Medical Decisions for Children
How Competing Interests Are & Should be Weighed

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Spring 2013

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Abstract

This thesis examines the impact of rapid changes in medical technology, and developments in related areas of the law, on the legal and ethical principles applied to determine whether medical treatment, including life-saving and -sustaining treatment, may be withheld from a child, and who (parents, the child, medical professionals, regulators) is empowered to make such decisions. Just over three decades ago, a decision in Bloomington, Indiana to allow parents to remove artificial nutrition and hydration from their newborn child, Baby Doe, held the eyes and ears of the entire country captive and prompted state and federal legislative responses designed to shape the outcome in future similar cases. How have legislatures and courts weighed – and how should they weigh – the competing interests of parents, children, medical professionals, and society (in the form of government) in deciding who determines medical treatments for a child, the rights and responsibilities of parents, children, and hospitals in making such decisions, and circumstances in which the state may intervene? As healthcare decisions about children are made every day, including decisions about the use and withdrawal of life-saving and -sustaining treatments, it is critical to examine how law and policy resolve conflicts among decision makers and to assess whether they are striking the right balance among competing interests. To do this, the thesis considers a broad array of related laws and judicial decisions along with medical policies and original interview research, to identify and assess the factors determining outcomes and how technological advances and other developments may affect future decisions.
Introduction

In the modern world, technology is changing every day. The advancements facing society have opened a door to a new type of life—a life that is medically sustained. Be it by medication, respirators, or defibrillators, medical technology is keeping humans alive in instances where the body fails. While some individuals see these advancements to be entirely beneficial, these developments create a state of being that is new and hard to define.

This thesis examines the impact of rapid changes in medical technology, and developments in related areas of the law, on the legal and ethical principles applied to determine under which circumstances life-sustaining medical treatment may be withheld or removed from a child. The values and rights of three major decision makers—the parents, the child patient, and the government—and their respective weight in making a final decision are discussed. The primary situation studied is when conflict arises between the views of the parents, children, and the government regarding the use of such treatments. While doctors and other medical professionals are an integral component to medical treatment decisions, their perspective is not included. This is because research showed a vast spectrum of values among physicians, making generalizations difficult. Additionally, the role of the physicians on a basic level is to provide information only. Healthcare providers can explain the diagnosis, the treatment options, and the corresponding probabilities of success. However, the role of doctors typically ends there, unless they are involved in the hospital’s ethics committee which will be explained later.

It is important to define at the outset the basic terms and concepts associated with the treatments and care that are the subject of this thesis. Life-sustaining medical treatment is more commonly referred to as life support. Life support is a group of medical measures that can be used individually or in combination to prolong a life. The goal of life support is to allow the
patient live a life as near to independent functionality as possible. An example is artificial nutrition and hydration, also known as tube feeding. A chemically balanced mix of nutrients and fluids are given to the patient through a tube that is inserted into the stomach, intestine, or vein. This treatment is not intended to improve or reverse the patient’s condition, and it aims only to maintain normal eating habits necessary for life. Cardiopulmonary Resuscitation (CPR) is also a subgroup of treatments that is used when a patient’s breathing or heart stops. Most people know CPR to be a series of compressions and breaths; however, CPR can also include drugs or shocks by a defibrillator to the heart to revive the heartbeat. Mechanical ventilation is frequently referred to as a respirator. This machine replaces or enhances the function of the lungs by forcing air into the lungs allowing the patient to continuing breathing. Life support measures do not necessarily improve or change the patient’s illness or condition, which is why these procedures are not classified technically as treatments. While some patients may experience an improvement in quality of life, the purpose is to maintain life.¹

Life support is used in cases where a patient has experienced bodily function failure. The failure may be due to illness or injury. There are four core functions that are measured to determine the condition and probability of life of a patient. These functions are regulated by the brain stem and include heartbeat, breathing, blood pressure, and swallowing. There are three commonly associated states of being in which life support is used to prolong life, and the differences are as follows. First, brain death occurs when the activity in a patient’s brain stem stops and it is confirmed to be permanently lost. The patient is pronounced dead as there is no chance to regain consciousness.² However, while determining exact function ability, a ventilator may keep a patient breathing who is brain dead. Second, Persistent Vegetative State (PVS) is

¹ Cleveland Clinic, *Understanding Life Support Measures* (2009)
² National Health Service Choices, *Brain Death* (2012)
declared when the patient has some functionality of the brain stem; therefore, the patient maintains some level of consciousness. A patient may respond to some senses or open and close his or her eyes. However, in most cases the core functions of the brain stem are damaged to varying degrees. This creates a spectrum of PVS patients and their abilities to perform any of the core functions without assistance. Life support can be used to replace those that are lost or support those that are weak. Finally, a coma is the state in which a patient maintains a low level of brain activity and is unconscious. A coma usually lasts between two and four weeks. The patient may not be able to perform the core functions such as breathing or maintain blood pressure independently, so life support may aid sustaining life until recovery.3

When faced with the decision to initiate or continue life-sustaining medical treatments as the result of terminal illness or injury, the patient or caretaker must make a difficult choice. If there is an emergency, it is common hospital procedure to perform life-saving measures such as CPR. In fact, if an adult wishes to be excluded from heroic measures, a Do Not Resuscitate (DNR) order must be filed in advance. An advance directive can also be filed by an adult to document the potential patient’s wishes regarding life-saving treatment. Also, an adult can appoint a durable power of attorney, who is a representative with the authority to make healthcare decisions for that patient if he or she becomes incapacitated. As discussed in detail below, it is important to note that while adults may become incapacitated, thus requiring the use of life support, minor children are already considered by virtue of their minority to be incompetent under the law to make medical decisions. Therefore, in cases where the patient is a child, someone else typically will need to make the decision as to whether to use life support, and as discussed throughout this paper, there are a handful of candidates with legitimate values and rights related to making these vitally important decisions.

3 National Health Service Choices, Coma (2011)
There are two broad sources of legal authority that allow for several decision makers to be involved. The first is the State Police Powers. These powers have been in existence since before statehood, predating the founding of America. These powers allow states to govern their residents, both children and adults alike, in matters of health, welfare, safety, and morals. However, these powers are narrowed by the United States Constitution, the supreme law of the land, and in particular the Fourteenth Amendment. The Fourteenth Amendment includes the Due Process clause, which is the federal limit on state power that restricts a state’s ability to act in a way that deprives someone of liberty unless there is a significant justification.\(^4\) The relevant liberties are often found in the Bill of Rights, commonly the freedom of speech, religion, the press, and a speedy trial. More recently, the right to privacy was established by the United States Supreme Court’s interpretation of the Due Process clause in series of cases, including *Roe v Wade*. The right to privacy encompasses a person’s freedom to make decisions regarding his or her own body, including medical treatment. This right to autonomy is almost absolute for adults, particularly in a non-abortion context; however, children are not given the same rights as adults under the law. The absence of autonomy for minor patients creates an obstacle to the usually patient-driven decision making when a child is faced with a serious illness or condition that poses the need for life-sustaining treatment.

This thesis examines how these most difficult and emotional decisions concerning the use, or withdrawal or withholding, of such treatments are made. It considers historical case law, law review articles, and interviews with scholars and decision makers to evaluate who has been granted a say and how a final decision has been reached regarding the withholding or withdrawal of life-sustaining medical treatment for children. It then considers how further technological

\(^4\) U.S. Const. Amend. XIV §1
advances in medicine may affect the balance of interests in future cases and offers recommendations for undertaking that balance.

**Parents’ Values and Rights**

A logical premise is that parents make the decisions when dealing with the care, including medical care, of children. Parents hold values associated with their children and family unit as well as legal rights to protect those values. Parents generally value protecting their children from harm. In the instance of withholding or removing life-sustaining medical treatment, harm can take two forms. There is first the more obvious harm of a potential death. However, harm can also be construed as the change in lifestyle or decrease in quality of life resulting from continued medical treatment. The decision of which is the greater harm might be left to be determined by the parents in each case. It is a subjective matter, and a generalization cannot be made as to which parents as a whole perceive to be more harmful for children.

Parents also value the impact the medical decision can have on the family unit. Regardless of the ultimate decision made to either continue or remove life support, there will be repercussions. Most pressing may be the financial and emotional impacts the decision will have on everyone. These may not necessarily be negative or burdensome, but rather they are a most likely a significant change for the family. The needs of the patient and other children may include 24-hour surveillance and care, expensive medications, or psychological counseling. Here the parents are likely to weigh the value of the common good for the family as a whole, much like the state does, which will be discussed further on in this paper. To the extent the parent holds religious beliefs, these are likely to frame all parental values within a perspective shaped by their beliefs. In particular the parents’ religious tenets may shape or dictate the way they view medical treatment or prolonging life.
There are certain responsibilities parents are assumed to fulfill for their children. In an interview with Dr. Richard Miller, professor at Indiana University and Director of the Poynter Center for Ethics, he stated that not all of these responsibilities are mandated by law. Parents are expected to provide for and protect their children. At the most basic level, parents are expected to provide food and shelter. However, parents are not required to create a healthy loving environment in the home. The traditional values commonly associated with parenthood are not necessarily included in the law. In fact, under the Due Process clause, parents are given great flexibility and authority to raise their children in their own manner. As noted above, no person may be deprived of life, liberty, or property without due process of the law.\(^5\) This safeguard allows individuals to act without undue interference by the government. Individuals have the liberty to procreate and raise their children as they wish, and the state can only intervene if there is a strong enough reason. For example, when it comes to education, the government has allowed for a parent to remove a child from public education in order to seek another provider, such as homeschool. If there is a concern that negligence has placed the child in immediate danger, however, the state can take away the parents’ rights. In the case *Prince v Massachusetts*, a nine year-old child was determined to be in immediate danger when selling religious materials on the highway. The aunt and legal guardian of the child claimed she was exercising her freedom of religion and liberty to raise the young girl found in the Due Process clause. The Superior Court of Massachusetts held the aunt could school and train her children and the girl regarding religious beliefs and traditions. However, Justice Rutledge writes in the opinion that when there is conflict between sacred private interests and the protection of children from abuse, “…the safest and most objective recourse is to the lines already marked out, not precisely but for guides,

\(^5\) Id.
in narrowing the no man's land where this battle has gone on.”\(^6\) The court valued the safeguarding of the child in hopes of providing opportunities for growth in order to lead an independent and well-developed life.

With respect to parental decisions about medical care, states generally have considered themselves to have a significant enough interest in the child’s medical well-being to intervene, and courts consistently have agreed that states have a significant justification to step in when withholding medical care may result in death. When a minor has not been adjudged independent, the court's authority to order medical treatment over a parent's objection is limited “to ordering the hospital to provide necessary medical treatment, not withhold[ing] treatment with the inevitable consequence of ending the minor's life”\(^7\). It is common that these parental objections are a result of religious beliefs. In *Muhlenberg Hospital v Patterson*, for example, the Superior Court of New Jersey ordered a blood transfusion for a six-day-old infant against the mother’s objection and claim of violating her right to practice religion. The court ruled a child cannot be a martyr for his or her parents’ religion.\(^8\) A handful of cases involving parents associated with Jehovah’s Witnesses establish a rule that a parent’s religion cannot dictate the use of medically necessary treatment if nonuse results in death.\(^9\) In the case *Jehovah’s Witnesses of Washington v King County Hospital Unit No. 1*, a large congregation of Jehovah’s Witnesses filed an action to declare their religious freedom to forego blood transfusions for adults and children. However, the Washington Code §§ 13.04.095, which enables the state to override a parent’s religious freedom

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\(^6\) *Prince v Massachusetts*, 6 ¶2, 321 U.S. 158; 64 S. Ct. 438; 88 L. Ed. 645 (1944)

\(^7\) *J.N. v Superior Court of San Diego*, see HN5, 156 Cal. App. 4th 523; 67 Cal. Rptr. 3d 384 (2007)

\(^8\) *Muhlenberg Hospital v Patterson et al.* , 128 N.J. Super. 498; 320 A.2d 518 (1974)

\(^9\) *Muhlenberg*, 128 N.J. Super. 498

*Prince*, 321 U.S. 158

*Lundman v McKown et al.*, 530 N.W.2d 807 (Minnesota 1995)

*State of New Jersey v Perricone*, 37 N.J. 463; 181 A.2d 751 (1962)
and compel a minor to submit to a blood transfusion, was found constitutional. Dr. Miller expressed concern that the dichotomy of religious belief and action is often nonexistent. Defining the ultimate best interest can be elusive. There are some cases where religious pursuit can harm someone such as human sacrifice practices. However, acts such as smoking peyote are not so evident. He suggests that it may not be in the best interest of the child to remove the ability to practice religion from a child. By removing the child’s religious beliefs the state may in fact be harming the child’s mental and spiritual well-being. Nevertheless, on existing law, a parent’s right to pursue religious freedom is not absolute, and it holds less weight than the child’s right to life.

Parents have certain right to seek medical care, including alternative treatment, even if the state disagrees with the parents’ choice. In the case In re Hofbauer, parents took their seven year-old son with Hodgkin’s disease to Jamaica for treatment. Immediately upon the family’s return to New York, the Saratoga County Department of Social Services filed a petition claiming negligence on behalf of the parents, which violated the New York Family Court Act. The Court of Appeals of New York ruled in favor of the parents and established two standards that if met, prevent parents from being criminally liable for negligence regarding alternative medical care. The court noted that first for a parent to be convicted of negligence, the child’s life must be placed in immediate danger, physically or emotionally, as a direct result of the parents’ actions or inactions. Specifically regarding the use of alternative medical care, two standards are used to determine if negligence occurred. First, the alternative treatment course must be advised by a duly licensed physician. Second, it cannot be rejected by a majority of health authorities.

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10 Jehovah’s Witnesses in the State of Washington et al. v King County Hospital et al., 278 F. Supp. 488 (1967)
11 In re Hofbauer, 47 N.Y.2d 648; 393 N.E.2d 1009; 419 N.Y.S.2d 936 (1979)
Alternative medicine does not include not seeking care, and as stated earlier, inactions can result in convictions. In Washington State v Williams, the parents were convicted of manslaughter for not seeking professional medical attention for their 17-month-old child. The parents were unaware the severity of their son’s illness without going to a doctor and did not avoid care due to religious belief. The young parents believed the child, who was sick for eleven days, had a toothache and attempted to care for child with aspirin. The court ruled that reasonably prudent parents would have taken the child to the doctor given his symptoms.12

A thin line of discretion lies between not seeking care and choosing physician-recommend non-treatment. In the case of Baby Doe, Judge John G. Baker, now on the Court of Appeals of Indiana, decided that when faced with two divergent medical recommendations from duly licensed physicians, the parents had the right to choose one or the other freely. Baby Doe was born in Bloomington, Indiana with esophageal complications and Down syndrome. One suggested surgery to fix the problem and another suggested surgery would not be successful. The parents opted out of surgery for their son; artificial nutrition and hydration were removed and the infant died shortly after. Discussed further in an interview with Judge Baker, he noted that the court did not need to become involved in what was traditionally a family matter if the parents had met the standard of care in seeking medical attention for their child. He reflected on his decision stating that in current times, he would have proceeded differently by appointing a guardian ad litem immediately and calling a court reporter to take notes of the discussion at the hospital. As a result of Judge Baker’s decision, Baby Doe regulations were passed by Congress broadening the definition of abuse to include the removal of food, fluids, and necessary treatments used to sustain life. The laws were struck down by the United States Supreme Court

12 State of Washington v Williams et al., 4 Wn. App. 908; 484 P.2d 1167 (1971)
only two years later because the federal legislation obstructed the states’ authority to govern their residents.\textsuperscript{13}

Parents are given great flexibility in raising their children regarding daily activity. Parents can choose food, hobbies, friends, and education for their children, and all of these aspects of life can considerably affect the health, safety, and well-being of a child positively or negatively. However, when a parent is exercises his or her right to raise their child in regard to medical treatments that flexibility constricts.

Some state courts have found circumstances under which a parent has the ability to remove life support from a child. The Illinois Supreme Court has outlined six criteria that, when all are met, permit a parent to remove life support: 1) the patient must be terminally ill, such that the condition is irreversible, incurable, and death is imminent, 2) the patient must be in PVS or permanently comatose, 3) the diagnosis of the patient must be agreed upon between the attending physician and two others, 4) the incompetent patient’s right to refuse treatment must outweigh any other state interest in prolonging life, 5) there must be clear and convincing evidence that the decision of a surrogate decision maker, such as the parents, aligns with that of the patient if he or she were competent, and 6) the court enter an order allowing the surrogate decision maker to exercise the patient’s right to refuse treatment. Similar language and criteria are seen in other rulings. For instance, the Georgia Supreme Court ruled, in \textit{In re Jane Doe}, that the parents could withhold life-saving medical treatment as long as the first three criteria listed above in the Illinois law were met.\textsuperscript{14} These circumstances are specific and involve several people to reach a final decision, and as seen in the Illinois law, the involvement of the court is required. These

\textsuperscript{13} Jon Tyson, \textit{Evidence-Based Ethics and the Care of Premature Infants}, Low Birth Weight 5 (1995)
\textsuperscript{14} Anne R. Crosswait, Comment, \textit{“Do Not Resuscitate Order” Allow for an Infant with AIDS}, \textit{26 J. Health L.} 7 (1991)
types of rulings strike a balance between the liberty interest of a parent and state’s interest. It keeps both parties involved with a judge as a determiner of fact.

**Patient’s Values and Rights**

A cornerstone of U.S. law is freedom for individuals, and patients value autonomy to make their own decisions regarding care. Most people thrive when in control of their own lives. One seemingly unique perspective of the minor population is the value placed on what is happening or available to them *today*. During adolescent development, children are more likely to engage in risky behaviors because young people value a short term gain more— or place more importance on short term pain or harm -- than they value a future potential improvement on their situation.\(^{15}\) While some may argue this is a naïve perspective and a disadvantage to youth independence because it may appear careless, it should not eliminate the consideration of the patient’s views if one considers that the young patient is the one living daily, and most closely, with the illness or condition, and his or her values may not need to be qualified for consideration.

As stated previously, these liberties are protected but not absolute. Patients value autonomy and have the right to refuse treatment. In *Schloendorff v. Society of New York Hospital*, Justice Cardozo stated "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.”\(^{16}\) In more recent decisions including one that received nationwide attention, *Cruzan v. Director, Missouri Department of Health* the United States Supreme Court ruled a competent person has a constitutionally protected right to refuse life-sustaining hydration and nutrition. The key word in these decisions is competent. Under the law, minors are considered incompetent and therefore are not granted equal rights as adults, including the right to refuse treatment. Children are continuously growing and developing

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\(^{16}\) Crosswait, *supra* at 5
their own thoughts, beliefs, and preferences, and until they reach a stage at which such thoughts and preferences are considered sufficiently formed and well informed, society considers there to be the need for a surrogate to make decisions for them.

One exception to the general principle of incompetency for minors is the emergence of “mature minor” rules. States have begun to develop mature minor rules that allow for a mature child to determine medical treatment courses for themselves based on their understanding of the diagnosis, treatment options, probability of success, and the seriousness of their condition.17 Author Jennifer Rosato argues that mature minor rules should actually be the standard because decisions regarding life and death hold the same gravity across all ages; these kinds of decisions determine the rest of the patient’s life, and that decision should be made by the patient. There are two types of mature minor rules. First is a “presumed” rule that allows minors of a certain age to consent to medical treatment. Alabama code allows children ages fourteen and older to consent to medical care, and Montana, Oregon, and Pennsylvania have similar statutes. The second type is a “true” mature minor rule which allows a child to consent to medical treatment if a court finds the individual to be mature enough to understand the diagnosis, treatment plan, and results of his or her decision. This type of rule acknowledges the developmental differences across adolescents. However these statutes may be interpreted to not include the right to refuse treatment as the language of the law is “consent to medical treatment;” also, interpretation of “treatment” may exclude life support as it does not treat a condition, it sustains life.18 These statutes have been read to allow minors to more easily access contraception and mental health care, and while it is unclear as to the intent of states’ presumed mature minor rules, by increasing

18 Jennifer L. Rosato, The Ultimate Test of Autonomy: Should Minors Have a Right to Make Decisions Regarding Life-Sustaining Treatment? 49 Rutgers L. Rev. 7 (1996), Also see n127
access to contraception and mental health care, the states may be improving public health and safety, suggesting a reason for such laws that is unrelated to the valuing of autonomy for its own sake or as a matter of personal freedom. If mature minor rules resulted in essentially lowering the age of maturity from eighteen for the purpose of medical decision making, and it may prompt a reconsideration of other age laws and their rationales as discussed further below.

In states where true mature minor rules exist in statutes (Alaska, Arkansas, Mississippi, Nevada, and Idaho, a judge must assess the minor’s maturity level. For assistance in this complicated endeavor, a judge may look toward other laws or instances involving discussion of maturity and age. Abortion laws are very pertinent to the discussion of maturity and consent to healthcare. As of 2013, 38 states have laws mandating involvement, either notification or consent, of a parent, adult relative, or legal guardian in order for an adolescent to have an abortion. However, there again is an exception to this requirement. In 37 of the 38 states, an adolescent can obtain judicial bypass, which is a petition to a judge for a waiver of parental consent or notification requirement. Judicial bypasses may be given if the adolescent does not want to seek parental involvement, if her doctor suspects potential harm as a result attempting to involve parent(s), or if parents have refused to consent to the abortion. When a judge is petitioned for the waiver, he or she must determine the maturity of the young woman. If deemed mature enough, parental involvement is no longer necessary. However, state codes generally do not provide criteria through which maturity is assessed.

The lack of guidance in the matter may be due to the fact that maturity is not a simple checklist of indicators. Author Ann Eileen Driggs discusses at length the difficulty of defining maturity because it is not just displayed in physical development; it is a combination of age and

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19 Rosato, see n129
actions. Research shows that once a person’s cerebral cortex is a certain width, higher level thinking skills are acquired. Other theories find the ability to compare facts and to understand consequences develops between ages eleven and fifteen. Some individuals believe the ability to make rational decisions is the result of experience in making mistakes and learning a lesson. This implies that a person has lived some requisite number of years past the age at which facts can be compared. However, learning from the wrong decision is not applicable in cases where the decision leads to death. In terms of learning from prolonged pain, research also shows that stress can cause flawed or impaired judgment.\textsuperscript{22} There is little doubt that a debilitating condition or disease causes stress to the patient; however, it most likely affects the parents as well. While adult parents would have more experience in handling stressful situations, it would still be unclear as to who has the lesser impaired decision-making capability at that time, the parent or the minor patient. Research also concludes that around age eleven, the brain reorganizes, and social understanding and impulse control are initiated. At age eleven, “the brain is believed to be very vulnerable, especially to traumatic experiences, and unable to handle social pressures and stress in the same manner as the fully developed adults brain.”\textsuperscript{23} Driggs also highlights courts’ use of the “Rule of Sevens” in criminal liability cases. The Rule of Sevens puts forth the notion that the ability to create criminal intent is one gained in the aging process. Children ages zero to seven, do not have the ability to form criminal intent and therefore cannot be found guilty of the criminal act. Children ages seven to fourteen are incapable of forming criminal intent, but that notation can be challenged with the burden of proof falling on the plaintiff. Children who are fourteen and older can form criminal intent and can be guilty of the criminal act, meaning the burden of proof lies on the defendant to prove his or her inability, or immaturity, to commit the

\textsuperscript{22} Driggs, \textit{supra} at 705
\textsuperscript{23} Driggs, \textit{supra} at 708
crime. Several courts agree with these presumptions of ability relating to age; however, they are inconsistent in application and determination in medical care decisions. For instance, Driggs notes that Illinois courts focus on the minor’s ability to understand his or her actions. New York courts try to determine an age of discretion. Pennsylvania considers hesitation in addition to fully understanding of the decision and subsequent complications or benefits. Tennessee courts look for maturity, experience, education, and judgment enabling the minor to make medical decisions.

This comparison creates a paradox in which a fourteen year old is capable and/or mature enough to be decide to end another person’s life; however, he or she may not be judged mature enough to decide to end his or her own life. Another paradox is created when a minor becomes a parent. Once parenthood is established, a minor assumes the constitutional rights of an adult. In that case, maturity and developmental status are not factors in that minor’s subsequent decision making. In fact, the minor is then expected to make reasonable, rational, and appropriate decisions not only for him or herself but for the child too. If the minor parent wishes to place the child for adoption, twenty-eight states allow her to do so without parental consent. Again, the ability to make this decision may not be grounded in maturity or age but in public health and safety concerns.

The absence of a consistently agreed upon concept of maturity allows for a judge to use his or her best discretion in the assessment. Laws setting age limits for various activities offer limited guidance, in part because it is not always clear whether such limits reflect an assessment of maturity or serve other concerns, such as public health and safety. For example, driving is a privilege, and when performed in a reckless, or immature, manner, places people’s lives at risk. However, sixteen year olds are trusted to drive responsibly. Yet, a judge may not wish to use

24 Driggs, supra at 701
25 Driggs, supra at 700
sixteen as a rule of thumb for determination of maturity because maturity may not have been the sole determinant in setting that age requirement. Other factors may have influenced the decision such as the public benefit of being able to drive a tractor on the family farm or drive to work in order to provide for a young family. Likewise, a judge may question whether the age of eighteen is actually an age of maturity or merely the age of majority. Several activities are permitted at age eighteen including voting, enlisting, smoking, and gambling. Determination of the basis for granting access to those activities at that age is challenging. Voting and enlisting require a maturity to handle stressful situations as well as the ability to reason and communicate at high functioning levels, and so the choice of eighteen may reflect a societal judgment about when such maturity is typically attained. Smoking and gambling, on the other hand, may be prohibited for minors because of the threat of addictive qualities on vulnerable brains –public health and safety concerns-- but ability to spend money responsibly may have been considered instead. The uncertainty illustrates that age laws are not an obvious measurement of maturity.

States’ Values and Powers

The state, federal or state government, has three main values that affect medical decision making for children. The first interest of the state is to protect life. It is evidenced in several forms, the first of which may arguably be most important. The United States Declaration of Independence states “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty, and the pursuit of Happiness.”26 This foundational document reflects the inherent value government places on life. The list of unalienable rights is not exhaustive, and items not listed may still be protected. However, life was important enough to explicitly name it in the document. Not only is life the first listed right of which one cannot be deprived, but all lives are declared “equal.” Two

26 U.S. Dec. of Indp. ¶2
pieces of legislation involving medical care for children reflect the premise of valuing all lives equally. Section 504 of the Rehabilitation Act of 1973 provide that health care for infants should not be withheld on the basis of mental or physical impairments, particularly “[n]o otherwise qualified handicapped individual . . . shall solely by reason of his handicap, …be subjected to discrimination under any program or activity receiving federal financial assistance.” 27 This act protects the rights of individuals with disabilities, and the voice given to them through this legislation exemplifies the state’s value of protecting life. Additionally, in 2002 the Born-Alive Infant Protection Act (BAIPA) was passed into law amending the U.S. code and clarifies that in congressional consideration of legislation and in administrative law, newborn infants are to be considered as “persons” and synonymous terminology. The act and following guidance from the former Secretary of Health and Human Services, Michael Leavitt, say that if a very premature infant is born-alive and its appearance and behavior is one of emergency, perceived by a prudent layperson observer, than medical staff must perform a medical screening examination. 28 This requirement essentially requires the infant to be admitted to the health care organization. Once admitted, the regulations of the Emergency Treatment and Labor Act (EMTALA) are applicable to stabilize or transfer the infant, which may require life-saving medical treatment such as resuscitation. The act is very specific about the definition of “born-alive” which is as follows:

“[T]he complete expulsion or extraction from his or her mother of that member [of the species homo sapiens], at any stage of development, who after such expulsion or extraction breathes or has a beating heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether the umbilical cord has been cut, and regardless of whether the expulsion or extraction occurs as a result of natural or induced labor, cesarean section, or induced abortion.”

While the motivation for passing BAIPA was controversial in that it was perceived to be an intended obstacle to certain types of abortion, the act more narrowly defines what life is and demonstrates a state’s interest in protecting all forms of life, in various conditions and stages of development. Judging someone’s quality of life is a contentious issue because it is largely subjective and a difficult concept to measure; it can include the availability and effectiveness of pain management, dependency on others, and the ability to perform activities ranging from personal hygiene to extracurricular hobbies. It is perhaps this complexity that has made courts reluctant to weigh it in these kinds of cases. In 1990 in the highly publicized case of *Cruzan v Director, Missouri Dept. of Health*, the court noted that a state may properly decline to make judgments on the quality of life at hand, and instead assert an interest in preserving life, which is unqualified, to be weighed against the constitutional rights of an individual. Cruzan was not a child; however, she was a woman in PVS and doctors had determined a very low probability of regaining mental functions. Under Missouri law she was neither dead nor terminally ill. The Court held that in absence of clear and convincing evidence of the patient’s wishes, the Supreme Court of Missouri could deny Cruzan’s family’s petition to remove artificial nutrition and hydration – in other words, strong evidence of the patient’s wishes was needed to overcome the state’s strong interest in preserving life, even the life of someone in Cruzan’s condition. During the case, the patient’s perceived lack of quality of life was brought to the Court’s attention, but the Court did not weigh that factor in reaching its decision.

Additional common law cases illustrate the state’s interest in protecting life. The *parens patriae* doctrine is frequently cited in cases regarding conflict in medical decision making for children. Parens patriae literally translates to “parent of the country,” and refers to the role that
states are sovereign and guardian of people who are disabled or incompetent. It is this doctrine in coordination with the Due Process clause that allows the state to intervene in family matters so long as there is strong enough justification. As discussed previously, the states have consistently found medical care that may determine life or death for a child when religious beliefs impede the decision making process to be a strong enough justification. The Superior Court of Georgia yielded to the presumption in favor of life in *In re Jane Doe*. A thirteen-year-old daughter was admitted to the hospital with a condition that was not diagnosable but was determined to be severe and deteriorating. Her parents disagreed over the continuation of life-sustaining medical treatment. The court weighed the state’s interest in protecting life, the parents’ ability to make decisions for their children, and the child’s best interest, taking into consideration the finality of a DNR order. As a result, the court returned to the protection of life found in the Constitution, and ruled in favor of life for the child. In the case *J.N. v Superior Court of San Diego County*, conflict arose when parents of an eleven month-old with severe brain damage objected to an order removing an artificial breathing tube from their child. The San Diego County Health and Human Services Agency had filed a dependency petition for the infant and his two year-old sister permitting state intervention in the discretion of their care. A dependency petition permits the removal of children from the physical care of their parents or legal guardians. Any interested party and submit a dependency claim, but they are typically filed by a child protective agency. Before dependency was determined, the hospital recommended the removal of life-sustaining care and the trial court ordered the discontinuation of treatment. However, the Court of Appeal of California ruled a full judicial hearing on the dependency of the child had not been conducted, and thus clear and convincing evidence of the child’s dependency had not been established. In

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this case, it was determined that until a child is declared a dependent of the court following a jurisdiction hearing, “the court's authority to issue medical orders over a parent's objection is limited to ordering the hospital to provide necessary medical treatment, not withhold treatment with the inevitable consequence of ending the minor's life.”\textsuperscript{30} Excluding the withholding or removing medical treatment from the court’s authority is another example of the state ensuring the protection of life.

The \textit{parens patriae} doctrine also allows the state to terminate or intervene in the parent-child relationship. An indirect example of the state’s interest in protecting life is the power to punish those who do not protect life. There are consequences when a person decides to take away another person’s right. In these cases, that right is the right to life, or the right to a chance at life. When a patient’s right to life is threatened, by the parents, physicians, or patient himself, then red flags are raised. In \textit{In re Green}, the court held that the state does not have a strong enough interest unless the child’s life is in immediate danger. Physicians are generally excluded from liability in state codes when they act to withhold life support based on advance directives because they are acting on the patient’s wishes; an example is seen in Indiana Code, which provides “[n]o civil or criminal liability is imposed on a health care provider for the failure to provide medical treatment to a patient who has refused the treatment” in accordance with additional requirements for refusal.\textsuperscript{31} The process of determining criminal claims against a parent is more challenging, and the cases are mixed. While history shows inconsistent prosecution finding parents guilty of manslaughter for withholding medical treatment from their children, some cases have resulted in such a conviction.

\textsuperscript{30} J.N., See HN5  
\textsuperscript{31} Ind. Code 16-36-4-7(c)
Whether parents are seen to have fulfilled their fundamental responsibilities, previously discussed, is vital in determining guilt. In *Washington State v Williams*, young parents of a then 17-month-old child were convicted of statutory manslaughter for not seeking necessary medical care for their child. The parents gave the baby medical attention at home, such as aspirin, but did not seek professional care. The court recognized the parents’ ignorance of the severity of their child’s illness; however, it was held not to be a legitimate defense. The standard in court is that a reasonably, prudent parent would locate and use necessary medical treatment for their child. The court held that the parents did not meet that standard. The standard for charging parents is “willfully and without lawful excuse omitting to furnish medical attention for child.”

While the court did not find their acts willful, there was not lawful excuse and prudent parents would have moved to find care.

States differ on their prosecution of parents who rely on religious or spiritual means to heal a child. For instance in New York and Oklahoma, statutes exempt those parents from criminal liability. In the New York case *People v Pierson* and in the Oklahoma case *Owens v State*, parents willfully and without lawful excuse did not seek medical care for ill children. Parents were found guilty of committing a misdemeanor, but no charges of manslaughter ensued. However, in Pennsylvania, there is a history of finding parents guilty of involuntary manslaughter when religious means or prayers are used for curative purposes. For example, in *Commonwealth v Hoffman*, a parent relied on prayers and oils to cure his child of scarlet fever. The court noted that actions or omission of actions committed by the parent were criminal under the law, and religion does not act as a defense for committing a crime. Similar circumstances were seen in Pennsylvania cases *Commonwealth v Breth* and *Commonwealth v Barnhart* in

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32 Williams, See Washington Official Reports HN4  
33 Kearney, supra 872-874
which a parent(s) claimed religious beliefs as a defense for not seeking professional medical care for the child.\footnote{Kearney, supra 877} In all three cases, the parents were convicted of involuntary manslaughter.

In order for a parent to be charged of criminal negligence, there first must be a strong enough justification for state intervention. According to New York statute, a neglected child is defined as a minor whose physical condition is impaired or facing immediate danger as a result of parental failure to provide a minimum degree of care.\footnote{Hofbauer, see \textit{HN2}} As mentioned previously, in \textit{In re Hofbauer}, the family court and Court of Appeals in New York found that a parent who chooses alternative medicine is not negligent. It is interesting that in cases such as \textit{Prince v Massachusetts} the mother was not criminally charged with negligence, even though her minor son was determined to be in danger selling religious materials on the highway. The mother was instead charged with violating child labor laws. When parents who fail to perform their responsibilities such that a child is at risk of harm, the state has a strong enough interest to intervene. By prosecuting those parents, the state demonstrates its interest in protecting life.

Certain steps must be taken in order before permitting the removal of life support. As seen above in the Illinois criteria for removing or withholding life support, a court must be involved, which inevitably prolongs the decision making process. The Indiana Department of Child Services (DCS) “Child Welfare Manual” states that DCS staff, resource parents, guardian ad litem, and other court appointed representatives do not have the authority to make a final decision regarding the medical care of children under placement of DCS, and the final decision must be made in juvenile court.\footnote{Ind. Dept. of Child. Serv., Child Welfare Manual, 5 §14 (2009)} These state approaches not only delay a decision, they require the involvement of several parties, which illustrates the state’s second interest, collective decision making. This may be best reflected in the American political system. The essence of
America’s democracy is that no single person can make a decision affecting the welfare of others, and that the sharing of multiple perspectives is likely to lead to sounder and more well-considered decisions. Thus, there are multiple parties in the decision making process including the President, congress, the courts, the electoral college, and the people.

The same desire for collective reasoning is true in potential life or death medical decisions for minors. In Illinois, three attending physicians and the court must be involved in the removal or withholding of life support. In the case *In re Jane Doe*, described above, each parent was granted full privilege of parental rights under the Due Process clause; however, due in part to the disagreement between the two, the court remained in its traditional role of favoring life instead of intervening in family matters. Also in cases involving the removal of life support, it is common practice to appoint a guardian ad litem to represent the incapacitated patient, especially if the patient is a minor or of disability. An ad litem is a qualified surrogate who denotes the patient’s best interest in the decision making process. Their mere presence in the process speaks to the state interest in collective decision making. A guardian ad litem for a minor is not only used to support and protect the child’s interest, but also highlights the court’s desire for a “mature” substitute for the patient who is distinct from the patient’s parents.

Another example of the preference of collective decision making is the emerging presence of ethics committees in hospitals. The need for ethics committees was first recognized after two highly publicized cases, the *Cruzan* case referenced previously and in *In re Quinlan*. In *Cruzan*, the court noted that the state’s involvement in the matter was inherent because the patient was in a state hospital. However, hospitals should have a mechanism for discussing difficult ethical decisions such as the removal of life support in both public and private institutions. In *Quinlan*, the twenty-one year-old patient had collapsed in 1976 and was placed on
life support. As her parents saw no improvements over time, they moved to withdrawal life-sustaining treatment, but the hospital refused. Finally, the New Jersey Supreme Court ruled in favor of the parents. Life support was removed, and Quinlan lived nine years before dying of pneumonia. The opinion written by Chief Justice Hughes in *Quinlan* states that physicians and parents shall consult “with the hospital ‘Ethics Committee’ or like body of the institution…”37

In 1992, shortly after the conclusions of these cases, the Joint Commission mandated that health care organizations have a way to address tough ethical issues.38 The Joint Commission, formerly known as the Joint Commission on Accreditation of Healthcare Organizations, is an independent not-for-profit which accredits over 20,000 healthcare organizations nationwide.39 Accreditation shows consumers the organizations meet certain standards for high quality care, one of which is the operation of a type of ethics committee.

The Joint Commission’s mandate leaves hospitals with several options in forming an ethics board or committee. There are no standard regulations listed for its involvement in patient cases or within the hospital as a whole. The ideal purpose and use of an ethics advisory committee (EAC) were outlined by Dr. Rich Miller in his book titled “Children, Ethics, and Modern Medicine” and further discussed in an interview with the author. Dr. Miller highlights the five main functions of an EAC which are as follows:

1. **Educate:** Teach the hospital staff about moral and legal standards in hospitals, particularly those standards specific to the respective state

2. **Review:** Look over case consultations to determine if formal policy is needed for future cases

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37 *In re Quinlan*, 70 N.J. 10; 355 A.2d 647 (1976), See “Conclusion”
39 Joint Commission, About the Joint Commission (2013)
3. **Support:** Informally advise and support healthcare providers in handling moral issues when attending to families and patients

4. **Craft Policy:** To construct official hospital policies regarding the delivery of care to patients

5. **Symbol of Standards:** To act as the adhesive in ensuring the institution as a whole is committed to moral standards by being the official vehicle for ethics discussions

These five functions are ideal for full integration of the EAC within a healthcare organization. However, the reality of EAC use varies across the country. Because of the Joint Commission mandate almost all general hospitals have a type of EAC, but in a survey published in 2007, the median utilization within 500 general hospitals was three cases in the year. The median may not accurately capture the full picture regarding ethics committees operations, and the diverse cultures and technological capabilities across geographic areas may also distort the number. Miller explains the varying forms of EACs as “window dressings, firefighters, or” fully integrated unit of the hospital. Some hospitals have an EAC to meet the Joint Commission requirement and they are only there for show. Others take advantage of an EAC in order to extinguish commotion highly controversial cases when they arise. Dr. Miller’s concept of a fully integrated EAC means the committee is committed and used continuously to perform the five main functions above.

In order to more clearly understand EACs, a personal interview was conducted with Valita Fredland who is a member of an Indiana University Health ethics committee that serves University and Methodist Hospitals in Indianapolis. Logistically, Fredland’s EAC has approximately twenty-five members who volunteer their time for the committee. It meets

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40 Miller, *supra* 220-221

41 O’Reilly, ¶3
monthly to review previous consultations, and subcommittee meets twice a month. Members rotate being “on-call” for consultation twenty-four hours a day, seven days a week. She said any person in the hospital can ask for consultation with the EAC if they desire. Fredland believes her EAC is well-involved in the hospitals when it comes to make decisions and discussing cases. She explained that decisions are made case-by-case, and sometimes there is no right answer. She noted that most of the time, the EAC is used after the fact as an oversight function of the hospital, which creates an opportunity to change policies for future situations.

While EACs are not required by law but rather mandated by an accreditation organization, they are often referenced or considered in court procedures as seen in the Quinlan and Cruzan decisions. In In re Jane Doe, the Superior Court of Georgia took into consideration the hospital’s bioethics committee opinion in weighing interests. The committee found after exhaustive discussion that continuation of life-sustaining treatment would be “abusive and inhumane.” It also recommended that all extraordinary medical treatment should be discontinued, and the minor child should not be resuscitated. Notably, however, the judge did not see fit to involve court in a parental dispute, and ruled in the familiar territory of favoring life. The courts’ recognition of ethics committees creates an interdependent relationship between decision makers where each entity is given the opportunity to explain the perceived circumstances, partake in weighing values and interests, and discuss its favored decision.

The third interest of the state is to protect and promote public health and safety. This is best illustrated in the medical field by the requirement for vaccination against specific diseases. When it comes to communicable, life-threatening diseases, the interest in the common good outweighs the right of an individual. In 1905 after a severe smallpox outbreak in Boston, the

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42 Case Notes, Right to Refuse Medical Treatment: Consent of Both Parents Needed to Remove Minor’s Life-sustaining Treatment, 25 J. Health L. 190 (1992)
United States Supreme Court ruled in *Jacobson v Massachusetts* that under the police powers given to states to govern their residents and to delegate authority to public health agencies, a state could mandate compulsory vaccinations.\(^{43}\) An individual does not have the liberty to contract and transmit a disease to others because harm is inflicted on society. Additionally, the states did not physically force individuals to comply with vaccination requirements. Instead, states regulated indirectly like mandating vaccinations for entry into schools. Four qualifications for vaccinations to be compulsory are that they must be 1) of necessity such that the disease poses a threat to the subject, 2) of no undue burden to obtain financially or in regard to accessibility to the subject, 3) of the intent to avoid harm, and 4) of lesser risk to the subject than the risk of the disease itself.\(^{44}\) Other examples of potential interest in public health and safety include age laws, abortion laws, contraception access, and mental health care availability, as discussed above. If societal common good is threatened, the state may have a strong enough justification to protect the greater public health and safety.

**Concerns for the Future**

While researching the history and laws regarding the withholding or withdrawal of life-sustaining medical treatment for minors, additional questions arose that may complicate the matter in the future. The first potential concern is the rapid advancement of technology and what it means for medical care and defining life. As technology, machines and knowledge alike, progress, it is most likely that more treatments will be created, potentially more cures will be discovered, and new machines will be invented. To some, these changes will be welcomed improvements. However, with these advancements comes worry. As seen in the language of state

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statutes, a patient must have a terminal, irreversible condition which will cause imminent death. As new treatment courses emerge, how will diseases be declared terminal? Terminal essentially means the disease or condition will cause death. This thesis focused on life-sustaining medical treatments, which inherently reveals the crux of this question. When life-sustaining medical treatment is used, has it created a non-terminal condition? As established in *In re Green*, if the child’s life is not in immediate danger, the state does not necessarily have the right to intervene. Therefore, in PVS and comatose patients, when a sedated life is maintained, there is no immediate danger until the machine is unplugged. Closely related to the definition of terminal is the determination of constituting a life. When infants are born without a heartbeat or not breathing, this is deemed an emergency. Most hospitals have policies that when in an emergency, CPR and other heroic measures are attempted without the need of parental consent. This is the case of *Stewart-Graves v Vaughn et al.* Parents brought a wrongful life claim against the hospital because 24 minutes of resuscitation attempts were performed on their infant who was born without a heartbeat and survived with disabilities. The Supreme Court of Washington ruled against the parents stating that when faced with an emergency, hospital policy to engage in life-sustaining techniques is in the interest of the state to protect life.45 Key terms used such as “life-sustaining” and “protecting life” assumes that the infant, who had no heartbeat, was indeed a life. If life is not determined by the presence of a heartbeat, the ability to breathe independently, and brainstem function, what then does determine life? If medical technology had not progressed to include life-support, perhaps the persistent vegetative state of being would not exist. It is a complex system that parents and patients must go through. A patient with a terminal illness must be provided the chance to seek professional or accepted alternative medical care where the condition may be diagnosed. If the parent does not seek medical care, even if the patient has a

45 Stewart-Graves et al. v Vaughn et al., 162 Wn.2d 115; 170 P.3d 1151 (2007)
terminal condition that care will not reverse, the parents may be found criminally negligent. Once diagnosed, the patient and/or the parents must become involved in the decision making process with the physicians, the ethics committee, and the court in order to refuse or remove life-sustaining medical treatment. It appears that regardless of the path taken, when medical treatment may no longer improve or cure a patient’s life, multiple decision makers become involved.

The notion of medicine needing to improve a patient’s condition leads to the contentious quality of life concept. Discussed above regarding the *Cruzan* decision, courts have the authority to weigh the interest of an “unqualified life,” meaning the quality of the individual’s life is not considered. This statement could mean that all lives are equal, and the Born-Alive Infant Protection Act of 2002 supports that stance. However, willingly avoiding the concept altogether may complicate the decision. When an adult visits with a physician and is prescribed a drug, the follow up appoint will mostly include a discussion of how that patient feels as a result of the drug. Questions about nausea, vomiting, mood swings and pain encompass the consideration of a change in quality of life. These same questions may be asked of a minor patient. If the doctor-patient relationship weighs the value of quality of life, why is it then removed in the courtroom? One answer may be that quality of life is entirely subjective to an individual. When a patient is incapacitated and physically cannot express his or her own perspective, omitting the discussion may be fairer. However, when a patient is capable of verbalizing his or her own discomfort or change in quality of life, in the case of a functioning child, it may then be disqualified based on age and the fact that children are incompetent under the law.

The impact on the population as a whole of not withholding or withdrawing medical care is another concern that emerges. Attempting to sustain all forms of life puts pressure on
resources that may eventually wear thin. Quantitatively, the population of the United States continues to grow; people live longer, and more infants, who may have died if born twenty years ago, are now living into adulthood. As the population increases, the amount of resources available to each person decreases. Additionally, if the population of dependent persons increases, there may be worry about the livelihood and productivity of the country. While this does not mean some people are not valued enough to live, the concern exists. If more people are living, and more of those people need some degree of care from others, at some point in the future the strain may be too much for the economy to bear. The financial impact of costly medical care could lead to a decrease in spending in other areas of the economy. This inevitably raises the question for policymakers: is it in the country’s best interest to protect all forms of life at all costs?

**Discussion**

The diversity of values and interests in each of the three major decision makers creates a complex system of rights, authority, and checks on power. When the patient is a child, no single person involved in the matter has the absolute authority to make a decision, even if the mature minor rule is applied because the court must adjudge the minor as mature. The varying degree of involvement of the patient, parent(s), physicians, hospitals, ethics committees, courts, and legislators results in an overwhelming amount of individual interests for consideration in a final decision.

Beyond the evident complexity of the situations presented in these decisions, three major themes are worth noting. Historically, and arguably successfully, these kinds of difficult situations are determined on a case-by-case basis. Broad-reaching federal legislation is not always successful. For instance, research conducted in 2005 in California on BAIPA showed that
more than half of neonatologists surveyed had never heard of the legislation, and only six percent of the total believed the medical screening requirement of the legislation, previously mentioned, should be enforced.\textsuperscript{46} In 1986, the United State Supreme Court affirmed the United States Court of Appeals for the Second Circuit in the case \textit{Bowen v American Hospital Association et al.} Bowen, Secretary of Health and Human Services at the time, had established requirements of expedited notifications and files as well as the involvement of state child protective service (CPS) agencies in the medical care of children, particularly infants, with disabilities. CPS agencies were instructed to prevent unlawful medical negligence toward infants with disabilities. These regulations stem directly from the Baby Doe case, and the Supreme Court affirmed they were invalid, as there was not clear and convincing evidence of a need for federal involvement in a traditionally state matter.\textsuperscript{47} As discussed previously, decisions surrounding the health and welfare of their residents are generally state affairs. Taken together, the police powers and the Due Process clause have meant that medical decisions regarding the life and death of children are to be handled by the state and the parents. This thesis only addresses general trends in value seen in case law. Each case is unique with different values each with relative weights. Thus, it is logical to continue in the tradition and address these decisions on an individual case basis.

Ethics committees can play an integral intermediary role in the decision making process and help weigh the interests. As a neutral advisor without loyalty to any one party involved, the EAC has the opportunity to understand the situation in its entirety and without bias. However, the EAC must be recognized and utilized appropriately within the healthcare organization to realize its potential. EAC flexibility can be advantageous to small organizations because the EAC can take the shape well suited for that community. One disadvantage discussed with both

\textsuperscript{46} Partridge, \textit{supra} 1088
\textsuperscript{47} Bowen \textit{v} American Hospital Association. 476 U.S. 610; 106 S. Ct. 2101; 90 L. Ed. 2d 584 (1986)
Dr. Miller and Fredland is member qualifications. A majority of EAC members are volunteers, and they may have no background in ethics or medicine. There is no way to determine if the people on the committee are “good people” in the sense that they themselves are ethical and morally conscious individuals. There is a potential for unqualified individuals with biases or political agendas to enter the discussion. One problem Fredland witnessed was the inclusion of doctors in EACs because instead of looking at the ethical issues, the physicians simply create different treatment plans. She said one of the first rules of participating on the EAC is to trust the medical team. Further development of EACs could greatly benefit the decision makers and serve the state’s interest in collective decision making.

The third, more subtle, theme is the determination of ability within children. It is clearly stated that minors are incompetent under the law. However, the acceptance of that fact may be changing. The inclusion of a form of a mature minor rule in states shows that perception of maturity may be different now. Various research and studies can point to different ways to measure maturity as previously discussed. However, validation of this research in the courtroom is not standardized. The Rule of Sevens is a common age-based tool for determining a child’s ability, in this case the ability to form criminal intent. Forming criminal intent may not be synonymous with maturity, but it does involve a recognition of the harmful impact of one’s actions, if courts recognize the ability for a fourteen year-old child to be legally capable and responsible for making the decision to commit a crime, it may be worth comparing the ability to make other large impact decisions, such as refusing treatment. Fourteen year-olds cannot be sentenced to death or life in prison without the chance of parole because the court recognizes that fourteen year-olds may not be fully developed and may change as that development continues. This balance of recognizing one’s ability but not making it a definitive rule should be mirrored in
medical decision making for children by allowing a maturity evaluation without definitive, and potentially constrictive, checklist of requirements to determine maturity.

**Recommendations**

As a result of the research conducted, five recommendations are made:

1. Determination of medical care for children should continue to be decided case-by-case by judges who familiarize themselves with the exact circumstances of each case and can sincerely weigh the unique factors respective to each case.

2. All states should require a mature minor evaluation of patients ages fourteen and older.

3. Ethics committees should be treated and act as an ethical oversight and advisory department within healthcare organizations.

4. Ethics committees for hospitals and other healthcare organizations should be required to educate parents, patients, and staff on the state codes involving life-sustaining medical treatment as well as the organization’s ethical standards and policies.

5. Further research on the development of adolescents and the performance indicators of a maturity should be conducted by entities such as the Department for Health and Human Services or state health departments and presented to courts, policymakers, and additional applicable agencies for use in deciding specific cases and creating regulations and laws.
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