates to who best represents the best interests of the child. Most people agree that there are instances where the best interests of the child are served by non-treatment. Who should be involved in deciding and who should have the final say if agreement cannot be reached, is still undecided.

Recognizing that our approaches to these issues differ, I will comment on my suspicion that different religious traditions may have a guiding effect. The viewpoints of social commentators and physicians will be presented to understand the criteria and assumptions upon which they base their views and discover if a consensus can be reached.

Religious Traditions

Many of the terms used and presuppositions upon which different theories rest are religiously based although not explicitly expressed as such. We are a nation of many different faith traditions, therefore, it is important to recognize that what we each believe and how we approach the moral dilemmas inherent in the care of the premature newborn reflects our underlying belief system about the world, without full knowledge of this fact ourselves. We should openly acknowledge that our different faith traditions cannot help but be reflected in our decision-making processes and accept this fact in the face of moral "universal" rules. Our ethical norms for conduct are vague generalities—respect for persons, beneficence, nonmaleficence
and justice—open to interpretation in that when they conflict, as they so often do, the supreme, overriding obligations as we each see them may differ. We understand and accept that some religious traditions have specific overriding norms, such as the refusal by a Jehovah's Witness of blood transfusions. Although we practice medical care as though guided by general ethical principles accepted by all in society, each patient experiences illness, health, pain and death differently, often because of their faith traditions.

Even faiths we call Judeo-Christian differ in their priorities and acceptable treatment options even though we might believe the similarities would be overwhelming since the guiding principles are the same. For example, some who represent the Roman Catholic faith believe the focus should be on each person as an entity. Therefore, life is not necessarily the highest value when the possibility of a life of extreme suffering and pain is highly probable. One the other hand, the Jewish faith teaches that life is inviolable and must be sought after at all cost, therefore, nontreatment might not be an acceptable option in any circumstance.16

Physician Points of View

For centuries midwives and physicians have been faced with the birth of babies with congenital anomalies and severe prematurity. Known as "basin babies", these infants were allowed
to die when their chances for a normal life were believed non-existent. While this practice was an unfortunate fact of life, it was accepted as the most satisfactory solution to a very tragic event. With the advent of the NICU, this practice was no longer a private matter handled by those in attendance. Rather, specialists with specific tasks were now involved, often immediately after birth, before there was any time to evaluate the infant's status or ask about parental preferences.

Some physicians feel that since prediction of future integrity of the infants is plagued by uncertainty, aggressive use of all available medical technologies is necessary. Others feel that when treatment will most likely lead to a life of severe impairment and suffering, it is not in the infant's best interest to treat aggressively. The question arises: Who should be the primary decision-maker in situations where a question exists as to whether treatment should be aggressively pursued or withdrawn?

The discussion of differing medical viewpoints will not be all inclusive, but will serve to present two major schools of thought regarding who the primary and ultimate decision-makers should be when choosing treatment options for critically ill newborns. One view, which places the responsibility with physicians and parents, will be represented by two neonatologists, Raymond Duff and A.G.M. Campbell. Dr. Norman Post, also a neonatologist, presents the alternative view that decisions should be made by ethics committees or by the courts,
the so-called forum approach.

The practice of selective nontreatment in the NICU was first openly acknowledged when Drs. Duff and Campbell published their article, "Moral and Ethical Dilemmas in the Special-Care Nursery", NEJM, in October, 1973. Here, they stated that of 299 consecutive deaths in the Yale-New Haven Special-Care Nursery, 43 (14%), were related to withholding treatment due to severe congenital anomalies. These difficult decisions were made, they claimed, after careful heart-wrenching consideration by parents and physicians who together concluded "that the prognosis for meaningful life was extremely poor or hopeless", and it was, therefore, in the best interests of all involved not to treat. Acknowledging the fact that many of the children treated in NICU's would have died natural deaths in times past, they felt the question must be "not can it be done, but should it be done?" Quality of life should be a serious consideration in their view, and the parents, with knowledge of their personal value systems, religious beliefs, emotional and financial resources, should be the ones to ultimately decide.

Duff and Campbell recognize that not all parents have the best interest of their child as primary and, therefore, assert that medical paternalism is legitimate and defensible in those situations where "clearly incompetent or irresponsible parents resist treatment that health professionals generally agree is needed and effective." But they go on to say that if this approach is used in other circumstances it will erode family and
professional autonomy, ignoring the sometimes abusive use of technology which may sustain biological existence but has little regard for the quality of the child's and family's existence. They continue:

...in defining and securing the child's best interests (whatever they are), the central (often sacred) role of the family must be acknowledged and supported even though the resulting decisions occasionally risk violating one or another of numerous, perhaps conflicting moral, religious, or legal doctrine. Since one cannot prudently ignore the family's limitations and interests even if considering only the child's interests, responsible decision-makers cannot avoid some "tragic choices"—that is, at times knowingly sacrificing, perhaps unfairly, one person's good or life in order to protect another's. With a sense of balance, irony and tragedy, it is understandable, right and common that the family's interests are sacrificed to benefit the child. With a similar sense, the converse may be true particularly when the child may benefit little even though the family sacrifices much.17

Family considerations should be taken seriously since living with a severely handicapped individual is clearly a family affair, and infants considered to have little or no hope of achieving meaningful humanhood i.e. little or no capacity to love or be loved could totally disrupt the family until and still end up in facilities characterized as "hardly more than dying bins."17 Although some fear families will too quickly allow infants to die, Duff and Campbell found that when given the choice, most families wanted maximal effort used to sustain their child's life.
The authors recognize that those involved in decision-making do not come to the process without their own interests and idiosyncratic backgrounds and needs which can have substantial impact on the process, thereby making it less than ideal. Physicians are often reluctant to deal with the issue of nontreatment because they feel to do so is to be disloyal to their profession and sets a poor ethical example. They fear prosecution, loss of research and teaching material and feel that such questioning is against the ethic of crusading against disease and death. These reasons for treating are obviously not always related to the child's best interests. Hospital committees, regulating agencies and courts, because of their own agendas, are even more far removed from the child's and family's interests according to Duff. They cannot "understand the sensitive feelings and complex inner values of individual family members and act in harmony with them."17

That both treatment and nontreatment decisions constitute unsatisfactory dilemmas for everyone involved, especially the child and family, is acknowledged, but they admonish "pretending there is no decision to be made is an arbitrary and potentially devastating decision of default."17 They fear that "mistakes" will be made, that just decisions will not always result, but feel if the parents and physicians do not have the best interests of the child in mind, who does? For this reason they feel that great latitude should be expected and tolerated in the outcome of decision-making processes and that only general guidelines should
be set. They point out that although staff members can leave if policies of their workplace are offensive to them, there is no escape for the children and families. They believe that it is not enough that families can turn to their religious and other means of support to adjust to decisions made by others, rather, they should be trusted to rely on those values and supports to help shape those decisions.

Norman Post, pediatrician and medical ethicist, objects to the notion that parents act as trustees for their children in all situations because they may not have sufficient information to know what is in the child's best interests and might have conflicting interests which will supercede those of the child. He points out that society recognizes the limits to parental authority as demonstrated by the child abuse and neglect laws that mandate state intervention on the behalf of the child when parents appear to take action endangering the health or well-being of the child.¹⁸

He believes that parents are in such a state of shock at the birth of a defective neonate that they are unable to assimilate the information necessary to make a clear and informed decision. Conflicts of interest exist if the child's conditions is seen by the parents as presenting a great burden to themselves and their family, which he feels automatically disqualifies them as suitable advocates for their child.¹⁸

Recognizing that physicians have their own values and preferences and control the flow of information to parents, Post
believes they should prevent the possibility of their influence by encouraging parents to talk with counselors and others representing different points of view. Post takes this further when arguing that the decision-making process should not be limited to the physician, family members and counselors, but should include the opinion of ethics committees and the courts, as well, because he believes the decision-making process can be considered correctly handled if it would be approved by an ideal observer with the following qualities:

1) omniscience, meaning having access to all relevant facts,
2) omnipercipience, meaning an ability to imagine vividly the feelings of others involved,
3) disinterest, meaning having no vested interest in the outcome,
4) dispassion, meaning not being overwhelmed by feelings so strong as to cloud critical thinking,
5) consistency, meaning similar cases would be decided similarly.

Post asserts that human subjects committees have been effective means for dealing with experimental care in institutions and believes this approach would yield the best results in the care of the critically ill newborn since
representatives from various groups such as clergy, lay public, social service, medicine, nursing and law could present different compelling arguments and reasoning. Post contends that the "public interest in protecting the rights of children will have to express itself through a process that will be unavoidably messy and at times unpleasant", but that, "we will not return to the days when parents owned their children or physicians given carte blanche to resolve such disputes." 20 While he believes that guidelines will never be clear enough to resolve all cases and will never attract universal support, the normal push and pull of public policy design will include changing regulations, statutes, court decisions, appellate opinions and ethical reflection and debate.

Post asserts that ethics committees and the courts are the appropriate place for decision-making in the care of the ill newborn based on the criteria presented above. But there is no guarantee that an ethics committee or the courts will live up to these expectations better than the family. In fact, I think they will do a poorer job. Ethics committees more than likely will not have access to all relevant facts since the family situation should surely be considered relevant and they can not know it better than the family. They also do not have any more ability to "imagine vividly the feelings of others involved" if they have never been there themselves. Consistency of decisions has not occurred and the likelihood of it here is even more obscure since
each committee would undoubtedly have its own unique mix and tone. Most importantly, ethics committees do not live with the consequences of their decisions and bring their own idiosyncrasies, beliefs, values and social and professional positions into this process, which might be different from those of the family.

Social Dialogue

The diversity of viewpoints presented here, each with its own compelling reasons and justifications, points out that guidelines that could be considered universally applicable do not exist. Peter Singer, an ethicist, argues that termination of the lives of defective newborns is morally justifiable because they should not be considered persons. He believes that the notion of sanctity of all human life is an obsolete and erroneous one claiming that if we look at human life as it really is, "at the quality of life that each human being has or can achieve", considering the human characteristics of capacity to reason, anticipate the future, communicate in a sophisticated manner and to be a fully self-conscious autonomous being, it will be possible to approach the difficult questions of life and death with ethical sensitivity rather than with the blindness to individual differences embodied in a regulative approach.

Conversely, James Gustafson, also an ethicist, argues that
the dilemmas in decision-making of the defective newborn result from a conflict between the desires of parents and the rights of the defective child to life. He is a strong defender of the sanctity of each child's life, asserting that the "power to decide does not imply that a right to decide exists." He claims that a moral obligation of parents and physicians is to keep the child alive, as each child has an intrinsic value irrespective of expected intelligence, capacity to contribute, or burdens he will impose if he survives. He suggests that what is meant by being human is found in giving to others and we are, therefore, obligated to respond to those less fortunate, even at personal expense and inconvenience.  

Robert Weir, author of Selective Nontreatment of Handicapped Newborns, holds that decisions should focus primarily on the neonate's medical condition, including predicted suffering and irremediable handicaps. Social worth should not be a consideration, but when life will be more harmful than beneficial for the child, nontreatment is justifiable. Recognizing that differences in application of moral principles occur between hospitals, he suggests that a consistent policy needs to exist to ensure equality of care in all settings. Weir argues that once the decision to withhold or withdraw treatment has been made, the next one concerns the manner in which that neonate will die, as intentional killing can be justified because compassion motivates us to prevent needless suffering.  

Paul Ramsey, a Christian ethicist, bases his beliefs
primarily on the Judeo-Christian one of sanctity of life; that life is a sacred gift from God which has intrinsic value at all levels of existence, therefore, no one can pass judgment about the quality of one life over another regardless of physical or mental defects. He argues that the criteria used when making decisions about defective neonates should be the same as that used for normal infants. Although Ramsey asserts that all defective neonates should be treated equally for similar problems, he recognizes that certain infants will not survive, regardless of treatment decisions and, therefore, distinguishes between infants who are "born dying" and those who are not. To treat those "born dying" is to prolong death, which he believes is not morally indicated. Yet, Richard McCormick, a Jesuit theologian who also approaches the issues from a Judeo-Christian perspective, comes to a very different conclusion. He asserts that it is the "spiritual goods of a love of God and others and the attainment of these goods that give a life value." It is not life itself that has value, as Ramsey would argue. McCormick asks, "What kind of a life are we saving?" He believes that treatment is indicated when the life being preserved is capable of realizing the spiritual goods of human relationships. In discussing the criteria that make a human relationship, McCormick does not include one's capacity to be productive or to contribute to society in a meaningful way, but argues that potential for human relationship is a legitimate and necessary criterion.

There is no agreement over what constitutes a 'quality' life
or the appropriateness of quality of life considerations in making decisions regarding the extent of treatment required. Different principles are seen to supercede others by those whose values direct them to consider sanctity of life of greater concern than the quality of that life. Questions remain as to who can best represent the best interests of the child—the parents and physicians, the more objective ethics committee, the courts or others. Indeed, it appears that universal guidelines are not possible if we accept the diversity in ethnic, religious and cultural traditions in our society. Yet, while these differing views exist, the government passed legislation mandating care, implying a consensus where none exists.

Legal Discussion

Most of us agree that a mentally competent adult's wishes not to be given treatment for an illness should always be respected. This view is generally accepted in common law to the extent that a doctor who treats a patient against his wishes is guilty of assault. The courts are becoming more involved in the decisions regarding the limits of treatment, since no universal authoritative guidelines yet exist, but some landmark rulings are being handed down. An appeals court in California recently decided that a patient suffering from any one of five potentially terminal illnesses had a constitutional right to refuse medical treatment by asserting that such a right is constitutionally
guaranteed and, therefore, a right which must not be abridged. One physician disagrees with this current "case-law" approach stating, "courts are being involved in these very individual and complex issues by patients who don't trust their doctors; by doctors who don't trust their patients; by administrators who are scared of the institutional implications; by District Attorney and other lawyers seeking personal or political advantage and," he is very sorry to say, "by doctors who are only too eager to pass the buck."

That the courts are not only inconsistent in deciding individual cases, but also increase the trauma for those involved, can be seen by the following cases.

In 1978, Shirley Dinnerstein, a 67 year old woman suffering from Alzheimer's disease with profound dementia, was admitted to a hospital with cardiac and other physical problems. When the question of a "do not resuscitate" order was addressed, it was taken to court as the Saikewicz court, previously mentioned, had stated that the court was the appropriate place of authority in making decisions to terminate or withhold life-support therapies.

This court stated that, in fact, court involvement was not necessary in this current case because it differed in one substantial way from the Saikewicz case; there was a loving and caring family involved in the case of Ms. Dinnerstein and her care was in a private facility rather a public one. They asserted that "public policy dictates careful external legal review of decisions made in cases of institutionalized
individuals as no family involvement exists.  

The judgement that families are the appropriate surrogate decision-makers for the critically ill adult when choosing treatment options has been upheld in numerous similar cases, but agreement over who should have authority in cases involving critically ill neonates does not exist. Commenting on the court involvement in this current debate one ethicist writes, "When a judge decides to play legislator on issues like the termination of treatment, in which there are strong and competing social values, and case law is embryonic, the result is likely to be very unsatisfactory indeed."  

The following case serves as an example.

In May, 1981, Siamese twins were born in Danville, Ohio, to a physician and his wife. The twins were joined at the waist, shared intestinal organs and three legs. The parents and obstetrician agreed that treatment would be futile and the decision not to resuscitate or feed, but to keep the infants comfortable and allow them to die was made. This did not happen as an anonymous caller contacted the Illinois Dept. of Children and Family Services complaining that the twins were being neglected, and a social worker who investigated the case filed a petition of neglect against the parents. The judge awarded custody of the twins to family services and against the wishes of the grieving parents, the twins were moved to a teaching hospital. Three weeks later criminal charges against the parents and physicians were filed, claiming they were guilty of
conspiracy to commit murder. This represented the first time in the U.S. criminal charges had been filed against parents or doctors for withholding treatment from a newborn infant with birth defects. The case was dropped when none of the nurses would link the parents or physicians with the orders not to feed the twins.26

On the other hand, in 1982 in the Baby Doe case, the care of infants with congenital anomalies became political rather than medical-legal issues as Baby Jane Doe, born with Down's Syndrome and a tracheoesophageal fistula, became a "cause celebre" when her parents' decision not to allow surgery became public knowledge. The hospital requested a court order for surgery. After hearing testimony from physicians with opposing recommendations and the baby's father, the court ruled that "Mr. and Mrs. Doe, after having been fully informed of the opinions of two sets of physicians, have the right to choose a medically recommended course of treatment for their child in the present circumstances."27 This ruling was upheld by the Supreme Court of Indiana, where the case had taken place.

Several "Baby Doe" cases followed as national attention was focused on this issue. In all of these cases the courts upheld the previous ruling that the parents had the authority to make treatment decisions for their critically ill newborns.

The political repercussions resulting from these decisions led to the "Baby Doe Regulations" put forth by the Department of Health and Human Services mandating treatment of these infants.
These regulations, which have gone through several revisions and recently gained Congressional approval, will be discussed in detail in the next section of this paper.

Several individuals involved in treatment of critically ill newborns feel this is a poor approach to the problem. Dr. A.G.M. Campbell, a neonatologist whose views were presented previously, feels that general policies or broad guidelines are necessary and helpful to ensure that due process occurs, but strongly disagrees with the current "case law" or regulation approach as fragmented. Rather, he believes the court involvement should be limited to situations where a consensus cannot be reached by those involved, the parents and physicians.26

Other pediatricians fear that allowing an infant to die without life-saving therapy may be interpreted by lawyers and "moralizing pressure groups" as illegal. Traditionally, the law has allowed great latitude in decision-making practices, leaving the authority with the parents and physicians. They feel this approach, which outlines recognized groups of chronically disabled infants that can be allowed to die, is detrimental to the closed and trusting relationships that should be nurtured among staff and between staff and parents in the NICU. Although doctors must practice within the law, they feel "it must be appreciated that rigid laws are of little help in reconciling the realities of modern medicine with the individual injustices of biology."26

Those who oppose the concept of selective nontreatment often
use the argument that once decisions are made about who should live or die we enter onto the "slippery slope". They ask: What will prevent us from then selectively killing children because they are not the desired sex or do not have the characteristics we want? In response to this fear one neonatologist states, "I should be the first to agree that the dangers would be great if governments, courts or even committees were to choose either for life or for death. That risk of tyranny is one of the strongest arguments for keeping their decisions firmly centered on the family and their medical advisers." Another commentator writes, "Any one parent can only do mischief on a small scale. The state can do harm on a large scale." 

The "Baby Doe" cases, although the first addressing nontreatment issues, were not the first brought to court concerning the integrity of the newborn. In the 1970's, with the crisis in medical malpractice, new sorts of claims were brought against medical practitioners, the so-called "wrongful birth suits". In these cases, parents sued their physicians on their own behalf for negligence that resulted in the birth of an unwanted child. "Wrongful life suits" have been brought on behalf of defective infants against a doctor or laboratory that did not give correct predictive information to parents about the possibility that the pregnancy might yield a defective child. The courts have not come to a consensus on these issues, with those in Michigan rejecting "wrongful life" cause of action and those in Washington allowing it.
These cases demonstrate that the courts have recognized the financial and emotional harms accompanying the birth of impaired infants as some of these decisions have ruled that the parents are entitled to recover financial costs while others have granted damages for emotional pain and suffering.\(^{30}\)

Another issue that must be dealt with within the legal framework is that of the mixed legal messages physicians are now forced to decipher. Legal constraints aimed at reducing health care expenditures suggest that the cost of care is to be considered an important factor in deciding both ethically and clinically appropriate treatment. The explicit constraints put forth in the "Baby Doe" regulations, and the implicit threat of malpractice litigation, suggest that cost cannot be an ethically or clinically relevant consideration. How is the responsible physician supposed to respond? How will a jury respond when the motivating factor in decision-making is economical rather than medical?

I believe it is important to recognize that what is lawful is not necessarily what one considers right, and what is unlawful is not necessarily wrong. Truly caring, responsible people must examine these ambiguities.
CHAPTER THREE

THE LEGISLATION
The Legislation

Why this particular approach was taken at this particular time and what factors make this situation, where the subject of concern is the ill newborn, so unique that the government took the dramatic step of pushing the boundaries that normally exist between private family events and those where societal imperatives are so great they dictate government involvement remains unclear. This issue will be addressed when describing the "Baby Doe" regulations, the cases that prompted their development and commentary regarding the appropriateness of this particular approach as a means to deal with decision-making in the care of the critically ill newborn. For completeness, the first "Baby Doe" case will be reiterated.

In April, 1982, in Bloomington, Indiana, a baby girl was born with Down's Syndrome and tracheoesophageal fistula. After her parents refused surgery and the hospital requested a court order to allow treatment, the court ruled that the parents, after being fully informed of the opinions of physicians with differing views, had the right to choose the medically recommended course of treatment for their child. This order, upholding the parents' refusal of treatment, was upheld by the Supreme Court of Indiana.

Political repercussions from this public process were manifested by several attempts by the Department of Health and Human Services (DHHS) to invoke Section 504 of the Rehabilitation Act of 1973, which prevents an individual from being
discriminated against because of a handicap. This act states that if a handicapped individual is denied participation in, or benefit from, any program or activity receiving Federal funding by reason of this handicap, the funding will be withdrawn.\textsuperscript{30}

In June, 1982, a Notice from the Office of Civil Rights of the DHHS stated this legislation applied to care of the defective newborn, and held that any institution that withheld treatment from an infant who could have undergone surgery to preserve life would have their funds withdrawn if that decision was based on the fact that the child had a handicap.\textsuperscript{30}

Federal authority was increased with a more forceful regulation issued in March, 1983, when DHHS published an "interim final rule" requiring that hospitals display posters informing the public of an anonymous-caller hot-line for anyone who believed a child was being "discriminatorily denied food or customary medical care".\textsuperscript{30}

The American Academy of Pediatrics, Children's Hospital National Medical Center and National Association of Children's Hospitals filed a joint action within days asking the federal court in Washington, D.C. to enjoin DHHS requirements put forth in this rule. On April, 1983, Judge Gerhard A. Gesell issued the injunction on procedural grounds only, as the normal comment period required for this type of action had not been met. But he went on to say that this interim final rule, ",...reflects no consideration whatsoever of the disruptive effects of a 24-hour, toll-free hot-line upon ongoing treatment of newborns...As a
finder of fact, this court is forced to conclude that haste and inexperience have resulted in agency action based on inadequate consideration. 30 He also made the comment that the rule referred to "customary medical treatment" as a guideline for determining action, yet, as the evidence received by the court made clear, there is no customary standard for the treatment of severely defective infants. 30

In July, 1983, the DHHS again presented the regulations as "proposed regulations", this time allowing the required comment period before the regulations would be in force and suggesting that hospitals establish ethics committees to deal with questions of treatment.

Many questioned the authority of the DHHS to tie care of the severely defective newborn to Section 504 of the Rehabilitation Act. This issue was never completely resolved as Congress enacted the Child Abuse Amendments of 1984 (P.L. 98-457), in December of that year, which requires the secretary of the DHHS to publish regulations to implement the provisions of the amendments which are almost identical in content to the regulations put forth by the DHHS. As of the writing of this paper, this is where the situation stands.

The amendments require that states establish programs and procedures within the state's protective service system to respond to reports of medical neglect, including the withholding of medically indicated treatment for disabled infants with life-threatening conditions. 30 Life-threatening conditions are
defined as including not only conditions that directly threaten the life of an infant, but also conditions that significantly increase the risk of the onset of complications that may threaten the life of the infant. Treatment includes "appropriate nutrition, hydration and medication which in the treating doctor's reasonable medical judgement will be most likely to be effective in ameliorating or correcting all such conditions." Exception to the requirement to provide medical treatment, but not the requirement to provide appropriate nutrition, hydration and medication, may be made only in cases in which:

---the infant is irreversibly comatose; or
---the provision of such treatment would merely prolong dying or 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; or
---the provision of such treatment would be virtually futile in terms of the survival of the infant, and the treatment itself would be inhumane.30

In cases where treatment will not totally eliminate a medical condition, but will give a child many years of life, the exception would not apply. Quality of life considerations are explicitly not permitted in treatment decisions.

The explicit involvement of the government in decisions previously private has caused much debate concerning our ultimate goals in medicine. Should decision-making regarding the application or withholding of treatment be placed in the hands of
the government? the courts? with ethics committees? with parents and physicians? Are the results arising from the existence of these regulations what was intended, or have realities of their application only complicated the situation?

The comments made since the first DHHS regulations were put forth have come from all sectors of our society. Physicians, parents, ethicists, reporters, and others have criticized the legislation for a variety of reasons. Before presenting their comments, it is important to go back to an earlier discussion in this paper regarding personal motivation and values. We must be clear in remembering that our personal viewpoints and value systems are reflections of our religious upbringing and systems of belief, cultural idiosyncrasies and place in society. Therefore, we must look at who it is that has put forth this legislative approach to solve these particular issues at this particular time, what their underlying motivations might be, and whether the supporters are of one mind. That there is evidence of a lack of understanding by some of the individuals most intimately involved in supporting this legislation is suggested by the following.

President Reagan, an avid supporter of this legislation, in his article, "Abortion and the Conscience of the Nation", in The Human Life Review of Spring 1983, writes of his action in applying the civil rights regulations to "protect" handicapped newborns, asserting that this action supports the Declaration of Independence and statements made by Abraham Lincoln, reinforcing
the notion that we must regard all life as being of equal value. Yet, his strong ally, C. Everett Koop, the Surgeon General, an experienced pediatric surgeon, and a proponent of the "right-to-life" viewpoint, admitted that there are situations where prolonging life was hopeless and cruel. Referring to the case of an infant with essentially no intestine, Dr. Koop remarked:

...these regulations never intended that such a child should be put on hyperalimentation and carried for a year and a half. Incidentally, I was the first physician that ever did that, so I know of where I speak. And we would consider customary care in that child the provision of a bed, of food by mouth, knowing that it was not going to be nutritious, but not just shutting off the care of that child...nor do we intend to say that this child should be carried on intravenous fluids for the rest of its life...

What does he mean? In my view, this does not give medical personnel anything useful to work with. According to the regulations now in effect, the child he is referring to would not be exempt by the criteria put forth, so which is it? Is all life of equal value as President Reagan asserts, or are there situations where treatment should not be pursued aggressively, as Dr. Koop suggests? By making this statement it appears to me that Dr. Koop is using the kind of quality of life determinations that are explicitly forbidden by the regulations and by doing so has unintentionally brought attention to the fact that common sense dictates that situations exist where it is not in anyone's best interest to apply technologies to sustain life. The
question that remains unanswered relates to who can best make these determinations when the outcome is uncertain.

One supporter of the legislation, Nat Hentoff, a frequent writer on issues relating to civil liberties, feels that the decision to withhold treatment for severely ill infants is a form of "infanticide" and that this decision should be a public one with court and government involvement. Although he states that when babies are "born dying", care should be withheld, he also states that in cases such as Tay Sachs disease,\(^{32}\) where a child's life can be prolonged for years, but the quality of that life will be poor due to pain and suffering, treatment should be withheld. This kind of exception is not permitted by the legislation. This, again, makes the point that supporters of this legislation do not have a full understanding of its implications and that in practice it has the capacity to inflict much harm, even though its intention was to do just the opposite.

In reference to confusing language contained in the legislation, Peter Singer and Helga Kuhse, ethicists, point out that excluding treatment of incurable disease as futile is vague and undefined, using a diabetic patient as an example. No one would regard insulin therapy as "futile", although the prospect of curing the underlying condition is, at this time, poor. That anencephaly, or intracranial bleeding or absence of intestine is as incurable as diabetes does not equate them, they claim. In all these conditions, the patient will be dependent on medical treatment for life. They argue that the "difference between
diabetes and the other three conditions is that the diabetic will be able to enjoy a near-normal life while no matter how much we prolong the life of the others, the chances of them having a life devoid of everything we regard as making life worthwhile is highly probable.\textsuperscript{31}

The qualities we ascribe to human beings that separate us from other species include those of consciousness, rationality, autonomy and self awareness and I have found no rationale that allows us to pretend that the life of a human being with all these distinctive qualities is of no greater value than the life of an individual that has never and will never experience them. Through my review of differing viewpoints, I found that there was agreement that situations arise where treatment is not in the best interest of those involved, however differently each may have defined the criteria. Although the criteria used varied as to degree, quality of life considerations were often used to justify nontreatment decisions.

There are questions as to the real intent of this legislation, some claiming that its supporters, many whom consider themselves "right-to-life" adherents, are actually trying to get at the issues of abortion and morality from another direction. This possibility gains credence when looking closely at the present legal situation.

Peggy and Robert Stinson, discussing the plight of their son Andrew, point out that they could legally have had an abortion when problems with their unborn fetus were first suspected, but
they chose not to. Yet once Andrew was born, they lost total control of the situation. It seems incongruous to me that it is legal to kill a fetus up until the time of birth but mandated that everything possible be done to sustain this same child, regardless of projected poor outcome, as soon as it is born.

As evidence of the political nature of the regulations, one commentator points out that no alternative means of dealing with discrimination against handicapped infants was proposed. Instead, the same administration that is trying to "take government out of the regulating business" and is insisting on subjecting even health related regulations to cost-benefit analysis is doing just the opposite here. 28

Many peripheral issues were involved in discussions of these regulations. The connection between these and other issues relating to individual control and determination is described by one member of the House of Representatives who stated that the debate on the "Baby Doe" legislation was "the most personal, gut-wrenching issue we faced this year". 25 He estimated that on the day of the vote, over half of all congressmen still had no firm position on the bill and stated that lobbying was intense. Once presented on the House floor, the infant care debate suddenly expanded into an open forum on abortion, euthanasia and other "right-to-life" issues. 33

Many doctors have expressed anger at the governmental intrusion into the inner workings of the NICU, as it suggests that doctors treat infants born with congenital defects or
prematurity casually. They claim that the new methods for treating so many of the diseases from which these infants suffer demonstrates just the opposite. They also fear that this approach intensifies the distress for parents who will become more apprehensive, suspicious and distrustful of physicians.

Doctors also fear liability, as the wording in the document itself is so misleading as to give little direction as to what might be considered appropriate care. This will encourage greater use of extreme medical therapies, they say, but not necessarily be in the best interests of the infants or families.

One physician commenting on the legislation writes that because the infants involved cannot "exercise their right to say no to medical treatment, they may become the political pawns of those who believe that life begins at conception and ends at birth. Children born with massive medical problems and defects are the victims of a severe disability—they cannot tell Surgeon General Everett Koop, Assistant Attorney General William Bradford Reynolds and the President of the U.S. to leave them alone. In that respect, they need help. If we fail to give it to them, any of us could become a victim of state-mandated medicine."

The medical director of a NICU in an open letter to Dr. Koop expressed his frustration at the mixed message sent by the present administration when he wrote,

I will make copies for you of our logbook documenting times when we have rejected new patient referrals into our regional center due to exhaustion of space, equipment and
personnel—space and equipment taken up in considerable degree by hopelessly damaged or defective children we will now be forced to keep alive at all cost...Remember, our resources are limited, and they are becoming increasingly more limited with each passing year the administration you represent reduces the maternal and child health care budget.

Although the politicians behind this legislation may feel gratified by what they perceive as having saved innocent infants, this heated remark expresses the frustration and anger felt by those now left to sort out the contradictory nature of the messages being sent and confront the realities of the effects they will have on a daily basis. Again, this points out what I see as a lack of understanding of the implications of these regulations in actual practice by those who support and instituted them.

The level of concern and understanding of the nature or scope of the problems involved when discussing the premature was questioned by one physician who stated, "The Baby Doe regulations place so much faith in medical intervention that we can completely forget that the main cause of premature births is poverty. Poor nutrition, poor housing and poor prenatal care have time and again been strongly associated with prematurity. That this legislation comes during an administration bent on decreasing the funding that would support the population which produces most of these infants is of note."31

Another commentator remarking on the level of concern demonstrated is George J. Annas, a lawyer, who argues that if legislative strategy is to be pursued, it should be extended to
all handicapped individuals deserving of the aggressive support of the federal government to help ensure that they are not denied needed medical services because of inability to pay. He states that the focus should not only be on the critically ill newborn who is handicapped, but support should be extended to them when they become children and adults, as well.28

The appropriateness of legal involvement is questioned by Albert Jonsen, Professor of Ethics at the University of California, San Francisco, who holds that the care of the handicapped infant should be done on a case-by-case basis since the development of interpersonal communication and human relationship should be the main criteria for decisions to treat or not treat. He argues that since parents do not own their children, their authority should be limited, even to the extent that their decision to treat their child may be revoked, since treatment itself can be detrimental. The law should intervene only where there is strong social purpose to be attained, otherwise the main participants in such decisions should be the parents of the infant and the physician, according to Jonsen.36

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published Deciding to Forego Life-Sustaining Treatment in 1983, was also critical of the DHHS approach to this problem, proposing intrainstitutional ethics committees be established to review the decisions made by parents and physicians with a primary advisory rather than authoritative role.30
The courts have addressed the issue of authority in decision-making in the NICU. Early in 1985, the Georgia Supreme Court ruled that the physician-patient relationship is the proper place for decision-making in termination of treatment decisions and that the court is not. An infant who had suffered a medical catastrophe 15 days after birth resulting in the destruction of 80% to 90% of her brain tissue, was now in an irreversible coma. The state court ruled that each patient has a constitutional right to have treatment ended, and in the case of the incompetent patient, the family must make that decision. This decision, they stated, recognizes the importance of the family in our society and is especially crucial when the issue involves a child. The court went even further when it stated that no ethics committee need be consulted unless the hospital chose to do so, and that the state has no interest in maintaining human life. They also found that there is no legal difference between the situation of infants and the incompetent adult who has made no living will.37

Effects of Legislation on the Family

Families are the primary social unit of our society and as such have the responsibility for emotional, physical, and financial support of its members from birth until death. Parents have the ethical duty to direct and protect their children, therefore, some assert that they not only have the duty to make life and death decisions for their infants, but they earn the
right as the primary source of protection for them.

Yet, many of the groups that support the view that all life has value and that all infants should be treated aggressively, are also the ones that hold the family as the primary unit of importance in our society. There are questions as to whether this legislation supports or harms family unity. Many claim that families are placed in an adversarial role by this legislation and that distrust of the parents in making a decision in the best interest of their child is an implicit statement. In fact, the Baby Doe regulations identify the hospital itself as a site of child abuse and imply that physicians are willing co-conspirators with parents in abusing and neglecting children by withholding food and needed medical treatment.

Support of the family was a primary concern of those behind this legislation as evidenced by the wording in the Federal Register of December 10, 1984, enacting the Child Abuse Amendments as it states: "It is the ultimate aim of the agency to protect the child, preserve the home and prevent the separation of the child from the family". How can this be reconciled with the following account presented to the Dade County Legislative Delegation in January, 1985:

A child is born to an average, middle-income family. Normally, a birth is a time of joy. But not so in this case. This child is born at 28 weeks, weighing less than two pounds, and measuring less than 13 inches. She is born at the extreme margin of what can be
called human life. She will undergo six months on a respiratory ventilator at the maximum dosages of oxygen possible. She will survive six brain surgeries, often without the benefit of anesthesia—a common practice with delicate neonates. She will fight several infections after two cardiac surgeries. She will have two major surgeries to try to correct her inability to eat by mouth. This will be done in a local hospital to the tune of between $70,000 to $80,000 every two weeks for 10½ months. She will survive. But she is blind, possibly deaf, eats through a tube in her stomach, she cannot sit, or walk or talk or know who I am. I am her mother.  

This family does not qualify for any type of federal financial assistance as eligibility does not take into account this child's astronomical medical expenses, nor the fact that they will be lifelong. If adoption had occurred, the adoptive parents would be granted a federal subsidy. To this fact this mother remarks, "This is the ultimate insult; having to cope with the tragedy of my daughter's condition, my family falls through the cracks of legislation." She stresses that the needs of the child must not be divorced from the needs of the family if we are to encourage the survival of the family unit.

This scenario fairly represents the realities of this current mandated approach to treatment and, I believe, shows that rather than the family being helped and supported there is the potential of its being severely disrupted or destroyed. Although the tone of this legislation is one of suspicion of parents and criticism has been directed at those parents who have chosen not to treat their critically ill newborns, little comment has been heard from them, nor has it been actively sought. Although it might be easy
to portray parents as overwhelmed by self-interest when they have chosen nontreatment, every account I read or parent I spoke with communicated the anguish, pain and love they feel for these unfortunate children. As they were not asked by legislators or the government in any formal fashion, what it is they feel, I will present several cases that I found to be representative.

The following is an excerpt from an article written by a mother who felt compelled to express her frustration at the negative connotations assigned to parents in situations similar to her own:

I think of her every year on her birth date, but I don't delude myself wondering what she would look like, or how would talk and speak. If she had lived, she would not have been able to do any of those things...She was malformed and diagnosed as trisomy 18, with the prognosis that she would not live more than a few months, maybe a year. My husband and I would have done anything to save that baby's life, to make her better. In the hours that followed, we had hoped that operations could be performed; we consoled each other with stories of remarkable children we had both known who were retarded or had birth defects. Nothing in my experience had prepared me for the feelings of shame and failure that descended upon me and, nothing in my life since has matched the depression and helplessness we felt while we waited for our baby to die. The baby's pain and suffering were our pain and suffering. I stayed home to take care of her...We met with social workers and doctors and tried to figure out how to manage the financial responsibility. We lived from day to day in a Kafka-like presence, too paralyzed to contemplate the future...

The baby died three months after her birth, but she was never "alone in the world". We cared for her and faced our responsibilities. Luckier than some other
"Does," we had no choice but to wait. However, those other Does are not shirking their responsibilities. They are trying to figure out, sanely and rationally, what will be best for their babies. They do not need squads of government inspectors or lawyers and judges to tell them what to do. The squads and lawyers and judges will have no part in the raising of these Baby Does, and it is inappropriate for them to be part of the agonizing decisions. In the rare cases where parents behave irresponsibly, there are trained, compassionate doctors to make those decisions.

Some events in life are simply so personal, so private that compassion and good sense demand they be left within the circle of family and family doctors. The parents should be left to work out their enormous difficulties as best they can. Alone.

The mother of a four year old multiply handicapped son writes:

In my love for him I must say that he deserved a better life...In the absence of complex medical procedures, severely handicapped infants expired quietly and mercifully. Today they are not allowed to die. They are the victims of the new technology and of the short-sighted laws that the government, in its confused compassion, is inflicting on us.

We must retain control over our technology, otherwise every new life-saving gimmick may bring in tow more human suffering. I ask that we recognize that sometimes, decisions have to be made--machines cannot make decisions.

It is interesting to note how quickly would-be decision-makers take refuge behind God. Suddenly, no one wants to "Play God". Isn't this the same God we have outwitted with our high-powered life-saving techniques? Do we expect the machines to play God? If we do believe in God and life after death, what are we afraid of?

While it is clearly wrong to take the life of another, is it right for society to force a person to live in the service of an abstract ideal such as equality? Is it compassionate to aggressively overcome nature's safeguards and compel a severely disabled person to live out a seriously restricted and painful life?
In a case involving a young couple expecting twins, the tragic effects of this legislation is aptly demonstrated. When the twins were born it was found that they were conjoined. There were two normal heads, one body with two legs and two arms, one heart and one thoracic cavity. This defect is uniformly fatal and the parents and physician decided not to aggressively support the infants' failing vital functions. This situation received media attention and several hospital personnel raised concerns regarding liability under the federal regulations. The infants were, therefore, transported to a NICU one and one-half hours away from the parents home. After more family discussion the parents decided they wanted the twins transferred closer to home so they could visit on a regular basis. This move was prevented when a federal investigation was initiated as an anonymous informant had called DHHS. A federal investigative team consisting of three investigators arrived and spent numerous hours with the hospital administrators, doctors, family members and legal counsel. As no breach of the law was found, the twins were then moved to the community hospital. The infants died six days after this transfer.41

The treatment of these twins, and the effects of this unfortunate event, were altered tremendously by the fact of this legislation, according to those involved. The decision-making process between the primary doctor and the family was markedly changed and the NICU staff engaged in unusually long discussions of even minor treatment changes and overdocumentation for fear of
later reprisal. The transfer of the infants to the community hospital close to the family was delayed pending the federal investigation. All said they felt "demeaned" and "under suspicion". The normal parental grieving process was altered and the emotional status of other families with infants in the NICU was disrupted by the investigation as they feared that the treatment was inadequate and questionable for their child as well. There was increased cost and utilization of administrators, doctors and lawyers, which prevented their attention to other duties. The physicians estimated that without this environment of heightened fear and the investigation that followed the anonymous phone call, these infants would most likely have succumbed within 24 hours.41

Another scenario that illustrates how this approach is leading to an out-of-control nightmare is detailed in a report by a British pediatrician visiting an American University hospital who registered his disbelief about observing the resuscitation of an 18 month old infant suffering from a cardiac arrest after he was told that the infant had no forebrain, therefore, no potential for intelligent life—and that this was the infant's twentieth resuscitation. The American doctor told him that, although he recognized the futility and expense this entailed, pressure from "pro-life" groups and the law was so great that he felt compelled to continue treatment.42 Certainly, these types of scenarios are not what was intended by those who instigated and supported this legislation, but stories like these are
increasing in number. As more families are forced to live through similar horrors, outspoken parents determined to register their outrage will increase public awareness and demand public rethinking of the forced use of technology. Parents will be the ones to push the hardest for restricting the use of our technologies to situations where benefit is to be gained.
CHAPTER FOUR

WHO LIVES WITH THE REPERCUSSIONS?
Who Lives with the Repercussions?

That society has compelling interest in the safety of its children is recognized by the child abuse laws which imply that parents do not always act in the best interests of their children. The state also has an interest in preventing systematic discrimination against classes of citizens. These laws have been applied to health related situations when the benefits from recommended treatment so clearly outweigh the risks that the state has felt compelled to intervene. This is routinely done in cases of children of Jehovah's Witnesses regarding blood transfusions and has recently been invoked when treatment for childhood cancer has been deemed highly beneficial by the medical community and parents have refused. I believe, however, that a distinction must be made between the invoking of child abuse laws in such instances and using them as a basis for the recent Congressional legislation mandating treatment for critically-ill newborns.

Parents are given decision-making authority and responsibility in all aspects of their children's lives. Not all parents make the decisions others think are best, but we allow this diversity as a fundamental right of freedom in our society. Since families, above all, live with the consequences of the decisions that are made, they should have an integral role in making them.

Many studies conclude that the usual patterns of family
functioning may be substantially disrupted from having a handicapped member. As the result of the burden of care for the child and lack of alternative adequate care-givers, families often have markedly decreased social interactions, mothers often have an increased workload, suffer physical strain from lack of sleep and exhaustion from lifting and carrying the child. Loss of career opportunities, tremendous financial stress, the need for frequent trips to the hospital and lack of any vacation are also common family experiences. Siblings frequently display maladjustive behaviors and poor school performance.  

It is estimated that up to 5% of the total cost of care for a handicapped child is paid for by parents with insurance and up to a third by those without insurance or who have used up their lifetime allowance, not an infrequent occurrence in these situations. In general, 15% to 20% of the costs of hospital care and 70% of the costs of outpatient care and medical supplies are paid out of the pocket by the family.  

In one extensive study of families with a severely handicapped child, it was found that every one of them had problems of a more or less serious nature relating to the presence of the child, indicating that potential harm to the family should clearly be a consideration in decision-making.  

These family effects are lucidly described by the mother of a severely handicapped child:  

I care for her at home now, because the option
of placing her in a foster home while I was still physically and emotionally able to nurture her was unacceptable to me even though it was medically recommended...She eats through a feeding tube in her stomach...and easily stops breathing during her frequent gagging spells...sleeps at half-hour intervals around the clock...disconnects the feeding pump that continuously pumps food through her gastrostomy tube...pulls the tube out and HCl oozes and burns her sensitive skin. My son has been emotionally scarred by what he has seen. He hides under the bed when his sister gags and stops breathing and he is the only child I know of who can perform CPR at age five. The financial stability we have worked so hard to achieve has been destroyed; we will be paying her medical bills until our death...as she used up her lifetime medical insurance benefits by her first birthday...My marriage could not withstand the strain nor the demand and as long as I care for her I will be unable to support myself and do not qualify for federal assistance of any kind. My daughter's condition has disabled the entire family.

The services we offer to families are dwindling at the same time mandated treatment is being imposed. Predictably, more families will be faced with situations similar to the one just described, and it is important to be aware of what society currently offers to those families who are unable to cope.

Services Available

Proponents of mandated care claim that society offers institutional care or adoption for parents who do not have the resources, financial or emotional, to care for their handicapped children at home. In reality, these are often not viable
options. The availability of institutional placement is limited and varies with locality, and impaired infants are often difficult to place by adoption. Above all, the idea of putting a loved one into an institutional setting, where care is often less than minimal, staffing poor, and cleanliness negligible, is not an easy decision for parents to make.

With public attention focused on the inadequacies in institutional facilities in the 1960's, admissions were decreased significantly resulting in many severely handicapped children remaining at home without adequate supportive services for their families. At this same time, medical technology and improved care prolonged the lives of severely handicapped infants and children. Since there was nowhere for them to go, many remained in acute care hospitals. Even with the greater need for community services since this shift, care in community settings is often fragmented, uncoordinated and merely custodial. In one extensive study of community care it was found that virtually every state has cited a shortage of residential placements. 44

Respite care services, which provide in-home care-takers so parents can have a few hours outside of the home, are continuously being decreased by the same administration that is increasing the demand for them. Along these same lines, parents live with the constant worry over who will care for their severely impaired child, or by then older adult, when they are no longer able because of old age or death. In my view, government efforts directed toward helping handicapped children reach their
full potential and aiding families with financial and emotional support would be more appropriate than mandating treatment which predictably increases the need for services and then cutting the budgets of programs that provide them.

What Do We Believe?

Our society elevates the individual, evidenced by our emphasis on autonomy through our informed consent doctrine, and continuing history of legal precedent in favor of the individual's right to choose in decisions including those of death. Court decisions granting authority to families to decide treatment in cases of an incompetent or comatose patient, and court decisions granting authority to parents to make treatment decisions for the care of their children, also substantiate this claim. We must ask, then, if this recent legislative approach where care is mandated, is consistent with our beliefs and values as a society.

In preparing this recent legislation, Congress relied heavily on lobbyists and groups who had been active in pushing for this approach but the views of parents were not actively sought even though the main intent of this legislation was purportedly to protect and nurture the family unit. A few organizations outside of the government have asked parents their opinions. Results from one such report requires that we seriously question this legislative approach.
In October, 1984, Woman's Day magazine reported that of nearly 120,000 women who responded to their survey, 64% opposed laws that require treatment of severely defective infants. This survey, conducted by Wellesley College Center for Research on Women, was the largest response to any survey ever published in a single issue of any magazine. Since this was not a true random survey, these figures may not be a totally accurate accounting, but the implication of the report is sufficient enough to indicate that the mandated approach to treatment does not accurately reflect majority opinion. Clearly, the limits of societal control are in question.

Summary

The individuals and process involved in decision-making when determining desired treatment options in the care of the critically ill newborn have undergone two distinct changes in the past twenty years or so. Up until about twenty years ago, the birth of a defective or critically ill newborn was a tragic event handled privately between the physician and parents, as medicine had little to offer. Then, in the 1960's, the concept of the NICU came into being, where sophisticated technologies were developed and specialists were trained to handle medical problems specific to the ill newborn. The inertia that developed from the excitement over the ability to sustain the lives of many newborns who previously would have died was dampened only with the
realization that not all children survived intact. Not only did some of these children suffer severe neurological and physical deficits, but it was also discovered that the treatments themselves could be detrimental. Physicians and parents, with much anguish and soul-searching, approached these realities as best they could, making decisions they felt would be in the best interest of their infant. They made decisions with the uncomfortable knowledge that the ability to predict what life would be like for that child was poor and the risks of both treatment and nontreatment were great. In 1982, this process was significantly altered when the so-called "Baby Doe" regulations were first instituted mandating care for all but the most severely ill infants.

Comments from many different sectors of our society concerning the dilemmas involved in treatment decisions in the care of the critically ill newborn have reflected the diversity of thought found in our society. Whether they were proponents of mandating aggressive treatment or of leaving the decision to the parents and physician, all shared one belief—that there is a decision to make in determining treatment options for these critically ill infants. Some stated that those infants "born dying" should be allowed to do so, while others stated that as the ability to predict is so poor, the parents and physicians should decide. I believe this admission, that not all infants should receive maximal treatment, points to the fact that all are making quality of life decisions. The differences lie in where
they draw the line and who it is that should have ultimate decision-making authority. How each person's religious tradition, family background and system of values impinges on this boundary-setting process must be recognized. Should families be allowed to make decisions with overt consideration of expected quality of life, expected longevity, suffering vs benefit? This takes us back to where we started—if we all have different values and beliefs and we come from a society that regards individual autonomy as a primary societal goal and the family unit as the responsible, nurturing unit—do we support the family in its right of authority or do we as a society have more compelling obligations and rights to protect the individual from his family in this particular realm? We must reconcile these two competing societal goals. By mandating care for the critically ill newborn we have not really dealt with the dilemmas we now face but have just heighted the trauma surrounding such tragedies.

Conclusion

With the current administration, the political climate has changed and the question of whether society should legislate morality has arisen. Shifting political winds should not dictate morality such that those unfortunate enough to get caught in the midst of one administration suffer lifelong, while those fortunate enough to be legislated by another, do not. The role
of the government should not be to mandate morality but rather support the concept of individual choice.

On the one hand, those with current political power espouse moral righteousness, but on the other hand, do not follow through with supportive services to truly back up what they believe. What are we supposed to make of these contradictions? It appears that a seemingly moral and religious minority is trying to impose their collective will on the majority. What results is not a true reflection of society.

The issues faced in the treatment of severely impaired newborns touch upon some of the most sensitive issues in our culture: procreation, family privacy and the definition of a life worth living. We must begin to come to grips with the complexity of these issues by acknowledging the pull of equally fundamental, but sometimes contradictory, moral imperatives and aims of medicine—to sustain life and ameliorate suffering.

With the lack of predictability of outcome, knowledge that the family has of its own limits, costs in family integrity, our emphasis on autonomy and the authority of families, I strongly believe that they should be granted the task of making these most difficult decisions, as they are not only our best chance at getting at the best choice for each particular infant, but they live with the consequences more than any of us can know.
REFERENCES


11. Harrison, Helen, "Parents' Role in Ethical Decision-Making", unpublished manuscript


16. Lebacqz, Karen, "Vive la Difference", unpublished manuscript


21. Singer, P., "Can We Avoid Assigning Greater Value to Some Human Lives Than to Others?" Dept. of Philosophy, Monash Univ., Clayton, source unknown


York Review, March 1, 1985


34. Caplan, A., "Is it a Life?", The Nation, Jan. 21, 1984, pg. 37


40. Sarin, A.V., "Life and Death Decisions", source unknown


42. ____, Chicago Tribune, March, 1985

43. Machado, L., letter to Atlantic Monthly, Jan 29, 1985

