MINORS’ RIGHTS TO CONSENT TO TREATMENT:
NAVIGATING THE COMPLEXITY OF STATE LAWS

David M. Vukadinovich

Copyright © 2004 by American Health Lawyers Association; David M. Vukadinovich

In 1914, Justice Benjamin Cardozo wrote that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.” Most states’ laws recognize that proposition and reflect it in statutes and case law governing consent to medical treatment. While the law is clear with regard to the right of competent adults to consent to or refuse medical treatment, state statutes generally are more complicated when the patient is a minor. While the law should, and does, attempt to balance the rights and obligations of parents and guardians against the privacy rights of minors, complicated state statutory schemes often fail to simultaneously address confidentiality concerns, public policy, and public health goals in a consistent and uniform manner. The result is a confusing set of seemingly arbitrary and sometimes conflicting provisions that require the detailed attention of healthcare providers to ensure legal compliance. Consequently, the interaction between the healthcare system and minor patients is often difficult because the healthcare provider may not understand when a minor patient may lawfully consent to treatment without the involvement of the minor’s parent or guardian. Providers and their counsel need to understand the statutory schemes governing treatment of minors to ensure that minor patients receive the best care possible, as well as to ensure legal compliance and protect against potential liability.

Legal compliance is important because failure to obtain effective informed consent may give rise to a cause of action for battery based on the healthcare provider’s intentional and unconsented touching of the patient. Additionally, failure to obtain effective informed consent may breach the fiduciary duty that a physician owes to her patient and give rise to a malpractice action. Thus, healthcare providers who fail to abide by applicable consent laws face potential civil liability…

I. General Legal and Public Policy Background

As recognized by Justice Cardozo, competent adults have the right to consent to or refuse medical treatment. That same right does not extend to minors, who generally are not considered mature enough to make informed healthcare decisions without the involvement of an adult. In most states, a

---

1 Schloendorff v. Soc’y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914), overruled on other grounds.

---
“minor” is any person under eighteen years of age. Absent an applicable exception, a healthcare provider may only provide medical treatment to a minor with the informed consent of the minor’s parent, guardian, or other lawfully authorized third party.

II. The Authority to Consent to Medical Services

A. Consent Authority of Parents, Guardians, and Other Authorized Adults

Generally, a minor does not have authority to consent to medical treatment and a healthcare provider must obtain the informed consent of an adult who is authorized under state law to act on behalf of the minor for purposes of making healthcare decisions. Such authorized persons include the minor’s natural or adoptive parent, a legal guardian, foster parent, or other authorized caregiver. In exceptional cases, a court may consent to medical treatment on behalf of a minor.

1. Natural or Adoptive Parents

For purposes of consent law, a minor’s “parent” means “either parent if both parents have legal custody, or the parent or person having legal custody” Absent a court order to the contrary, either natural parent may consent to medical treatment on behalf of a minor child. That general rule applies regardless of whether the child’s natural parents are married or divorced and whether the child is born in or out of wedlock. Individuals who have legally adopted a child have the same consent rights as natural parents.

—

10 According to the Center for Health and Health Care in Schools, all states except Alabama, Nebraska, and Pennsylvania recognize eighteen as the age of majority for purposes of consenting to medical treatment. See Heather Boonstra & Elizabeth Nash, Minors and the Right to Consent to Health Care, THE GUTTMACHER REPORT ON PUBLIC POLICY, Aug. 2000, at 7, available at www.healthinschools.org/sbhcs/papers/guttmacher.asp (last visited Sept. 5, 2004). In Alabama and Nebraska, the age of majority is nineteen and in Pennsylvania it is twenty-one. Id.

11 See, e.g., DEL. CODE ANN. tit. 13 § 707(b) (2003).


13 See, e.g., MD. CODE ANN., FAM. LAW § 5-203(b).

14 See CAL. FAM. CODE § 7602. A court may award sole legal custody to one parent. See id. § 3006. In the case of a minor born out of wedlock, it may be difficult to prove paternity. If a healthcare provider has any doubt, the provider should ask for documentation, which may include a copy of the minor’s birth certificate that includes the father’s name.


One area in which there is often confusion concerns the consent rights of stepparents. Unless a stepparent legally adopts a child, the stepparent does not, by virtue of marrying the child’s natural parent, have any legal authority to consent to treatment on behalf of the child. While potential liability may be minimal when a healthcare provider renders routine treatment pursuant to the invalid consent of a stepparent, a provider should exercise diligence to ensure the authority of a stepparent when rendering higher-risk treatment. A stepparent may gain lawful consent authority either through legally adopting a child or through designation as an authorized caregiver…
A healthcare provider may render treatment pursuant to the consent of either parent, and the provider does not need to seek the consent of both parents. In some cases, however, a minor’s parents disagree as to the proper treatment for their child. Such disagreements often arise when the parents are divorced, separated, or otherwise acrimonious towards one another or when the suggested treatment is controversial. While both parents may have genuine concern for their child’s wellbeing, their failure to agree on a medically appropriate course of treatment places the healthcare provider in a legally difficult situation. For example, parents may disagree with regard to cochlear implants for a deaf child or to similar controversial procedures that may or may not be in the child’s best interest. While a healthcare provider who is aware of such a disagreement may lawfully proceed on the consent of either parent, a cautious approach requires that, in the absence of an urgent or emergent condition, the provider abstain from treatment until the parents come to agreement or, in extreme cases, one of the parents obtains a court order.

2. Guardians

Where a court has appointed a guardian for a minor, the ability of the guardian to consent to medical treatment depends on the scope of authority granted by the court and the type of treatment sought. While a guardian may consent to ordinary medical care, a guardian may be statutorily precluded from consenting to nonroutine treatment. For example, California law provides that a guardian may not consent on behalf of a minor to placement in an inpatient mental health treatment facility, the administration of experimental drugs, convulsive treatment, elective sterilization, or psychosurgery. Additionally, a guardian may not consent to surgery on a minor age fourteen or older without the additional consent of the minor or a court order.

When a healthcare provider renders treatment other than routine care to a minor under guardianship, the provider should document the authority of the guardian to give consent by obtaining a copy of the official certified letters of guardianship. The guardian should be able to produce the letters of guardianship without undue burden. If the guardian is unable to produce the letters of guardianship, the provider should contact the juvenile court to confirm the guardian’s scope of authority.

3. Foster Parents

Licensed foster parents may consent to routine medical and dental treatment for minors placed with them pursuant to a court order or with the voluntary consent of the person having legal custody of the minor. For other than routine care, a foster parent, or the healthcare provider who is called on to render services, should consult the juvenile court to determine whether the foster parent has authority to give consent. Nonroutine care may include non-emergent surgeries, elective procedures, and controversial or experimental treatments.

---

18 CAL. PROB. CODE § 2356 (2000).
19 CAL. PROB. CODE § 2353(b) (2004).
20 See, e.g., CAL. HEALTH & SAFETY CODE § 1530.6 (2004); N.J. STAT. ANN. § 30:4C-26.16(a).
A healthcare provider should document the authority of a foster parent to give consent to medical treatment by obtaining a copy of the court order placing the minor in foster care. In most cases, the foster parent should either have or be able to obtain a copy of the court order without undue burden.

4. Authorized Caregivers

Adult, nonparent caregivers with whom a minor lives may also give consent to medical treatment for a minor. This statutory device is useful when a child’s parents are absent or deceased and the caregiver has not legally adopted the minor. For example, the situation often arises when a minor lives with his or her grandparents, or other relative, even though the minor’s parents have not relinquished legal custody.

To qualify as an authorized caregiver, many states, including California and Delaware, require the adult caring for the minor to complete a Caregiver’s Authorization Affidavit (Affidavit) or similar document. The Affidavit has two functions. First, it may be used by an adult caregiver with whom the minor lives to consent to medical treatment necessary to enroll the minor in school. Second, the Affidavit may be used to allow an adult caregiver who is a “qualified relative” of the minor and whom the minor lives to consent to any necessary medical treatment on behalf of the minor.

A healthcare provider who relies on an Affidavit has no obligation to make any further inquiries or to investigate the truthfulness of statements contained in the Affidavit. Additionally, any person who acts in good-faith reliance on an Affidavit to provide medical or dental care, without actual knowledge of facts contrary to those stated in the Affidavit, cannot be subject to criminal or civil liability or professional disciplinary action for such reliance.

5. Third-Party Authorization

A third party who is not an authorized caregiver may consent to medical treatment of a minor pursuant to the written authorization of the parent or guardian. To be valid, the authorization must be in writing and executed by the parent or guardian.

__________

21 CAL. FAM. CODE § 6550 (2004); see also TEX. FAM. CODE ANN. § 32.001(a) (2004) (authorizing a minor’s grandparent, adult sibling, or adult aunt or uncle to consent if the parent is not available).
23 For purposes of California’s authorized caregiver provisions, a “relative” is any one of the following: “spouse, parent, stepparent, brother, sister, stepbrother, stepsister, half brother, half sister, uncle, aunt, niece, nephew, first cousin, or any person denoted by the prefix “grand” or “great,” or the spouse of such person even after the marriage has been terminated by death or dissolution.” CAL. FAM. CODE § 6550(i)(2); see also DEL. CODE ANN. tit. 13 § 707(a)(3).
29 CAL. FAM. CODE § 6552.
30 Id.
32 California law provides that caregivers who are relatives may also authorize care if qualified under Section 6550. However, foster parents do not have statutory authority to execute a third party authorization. See CAL. FAM. CODE § 6910.
Third-party authorizations are most commonly used when a child stays with a friend or relative for a short time. For example, parents may leave their child with a friend or neighbor for a day or two and provide the friend with a note that allows the friend to consent to necessary medical treatment while the parent is away. Alternatively, a third-party authorization can be used by a parent to allow another adult to take the child to a physician’s appointment by providing written authorization applicable to that specific encounter. For example, a parent may write a note authorizing a friend to take a sick child to the doctor at a time when the parent is unable to attend the appointment.

Healthcare providers should rely on third-party authorizations only to provide routine medical treatment. Additionally, while not required by law, a provider should attempt to contact the parent or guardian prior to rendering non-emergent treatment pursuant to a written authorization if the written authorization is not specific to the encounter. The provider should document her contact attempts and, if applicable, document that the parent provided consent over the telephone. Of course, if the parent or guardian objects to treatment, the provider should abstain from providing any non-emergent services until the consent of the parent or guardian is obtained.33

…

33 Consent is presumed if the minor requires emergency medical services. See, e.g., MASS. GEN. LAWS ch. 112, § 12F (2004).
REID, Associate Judge:

This poignant matter involves a “do not resuscitate” order (“the DNR”) entered by the Superior Court of the District of Columbia in the case of a neglected child, K.I., who, since birth approximately two years ago, has suffered continuously from several serious medical problems. Currently the child is in a comatose state and has been described as “neurologically devastated…”

Both B.I., K.I.’s biological mother, and D.M., K.I.’s putative father, noted appeals from the trial court’s judgment. B.I. contends that … as a parent, she has the right to decide that K.I. should be resuscitated, and thus, the court erred by applying the best interests of the child standard, instead of the substituted judgment test (which would have allowed her to be the surrogate for the child), in deciding whether to issue the DNR… D.M., contrary to the position of B.I., supports the DNR but also complains that the trial court should have recognized his alleged right to parental privacy and parental autonomy.

We affirm because we conclude that (1) the trial court properly exercised its parens patriae authority in a case involving a prior neglect adjudication, and did not err in deciding to apply the best interests of the child rather than the substituted judgment standard; nor did it abuse its discretion in determining that issuance of the DNR was in the best interests of K.I.; (2) the trial court in fact based its judgment on the clear and convincing evidentiary standard; and (3) D.M. failed to assert any parental rights in the trial court to which he may be entitled; however, any such rights have not been terminated.

The record before us shows the following facts. On June 15, 1997, K.I. was born prematurely at twenty-six weeks gestation. K.I.’s treating physician at the Hospital for Sick Children, Dr. Glenn Hornstein, who testified at the DNR hearing, stated that as a result of the premature birth, K.I. “developed BPD; or broncho pulmonary dysplasia,” an abnormal condition of the lung cells which requires the child to use oxygen. In addition, K.I. suffered from “hemoglobin SC disease, which is similar [to] or it is sickle cell disease, just a mild variance”; “reactive airways disease,” characterized by wheezing; and “gastro-esophageal refl[u]x.”

K.I. was released from the neonatal intensive care unit of the hospital in November 1997 to the biological mother, B.I. Beginning on November 24, 1997, for a period of five weeks, B.I. and K.I. stayed in an apartment in the Northwest sector of the District of Columbia with D.M., K.I.’s putative father who claims to be K.I.’s biological father. K.I. was required to wear a heart monitor and an apnea monitor, take medication for the lungs, and use oxygen continuously. D.M. became concerned when B.I. would take K.I. off the oxygen and heart monitor and fail to give the child the lung medication. He also was troubled when he saw B.I. consume about three “40–ounce … very strong beer[s]” every day. He stated, at the August 26, 1998 neglect proceeding, that B.I. became intoxicated and would “start stumbling and falling and get very silent and have a nasty attitude.” B.I. would “leave the house and leave [D.M.] there with the baby and come back a day later or two days later.” On December 28, 1997, B.I. left D.M.’s home. She carried K.I. with her but failed to take the oxygen. D.M. alerted Howard University that K.I. was without her oxygen.

---

1 Ed. Note. Parens patriae authority refers to the state’s duty to intervene to protect citizens who cannot protect themselves—such as children.
On December 29, 1997, in response to D.M.’s alert, Edmond Lahai, then an employee of the District of Columbia Department of Human Services, Children and Family Services Administration, searched for B.I. and K.I. When he located B.I., she initially denied that K.I. was with her. Mr. Lahai found two Metropolitan Police officers, and when he returned with the police to the abode where B.I. was staying, she admitted that K.I. was with her. K.I. had no oxygen and no monitors.

A neglect petition was filed against B.I. on December 31, 1997. The petition alleged that B.I. failed to: (1) provide K.I. with the requisite medical care; (2) schedule appointments for K.I., and (3) use K.I.’s monitoring devices or tube feeding procedure. Mr. Lahai testified, at the hearing on the neglect petition, that when he saw B.I. on December 29, 1997, she “slurred ... her speech, ... was incoherent[,] would not walk straight and ... had a strong smell of alcohol...” [The court found that K.I. was a neglected child].

On December 29, 1997, Mr. Lahai took K.I. to Howard University Hospital. Later, K.I. was transferred to the Hospital for Sick Children. When K.I. began to experience respiratory distress at the Hospital for Sick Children and her condition worsened, Dr. Hornstein transferred the child to Children’s Hospital on July 21, 1998. On that same day, K.I. went into cardiac arrest and suffered hypoxia, which involves “a deprivation of oxygen to the cells and to the brain.” Resuscitation efforts lasted for approximately twenty-five minutes. After the resuscitation efforts ceased, K.I.’s heart began to function again. However, the following day she experienced a seven-hour seizure which terminated only after the administration of “phenobarbital medication which ... put K.I. into a pentobarb-like coma ... to control the seizure.”

On August 22, 1998, K.I. was returned to the Hospital for Sick Children, where she continued to experience severe medical problems. At the DNR hearing, Dr. Hornstein described the child’s current condition—no “purposeful movements,” persistent “myochronic jerks” [involving] “shaking of [the] arms and legs.” In addition, according to Dr. Hornstein, K.I. “withdraws to pain or ... feels discomfort when people do interventions such as ... when [he] attempted to place [an] IV in [K.I.’s] ... hand, [K.I.] actually was grimacing and sort of writhing and moving around as if in discomfort.”

Due to K.I.’s persistent medical problems, the trial court “held a hearing to determine the propriety of aggressive resuscitation efforts in the event that [K.I.] suffered pulmonary or respiratory arrest.” Several persons testified, including experts in pediatric critical care, bioethics, and ethics as well as B.I. and D.M. B.I. opposed the DNR, asserting her right as a parent to make any decision concerning the nature of resuscitation efforts. D.M. agreed with the issuance of the DNR. The testimony taken at the DNR hearing is described in the attached copy of the trial court’s memorandum opinion and order. Suffice it to say here that according to the trial court’s memorandum opinion, signed on October 16, 1998, Dr. Gabriel Jacob Hauser, a professor of bioethics at Georgetown University, the Chief of Pediatric Critical Care Service at the Georgetown University Hospital, and the former chair of the hospital’s ethics committee, testified that: “While [K.I.] is capable of feeling pain and discomfort, [the child] responds to no other stimuli; ... is unable to react to [the] environment, cannot contemplate events taking place [in close proximity], and is incapable of giving or receiving love.” Furthermore, “the possible resuscitation efforts that would be used on [K.I.] in the event of cardiac arrest or respiratory failure, assuming no DNR order is in place.... [w]ould entail substantial amounts of pain and discomfort.”

The trial court concluded that because of its jurisdiction over a neglected child and its role as parens patriae, it had the authority to determine whether to issue the DNR, but that:

[T]he issuance of a DNR order must be predicated upon a finding by clear and convincing evidence both that it is in [K.I.’s] best interests to forego aggressive revival measures, and that [B.I.’s] refusal to consent to the issuance of the DNR order is unreasonably contrary to [K.I.’s] well-being.
In addition, the court determined that the best interests of the child rather than the substituted judgment standard applied “in cases involving minor respondents who have lacked, and will forever lack, the ability to express a preference regarding their course of medical treatment.” Under the best interests of the child standard, the court was “satisfied by clear and convincing evidence, that upon balancing the burdens of continued life against the benefits and rewards of furthering life, [K.I.’s] best interests would be served by issuing a DNR order…” Moreover, in light of the expert testimony provided at the DNR hearing, B.I.’s “sporadic history of attending to [K.I.’s] medical needs, and [B.I.’s] statements made to [the trial] court regarding her desire to keep [K.I.] alive at all costs,” the trial court found B.I.’s “refusal to consent to the entry of [the DNR to be] both unreasonable and contrary to [K.I.’s] best interests.”

ANALYSIS

B.I. argues that, as a parent, she has the right to determine whether, and in what manner, K.I. should be resuscitated, and thus, the court erred by applying the best interests of the child instead of the substituted judgment standard in deciding whether to issue the DNR… D.M. asserts that the DNR should be upheld but “with reservation of parental rights of determination vested in the father, with the Court as arbiter only of parental differences of opinion and with the suggested ethics committee guidelines and mechanisms…”

The Jurisdictional Issue

We turn first to the issue of the trial court’s jurisdiction over this matter. We conclude that the trial court properly exercised jurisdiction over this matter because of the adjudication of K.I. as a neglected child; the trial court’s role as parens patriae; the disagreement of the biological mother, B.I., and the putative father, D.M., as to whether K.I. should be resuscitated in the event of cardiac arrest or respiratory distress; the serious medical condition of K.I.; and the best interests of the child concept.

The Family Division of the Superior Court (“the Division”) has jurisdiction over cases pertaining to neglected children… There is substantial evidence in the record showing that while K.I. was under the care of B.I., B.I. frequently consumed alcohol, took away K.I.’s required oxygen and monitors for apnea and the heart, and failed to provide adequate care for the child; thus, K.I. was properly adjudicated a neglected child.

Given the lack of appropriate attention and care by B.I., the trial court assumed its role as parens patriae “to promote [K.I.’s] best interest,” … and to provide necessary relief… The court’s exercise of its discretion as parens patriae was essential since the District government took no position on the resuscitation issue and because B.I. and D.M. had a fundamental disagreement concerning resuscitation—D.M. supported the need for the DNR, while B.I. opposed the DNR and favored the use of a variety of medical techniques, “including intubation, defibrillation (shock with electric paddles), and interosseous efforts at introducing medication into [K.I.’s] system” in an effort to reverse any cardiac arrest or respiratory distress. B.I.’s goal is to keep K.I. “breathing…”

Although biological parents have a “fundamental liberty interest ... in the care, custody, and management of their child [which] does not evaporate simply because they have not been model parents or have lost temporary custody of their child to the State[,]” Santosky v. Kramer, 455 U.S. 745, 753, 102 S.Ct. 1388, 71 L.Ed.2d 599 (1982)... that interest is not absolute since “[t]he paramount concern is the child’s welfare and all other considerations, including the rights of a parent to a child, must yield to its best interests and well-being.” Davis v. Jurney, 145 A.2d 846, 849 (D.C.1958)… Although B.I. clearly has a liberty interest “in the care, custody and management of [K.I.],” K.I.’s well-being takes precedence over B.I.’s parental rights...

In short, the trial court did not err in exercising jurisdiction over the DNR issue rather than yielding to
B.I.’s wishes as a parent.

The Substituted Judgment Versus the Best Interests of the Child Standard

B.I. insists that, after the trial court decided to exercise jurisdiction over the DNR matter, the court should have applied the substituted judgment rather than the best interests of the child standard in determining whether to issue the DNR…

Historically, the substituted judgment standard arose in estate cases involving incompetent persons, and generally has been invoked in cases of adults who at one time were competent but later became incompetent... In applying the doctrine, “[t]he court, as surrogate for the incompetent, is to determine as best it can what choice [the] individual, if competent, would make with respect to medical procedures.” “[T]he substituted judgment inquiry is primarily a subjective one,” and … we set forth factors to be followed in ascertaining the decision that the incompetent person would make. These factors include giving “the greatest weight ... to the previously expressed wishes of the patient.”

“The [substituted judgment] doctrine has been helpful in the case of adults, but it is difficult to apply to children or young adults…” Moreover, unlike K.I.’s situation, in one of the cases cited by B.I. which involved a minor, there was no neglect adjudication, and both parents agreed to petition the court for approval to remove life support systems. In the other case regarding a child, Custody of a Minor, 385 Mass. 697, 434 N.E.2d 601 (1982), the court took into consideration the best interests of the child in reaching its conclusion…

To attempt to apply the substituted judgment test in this case where B.I. and D.M. disagree; where K.I., a child born in June 1997, has never been healthy; has issued no oral or written directives as to medical matters or formed any opinions about anything, let alone a value system; not only would be impossible, but also would violate the spirit of the substituted judgment standard, the purpose of which is to implement the wishes of the incompetent individual. Consequently, we hold, consistent with the trial court’s memorandum opinion, that “in cases involving minor respondents who have lacked, and will forever lack, the ability to express a preference regarding their course of medical treatment,” and where the parents do not speak with the same voice but disagree as to the proper course of action, the best interests of the child standard shall be applied to determine whether to issue a DNR.

…
HALLER, J.

As a result of devastating brain injuries allegedly inflicted nonaccidentally on 11–month–old Cyrus N., the San Diego County Health and Human Services Agency (Agency) filed dependency petitions in the juvenile court on behalf of Cyrus and his two-year-old sister, Jenna N. After the detention hearing, but before Cyrus was adjudged a dependent of the court, the medical professionals treating Cyrus recommended the court authorize removal of his temporary breathing tube and issue a “Do Not Attempt Resuscitation” (DNAR) order in the event Cyrus was unable to breathe on his own. Following a noticed hearing, and over the objections of Cyrus’s parents, the court issued both orders.

We conclude the court had the authority to issue an order permitting removal of the breathing tube because a dependency petition had been filed, the evidence showed the treatment was medically necessary and the court properly balanced Cyrus’s interests against those of his parents. However, we further conclude the court had no authority to issue a DNAR order because Cyrus had not been adjudged a dependent and the court had not conducted a full evidentiary hearing at which it made findings by clear and convincing evidence. Absent true findings made at a jurisdiction hearing, the court’s authority was limited to ordering medical care that would sustain or improve Cyrus’s condition and did not extend to decisions to withdraw or withhold life sustaining medical treatment.

***

Cyrus is the son of C.C. and J.N. (together the parents). On September 16, 2007, Cyrus was taken to the hospital following a massive head injury. He was immediately intubated and then transported by ambulance to Children’s Hospital. Medical tests showed Cyrus had an extensive subdural hematoma covering the entire left hemisphere of his brain, retinal and vitreous hemorrhages in both eyes, but no skull fracture or impact site. The treating physicians determined Cyrus’s injuries were highly suspicious for nonaccidental trauma, and were consistent with shaken baby syndrome. The injuries were inconsistent with C.C.’s explanation that Cyrus had fallen from the bathroom sink and hit his head on the linoleum floor. Cyrus remains in a coma and on life support.

Although the parents were informed Cyrus’s brain injuries were life-threatening, they arrived at Children’s Hospital between one and two hours after Cyrus arrived by ambulance, saying they got lost. When National City police detectives took C.C. home for an interview and reenactment of the incident later that day, they noticed the apartment smelled strongly of cleaning solution and appeared to have just been cleaned. The police arrested C.C. on charges of felony child abuse. J.N., who was at work when Cyrus’s injuries occurred, refuses to believe C.C. caused Cyrus’s injuries. J.N. posted bail for C.C. and she has returned to the family home. The district attorney has filed felony child abuse charges against C.C.

On September 19, 2007, Agency filed a petition in the juvenile court alleging C.C. inflicted severe

---

1 Ed. Note. A child is adjudged dependent if a court determines that the child has been has been abused, neglected, or abandoned or has no parent or guardian able or willing to provide adequate care. A dependency case is another term for a child protective case.

2 Ed. Note. A dependency petition generally alleges that the child has been abused, neglected, or abandoned.
physical abuse on Cyrus. At a detention hearing, the court found a prima facie showing had been made, detained Cyrus in out-of-home placement, and set a jurisdiction and disposition hearing for October 10, 2007.

On September 28, 2007, a hospital bioethics consultation team, consisting of a doctor, nurse and social worker, met with the parents regarding Cyrus’s medical treatment plan. The consultation report noted Cyrus was “neurologically devastated with no reasonable hope of returning to normal or his previous level of functioning.” The team reported Cyrus’s “existence has become a biological/organic one, not a biographical one, in that he lacks current and projected social (interpersonal relationships) and intellectual life (consciousness and interaction) spheres of living.” In the team’s opinion, curative options had been exhausted and further medical treatment offered no benefit to Cyrus other than sustaining his organic life. The team recommended against life-sustaining medical treatment, which would require frequent and invasive procedures for the rest of Cyrus’s life. The parents, however, want ongoing life-support efforts for Cyrus because they hope “he may survive on his own and have a miraculous recovery.” The team recommended appointment of a guardian ad litem for medical decisions (medical guardian) based on the parents’ potential conflict of interest and their inability to make decisions in Cyrus’s best interests.

At the request of counsel appointed for Cyrus in the dependency proceeding, the court heard argument on the appointment of a medical guardian. The parents received notice of the hearing and were present with counsel. The court denied J.N.’s request for a contested hearing, suspended the parents’ rights to make medical decisions for Cyrus and directed a medical guardian be appointed.

On October 10, 2007, the date set for the jurisdiction and disposition hearing, the court entertained the medical guardian’s requests for an order to remove Cyrus’s breathing tube and issuance of a DNAR directive. The evidence before the court consisted of the medical guardian’s report, her points and authorities supporting her requests for the court’s orders, the hospital bioethics consultation report and several medical reports, including results of a recent brain scan. The medical guardian stated Cyrus’s brain function continues to deteriorate. She explained Cyrus’s doctors recommend removing his temporary breathing tube because of the physical discomfort and risk of infection from having the tube remain in place. She further reported Cyrus had been medically ready for removal of the temporary breathing tube for more than two weeks, and the doctors believed there is a very high likelihood Cyrus will breathe independently if extubated. However, because there is a possibility Cyrus will not breathe independently, the doctors will not remove the breathing tube without a medical directive regarding resuscitation efforts. Consequently, the medical guardian argued, it was in Cyrus’s best interests for the court to authorize a DNAR order in conjunction with removal of the breathing tube. Cyrus’s counsel and Agency agreed with the medical guardian’s position. The parents, who were present with counsel, opposed the requests without submitting any evidence. They argued the court could not make the requested orders because Cyrus had not yet been adjudged a dependent.

After considering the documentary evidence presented and hearing argument of counsel, the court granted the medical guardian’s requests for an order allowing extubation and a DNAR directive. It found an order allowing extubation was medically necessary and in Cyrus’s best interests and further found a DNAR

---

3 Ed. Note. A detention hearing is held anytime a child is removed (“detained”) from the home to determine whether out-of-home placement is necessary pending the jurisdiction hearing (described below).

4 Ed. Note. A jurisdiction hearing is held to determine whether the allegations in the dependency petition are true. If the allegations are proven, the court acquires authority over the minor and then conducts a disposition hearing to determine what to do with the child—whether to return the child to the parents’ care or make decisions on the child’s behalf.
directive was in Cyrus’s best interests. The court set an evidentiary hearing for October 15 to address any further medical issues, including the status of Cyrus’s medical condition following extubation and whether to continue the DNAR order…

J.N. filed a writ petition, arguing: (1) the court had no authority to suspend his right to make medical decisions for Cyrus until Cyrus was declared a dependent; (2) due process entitled him to an evidentiary hearing before the court appointed a medical guardian for Cyrus; and (3) he was entitled to adequate time to review the medical guardian’s requests and to an evidentiary hearing before the court issued its orders. We issued a stay of the orders authorizing removal of the breathing tube and issuance of a DNAR directive, and requested responses from the parties…

I. The Juvenile Court Had No Authority to Issue an Order to Withhold or Withdraw Life–Sustaining Medical Treatment for Cyrus

In In re Christopher I. (2003) 106 Cal.App.4th 533, 548, 131 Cal.Rptr.2d 122 (Christopher I.), the court addressed the appropriate “standards to apply when deciding whether to withhold or withdraw life-sustaining medical treatment from a child who is a dependent of the juvenile court.” In that case, the juvenile court had declared Christopher a dependent and had removed him from parental custody based on findings he sustained severe physical injuries inflicted nonaccidentally by his father, and his mother failed to protect him… As a result of his injuries, Christopher was neurologically devastated and in a persistent vegetative condition with no cognitive function and no hope for any meaningful recovery. His life was sustained by a ventilator and a gastrointestinal tube… Christopher’s mother, over his father’s objections, sought authorization for a “Do Not Resuscitate” order and withdrawal of Christopher’s life-sustaining medical treatment. Following a contested evidentiary hearing, the juvenile court found by clear and convincing evidence it was in Christopher’s best interests to remove him from the ventilator.

On appeal, the court discussed the juvenile court’s authority to consider and rule on withdrawal of Christopher’s life-sustaining medical treatment, and concluded such authority derived from section 362, subdivision (a): “ ‘When a child is adjudged a dependent child of the court… the court may make any and all reasonable orders for the care, supervision, custody, conduct, maintenance, and support of the child, including medical treatment, subject to further order of the court.’” The court held the juvenile court’s statutory authority allowing it “to make decisions regarding medical treatment for dependent children within its jurisdiction necessarily includes decisions to refuse or withdraw medical treatment, including life-sustaining medical treatment.” The court reviewed other relevant provisions of the Welfare and Institutions Code and noted no statute restricts the juvenile court’s authority to make all reasonable orders relating to medical treatment once a child has been declared a dependent… We are in full agreement with the holding in Christopher I.

A. The Juvenile Court’s Authority to Order Necessary Medical Care for Cyrus Before a Declaration of Dependency Is Controlled by Section 369, Subdivision (b)

Unlike the minor in Christopher I., Cyrus has not been adjudged a dependent child … and there have not yet been findings based on evidence at a jurisdiction hearing that Cyrus suffered serious physical harm nonaccidentally inflicted by C.C. Thus, section 362, subdivision (a) does not control as it did in Christopher I. Rather, the controlling statute is section 369, subdivision (b), which allows the court to intervene when a minor, who has not yet been declared a dependent, is in need of medical treatment and there is no parent capable or willing to authorize that treatment. Section 369, subdivision (b) provides:

“Whenever it appears to the juvenile court that any person concerning whom a petition has been filed with the court is in need of medical, surgical ... or other remedial care, and that there is no parent ... capable of authorizing or willing to authorize the remedial care
or treatment for that person, the court, upon the written recommendation of a licensed
physician and surgeon ... and after due notice to the parent ... may make an order
authorizing the performance of the necessary medical, surgical ... or other remedial care
for that person.”

Agency, minor’s counsel and the medical guardian argue that once a dependency petition has been filed
on behalf of a minor, section 369, subdivision (b) gives the juvenile court authority to make all medical
decisions on a minor’s behalf, even DNAR directives. We disagree.

The clear import of section 369, subdivision (b) is to permit medical decisions to be made for a minor
upon the filing of a dependency petition. It recognizes the practical need to allow the court to make
decisions that are in the minor’s best interests, and is consistent with the overall objective of the
dependency scheme to protect minors until they can safely be returned to a parent... But the focus of that
provision is on treatment that is necessary to improve, sustain or preserve a child’s medical condition.
Section 369, subdivision (b) permits the court to authorize the performance of necessary medical care
(i.e., medical treatment to sustain life or improve the patient’s condition); it does not permit the court to
authorize the nonperformance of medical care (i.e., a DNAR directive or withdrawal of life-sustaining
medical treatment). The language “or other remedial care” used in section 369, subdivision (b) supports
this interpretation because it allows the performance of medical care that is intended to be corrective or
curative, not life-threatening.

In contrast to the court’s broad authority under section 362, subdivision (a) to make “any and all
reasonable orders” for a dependent child, including decisions to withdraw life-sustaining medical
treatment... the court’s authority under section 369, subdivision (b) is not so far-reaching when a minor’s
dependency is unadjudicated, the request to authorize medical treatment is contrary to the parents’ wishes
and the requested treatment will inevitably result in the minor’s death. Absent true findings made at a
jurisdiction hearing, the court’s authority is necessarily limited to ordering medical care that will sustain
or improve the minor’s condition, not end it. (§ 369, subd. (b).) After a minor has been adjudged a
dependent, the court acts as parens patriae and its authority to make decisions on behalf of the minor is
unquestionably broad... Before that adjudication, the court’s authority over medical decisions is limited
by section 369, subdivision (b).

B. The Court Could Properly Authorize Removal of Cyrus’s Breathing Tube, But Not a DNAR
Directive

At the hearing on October 10, 2007, the medical guardian made two requests: (1) an order to remove
Cyrus’s temporary breathing tube; and (2) the issuance of a DNAR directive. The uncontradicted
evidence showed the breathing tube was no longer medically necessary, it posed an increasing risk of
serious complications and discomfort for Cyrus, and there was a high likelihood (80 to 90 percent chance)
Cyrus would breathe independently once the tube was removed. After considering the evidence and
carefully balancing the interests of all parties, the court found the performance of this requested procedure
was medically necessary and in Cyrus’s best interests. The evidence fully supports this finding.
Moreover, because this procedure would likely maintain and improve Cyrus’s condition, the court had the
authority under section 369, subdivision (b) to make this order.

By contrast, the court did not have the authority to order the requested DNAR directive in the event Cyrus
cannot breathe independently following removal of the temporary breathing tube. Unlike the removal of
the breathing tube, which was shown to be medically necessary, this order withholds treatment, is not
remedial, and will inevitably result in Cyrus’s demise. Until a minor 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.

***

II. The Court Was Not Required to Conduct a Full Evidentiary Hearing Before Appointing a Medical Guardian

J.N. contends his due process rights were violated when the court failed to hold an evidentiary hearing on whether to appoint a medical guardian for Cyrus. The argument lacks merit. The juvenile court has discretion to appoint a guardian ad litem for a minor… The guardian ad litem is appointed merely to aid the court and enable it to protect the minor’s rights by making decisions in the minor’s best interests… Due process is satisfied when the court provides the parent with an informal hearing and an opportunity to be heard on the issue… At the informal hearing, the parent must be given the opportunity to respond, and there must be an explanation of the guardian ad litem’s purpose and what authority will be transferred to that person…

Here, J.N. received notice through his attorney that minor’s counsel would request a medical guardian for Cyrus. The request was based on the recommendation of the hospital bioethics consultation team, which concluded the parents had a potential conflict of interest and were unable to make decisions in Cyrus’s best interests. The court conducted a hearing at which all parties participated regarding the medical guardian’s appointment. Because J.N. received notice and had an opportunity to be heard, his due process rights were not violated.

***

DISPOSITION

Let a peremptory writ issue directing the superior court to vacate its order of October 10, 2007, authorizing removal of the breathing tube and issuance of a DNAR directive, and enter a new order, consistent with the views expressed in this opinion, authorizing only the removal of the breathing tube. In all other respects, the petition is denied. The stay issued by this court on October 11, 2007, is vacated. The opinion will be final immediately as to this court.
INTRODUCTION: ADOLESCENT MEDICAL DECISION MAKING AND THE LAW OF THE HORSE

Amanda C. Pustilnik & Leslie Meltzer Henry

15 J. Health Care L. & Pol’y 1 (2012)
Copyright (c) 2012 University of Maryland School of Law; Amanda C. Pustilnik; Leslie Meltzer Henry

In the last century, the legal and ethical doctrine of informed consent—which obligates health care providers to provide patients with the information necessary to make knowledgeable, voluntary, and rational decisions about their care—has transformed the doctor-patient relationship from a paternalistic one, in which “doctors know best” about their patients’ healthcare, to a more collaborative one, in which patients and doctors work together to make treatment decisions. While this framework invites adult patients to participate in their health care, it generally entitles adolescents to do the same only in three circumstances: emancipated minors, mature minors, and minors seeking treatment for certain medical conditions, such as sexually transmitted diseases, alcohol or drug misuse, and pregnancy. Otherwise, minors are generally thought to lack the requisite decision-making capacity to consent to health care.

In recent years, however, the ethical doctrine of assent has gained traction as a mechanism to invite children of various ages, but particularly adolescents, to voice their treatment preferences. The American Medical Association views adolescents as increasingly capable of independent relationships with their health care providers, and the American Academy of Pediatrics suggests that “as children develop, they should gradually become . . . the primary partners in medical decision-making, assuming responsibility from their parents.” Both organizations endorse adolescent assent, but there is little agreement among health care providers, bioethicists, and others as to what assent requires, the age at which children can “assent,” the amount and kind of information health care providers ought to disclose to children, and how to assess children’s understanding of that information. Consequently, some commentators contend that “assent is in the midst of an identity crisis.”

Nowhere is this crisis more problematic than when adolescents refuse to assent to a particular procedure endorsed by their parents. Should physicians proceed over an adolescent’s dissent when the patient refuses surgical repair of a malformed ear, an orthopedic device to manage scoliosis, or psychotropic medication to manage attention deficit disorder? These treatment refusals, though not without physical and psychological harm, are not fatal. But how should the assent doctrine, in the absence of relevant laws, respond to the adolescent with cancer who refuses further rounds of chemotherapy? Does the patient’s age matter in this context? What about other indicia of maturity and decisional capacity, such as the patient’s previous health care experience? As the assent doctrine develops, these questions about the moral authority of adolescents’ decisions will require continued and thoughtful attention.

C. Adolescent Difference as the Consistent Foundation

Despite the heterogeneity of laws governing adolescent decision making and the absence of a clear paradigm for adolescent assent, policies on adolescent decision making should, indeed must, share fundamental similarities. Although there are many good reasons to support heterogeneity within and across regimes on any particular topic, to argue that special policies ought to exist for adolescents is to grant that adolescents and adults are different. Without acknowledging that adolescents are distinct from adults, separate regimes for adolescents and adults would lack justification. Further, even if the legal relevance and treatment of the bio-social differences between adults and adolescents varies within and across jurisdictions, the law’s representation of the differences that justify these distinct regimes must be conceptually stable—or the law risks truly fatal inconsistency.
So what differences justify separate regimes for adolescents and adults? This is the core question, because the ways in which adolescents and adults vary must inform the ways in which our laws and ethical norms treat them differently. And this is the question on which neuroscience can shed at least some light.

Neuroscience can inform legal regimes relating to adolescent decision making, although it cannot fully explain them, by substantiating and verifying, or negating, the ideas of difference on which such policies currently rest. Findings based in neuroscience can inform decision-makers about potential fallacies or anachronisms built into policies’ construction of adolescent needs and capacities, which support reform. Or, these findings can help verify the bases on which a particular regime is constructed. On the other hand, neuroscience may not be affirmatively relevant to every area of adolescent decision making, but it at least plays a negative role as to each: Certainly, legal and ethical regimes established specifically to account for differences between adolescents and adults should not embody presumptions or achieve outcomes that are contrary to the actual nature of the differences between these groups. This is neither because science trumps policy nor even because any particular scientific fact mandates particular policy treatment; rather, it is because when law or ethical norms are premised on, and justified by, a set of facts-about-the-world, like the differences between adolescents and adults, it must adhere to its own foundations or risk becoming absurd.

To orient readers, the next section will briefly introduce key differences between adolescent and adult brain structures and functions.

II. Biological and Experiential Differences Between Adolescent and Adult Brains

Neuroimaging provides powerful evidence of how the typical brain develops during adolescence. Functional imaging studies comparing the brains of adults and adolescents are identifying the biological underpinnings of average behavioral similarities and differences between these groups, giving new substance to conventional distinctions between these life stages. Researchers’ key findings relate to the balance in adult and teen brains of executive function, emotion, and responsiveness to social cues.¹⁷ The main findings as to each of these brain functions will be addressed in turn.

A. Adolescents Have Less Developed “Executive Function” and Process Social Cues Differently than Adults

Imaging studies show that adolescents have developing, but incomplete, prefrontal cortices, which may indicate immature executive function.¹⁸ The prefrontal cortex (“pfc”) is the large, crennelated surface layer of the brain’s frontal lobes and is also the last region of the brain to develop fully.¹⁹ Although researchers have associated the pfc with hundreds of functions,²⁰ they generally agree that the pfc is the seat of “executive control.”²¹ These are inhibitory functions, like impulse control, long-term planning, and cost-benefit analysis. The pfc may be characterized as the seat of “free won’t”--of our ability to put the brakes on.²² Neuroscientists hypothesize that a less-developed pfc may correlate with a lesser ability to control impulsivity, weigh future consequences, and engage in rational, cost-benefit analysis--hallmarks of typical behavioral differences between teens and adults.²³

Research suggests not only that adolescents reason less effectively than adults but that they reason differently: Teens appear to evaluate risks relationally (“What do my friends think about this?” “What will my friends think of me if I do/don’t do this?”) rather than independently (“Is this a good idea?”).²⁴ One way to view this peer-orientation is that teen cognition is the original crowd-sourcing; this is not necessarily the wrong way to make decisions but it might have different costs and advantages than the decision-making styles more typical of adults.²⁵

Professor Abigail Baird’s research shows the power of social cognition in adolescents.²⁶ She and her research
team asked subjects during interviews and during brain scanning sessions to evaluate dangerous activities, like whether it would be a good idea to set their hair on fire or to free-swim with Great White sharks. Adults had immediate, negative autonomic responses—as well as quick verbal replies. Adolescents, though, tended to read the social barometer before answering one way or another, checking what a peer thought before answering the question. When they evaluated the high-risk scenarios in the scanner, they failed to show the immediate, physiological fear signals that cue adults to avoid bad risks. The teens did, however, show automatic fear activation when they contemplated social rejection. In other words, Baird’s research suggests that typical teens respond on a pre-conscious, neurological level to the threat of social rejection the way adults respond to threats of immolation and death.27

These neurological findings may help explain why exhortations to teens not to succumb to peer pressure are of limited, if any, value. Expecting to change a typical teen’s behavior by telling him to stand firm in the face of peer ridicule might be akin to telling a typical adult to stay put in the face of a shark attack; not utterly useless, but close. Based on these and other findings, we might expect—and data confirms—that teens are most likely to act impulsively, break the law, and make bad choices in situations where peer salience is high.28 When teens are on their own, however, or are structurally insulated from peer-related considerations, their cognition and decision making is equivalent or even superior to that of adults. This kind of finding could be useful in evaluating and constructing legal regimes related to adolescent decision making.

This relational nature of adolescent decision making is not merely (or not necessarily) a flaw resulting from underdevelopment. Instead, the acute social sensitivity of adolescents itself plays a crucial developmental role. In their article in this issue, clinical psychologist Abigail A. Baird and her co-authors Christy L. Barrow and Molly K. Richard describe adolescence as being analogous to the “critical period” of early childhood in which infants must acquire human grammar.29 In the “sensitive period” of adolescence, they contend, teens learn the social language of adult interaction.30 Just as babies babble and stutter acquiring primary language, adolescents’ sometimes inept and incomplete social “utterances” should be understood as practice with social “language.” On this view, the behavioral “babbling” of adolescence—as awkward, painful, and sometimes harmful as it is—is the essential practice adolescents require to develop into agents who can participate fluently in their particular social world.

B. Teens Must Connect Emotion and Reason Through Experience

Executive function and emotional responses are not just less developed or different in teens: These two capacities are also less closely linked than in the typical adult brain.31 As a result, a teen may intellectually understand an issue and emotionally have a response to that issue, but those two processes may occur nearly in parallel rather than in dialogue.32 This implicates decision making, because decisions are not simply, or even primarily, rational: Emotional and executive functions must work together to bring about almost any kind of decision.33

For the pfc to receive and then inhibit impulses arising from the brain’s limbic regions, these brain regions must be connected to each other via nerve fibers. In adults with normal impulse control, long, thick “tracts” of nerve fibers connect the prefrontal cortex with key limbic areas.34 Research correlates the density and extent (literally the length) of the fibers tracts with impulse; several experiments have succeeded in using the strength of these connections in predicting self-control in laboratory tasks.35 Adults have these neural connections because they developed them during adolescence; adolescents, who may have highly developed verbal and intellectual capacities, are still in the process of developing these inhibitory and evaluative connections between intellect and drive or emotion.36 If people were cars, it would be as if we came out of the factory with all the acceleration—all the drive, or drives—we will ever have but with our brake cables only weakly connected. For the brake cables to connect more strongly over time, the precarious car must take to the road and practice braking.37
The brain develops its executive control, inhibitory strength, and synthesis of emotion and reason through the marriage of time and practice. This is because mature decision making arises from ontogeny and experience. Adolescents thus need not only time but also the right kinds of experiences, which might include patterning and modeling on good mentors, taking risks and making mistakes, engaging in meaningful reflection on one’s own experiences and those of others, and participating in formal and informal education that cultivates moral and humane virtues.

***

Assistant Professor of Law, University of Maryland Francis King Carey School of Law. J.D. Yale Law School; B.A. Harvard College.

Assistant Professor of Law, University of Maryland Francis King Carey School of Law; Associate Faculty, Johns Hopkins Berman Institute of Bioethics. J.D. Yale Law School; M.Sc. University of Oxford; B.A. University of Virginia. We thank Lauren Elfiner, Nikola Nable-Juris, and Christine White for their excellent research assistance.


Id.

See AMA Council on Ethical and Judicial Affairs, Code of Medical Ethics Op. 5.055-Confidential Care for Minors (last updated 1996) (discussing a physician’s ethical duty “to promote the autonomy of minor patients by involving them in the decision-making process to a degree commensurate with their abilities”).

Comm. on Bioethics, supra note 11, at 316.

Yorma Unguru et al., Rethinking Pediatric Assent: From Requirement to Ideal, 55 Pediatric Clinics N. Am. 211, 212 (2008).

Id. at 216.

Among the wealth of literature in this field, see, for example, B.J. Casey & Rebecca M. Jones, Neurobiology of the Adolescent Brain and Behavior, 49 J. Am. Acad. Child & Adolescent Psychiatry 1189 (2010); Jay N. Giedd et al., Brain Development During Childhood and Early Adolescence: A Longitudinal MRI Study, 2 Nature Neuroscience 861 (1999).

For a synopsis of how brain images are made and interpreted, see, for example, Laurence R. Tancredi & Jonathan D. Brodie, The Brain and Behavior: Limitations in the Legal Use of Functional Magnetic Resonance Imaging, 33 Am. J.L. & Med. 271, 272-76 (2007) (describing the mechanics of EEG, PET, and fMRI image production and interpretation). For a discussion of the “limitations and distortions” of fMRI, see id. at 278-80 (noting that, among other difficulties, brain images can “vary significantly both between subjects and across sessions [with the same subject]”).


J. Grafman et al., Fables of the Prefrontal Cortex, 18 Behav. & Brain Sci. 349 (1995) (identifying, in a seven-page list, the hundreds of human abilities and characteristics that various researchers have localized to the prefrontal cortex).

Id. Gazzaniga describes “free won’t” as the ability to suppress inappropriate thoughts, speech, or action. While the pfc may enact “free won’t,” pfc maturation alone cannot account for how the brain determines what is or is not appropriate under the circumstances and, therefore, when to apply the brakes.


Scott & Steinberg, supra note 23, at 38, 45, 48-50 (describing adolescents’ peer orientation and research on the neurological and psychological bases of teens’ peer orientation).


Baird et al., supra note 26.


See Antoine Bechara et al., Different Contributions of the Human Amygdala and Ventromedial Prefrontal Cortex to Decision-Making, 19 J. Neuroscience 5473 (1999) (a classic paper setting out early proof of the “somatic marker hypothesis,” which “proposes that decision-making is a process that depends on emotiona”). The somatic marker hypothesis has since become widely adopted. See, e.g., Jonathan Haidt, The Emotional Dog and Its Rational Tail: A Social Intuitionist Approach to Moral Judgment, 108 Psychol. Rev. 814, 814 (2001) (arguing that judgments, particularly moral judgments, are “generally the result of quick, automatic evaluations,” while rational faculties create post hoc justifications for fundamentally emotionally-driven responses). Despite the reputation emotion has had over the years as a sort of flaw that undermines reason, studies of brain-damaged patients show that decision making based on reason alone results in severely impaired decision making. Patients with damage to the ventromedial prefrontal cortex (vmPFC) suffer from pervasive lack of emotion - a kind of “acquired psychopathy,” which leaves them rationally intact but emotionally flat; these and other brain-damaged patients have extreme difficulty making putatively “rational” decisions in the absence of any inner emotional cues. Hannah Damasio, Disorders of Social Conduct Following Damage to Prefrontal Cortices, in Neurobiology of Human Values 37, 37-46 (Jean-Pierre Changeux et al. eds., 2005) (surveying acquired impairments in conduct, judgment and decision making).

Casey et al., supra note 31, at 25 (reviewing recent imaging and impulse control research on white matter tracts connecting the pfc and subcortical regions).

Id. (noting that “frontostrial connection strength positively predicted impulse control capacity, as measured by performance on a go/nogo task”).
36 Id.

Case Study

Michael, a fifteen-year-old with metastatic osteosarcoma, has not responded to conventional therapy. For almost one year, he was treated in a therapeutic, randomized clinical trial, which consisted of standard therapy (up-front chemotherapy, limb salvage surgery, and postsurgical chemotherapy). When his cancer responded poorly to up-front therapy, he was randomized to receive additional “experimental” chemotherapy.

Michael has a very close relationship with his mother, and he has been an active participant in every treatment conference. For the most part, Michael tolerated the treatment; however, he struggled both physically and emotionally with the last three months of treatment. Michael’s end-of-therapy scans confirmed that the tumor was still present in both the bone and the lungs.

Michael’s mother wants to proceed with an (unproven) experimental therapy in an effort to prolong his life. Michael, on the other hand, does not desire this intervention. Michael asks the physician not to administer the drug and to allow him to die on his “own terms.” Michael’s mother (emphatically) states that this is her decision to make and not his. She adds that if the physician is not willing to treat him, she will take him to a doctor who will.

This case raises many important questions. For example, as Michael’s physician, are you comfortable with the decision he is asking you to allow him to make? How do you balance Michael’s goals with those of his mother’s and your own? How can you (or should you) find a way to enable Michael’s mother to allow him to transition into control of his own health care management? Who ultimately is responsible for Michael’s care and health? Should the fact that the treatment in question is considered experimental make a difference?

I. Introduction

Medical decision making involving older children requires the physician to obtain both the patient’s assent and parental permission. Pediatricians are ideally positioned to deal with the inevitable conflicts inherent in these situations as exemplified in the case study above. In order to address the questions that this case study presents, this article will first explore the decision making capacity of children and explain the concept of assent as related to a minor’s decisions regarding his or her treatment regimen. Next, the article will discuss recent research, which demonstrates the need for direct communication between parents, physicians, and children. Lastly, this article will conclude with recommendations for a practical decision-making model and a discussion of the case study presented above.

II. Decision-Making Capacity and Assent

By definition, “children constitute a vulnerable population.” The vulnerability of children relates directly to their limited decision-making capacity (i.e., the ability to make reasonable decisions). Thus, because many children, especially infants and young children, lack decision-making capacity to make informed and voluntary decisions,
they are deemed vulnerable and merit special protections. Older children and adolescents, however, often possess the capacity for decision making and therefore may be qualified to make select decisions while unable to make others. It is usually the pediatrician’s role to determine if a child or adolescent has the ability to make a given decision. Thus, it is appropriate and ethically justifiable to solicit assent from children who are unable to make autonomous choices.

Assent refers to the active agreement of a minor to participate in a diagnostic or treatment regimen. The ethical principle of pediatric assent recognizes that children (especially adolescents) are capable of participating at some level in decision making related to their care. The assent requirement seeks to respect children as individuals with emerging autonomy. Above all else, assent is about respecting a child’s “developing capacity,” assisting the child in understanding his condition and treatment at a developmentally appropriate level, and involving him in appropriate decision-making tasks.

Meaningful assent requires an appreciation of the child’s developmental stage and recognition of his basic preferences. A child should be included in medical decisions to the extent that he or she is able to and wants to be involved. Parents and physicians need to encourage children to communicate openly so that children may be active participants in the assent process. Shared decision making empowers children to the extent of their capacity.

Like other areas of child development, capacity for decision making occurs along a spectrum and evolves with time and experience. Factors influencing this process include a child’s maturity level, ability to reason and consider the impact of their decision, including relevant alternatives and consequences, and prior decision-making experience. With regard to the latter, one might imagine two children of the same age, Jane and Joe. Consistently throughout her life, Jane’s parents have allowed her to participate in and to make decisions. As Jane has demonstrated an appreciation for and gained experience with the decision-making process, her parents have gradually allowed her to participate in and make more substantive decisions. Joe’s parents have adopted a different approach. They have allowed him to make routine choices but have not given him the chance to participate in making significant life-decisions, preferring instead to make such decisions on his behalf. As one might surmise, Jane is seemingly better prepared to appreciate and to understand the nuances of medical decision making than Joe, who has been insulated from making life-decisions and who may be less equipped to participate meaningfully in and to assent to medical (and research) decisions. Accordingly, no two children attain decision-making capacity similarly.

As recognized in common law, minors possess varying degrees of decision-making capacity. The rule of capacity, also known as the Rule of Sevens, is strictly an age-based criterion. Accordingly, minors under seven years of age have no such capacity; minors “between seven and fourteen have a rebuttable presumption of no capacity”; and minors “between fourteen and twenty-one, have a rebuttable presumption of capacity.” Evidence from the social sciences supports the notion that, in general, children fourteen and older appear to be as competent as adults in making informed treatment decisions. As the example of Jane and Joe illustrates, age alone, however, is not an adequate indicator of a child’s ability to understand.

A. Limits of Assent

In pediatric medicine, shared decision making is a worthy and valuable standard. Shared decision making strives to respect both parents’ and children’s preferences and values while meeting the goals of medicine. Typically, parents and children share similar ideals and more often than not, in medical situations, the two align with one another. However, disagreements do occasionally occur and this has clear implications for assent. Every effort should be made to secure a child’s readiness to accept treatment, but as recognized in the law, it is the parents, not the child, who are the ultimate arbiters of decision making. Accordingly, parents may compel their child to
accept a treatment, so long as that treatment is in a child’s best interest. In other words, parental permission may trump a child’s assent. The principle of respecting a child as a developing person requires that physicians inform the child that while they value his or her opinion, in specific instances his opinion may be overridden. Failure to do so has the potential for damaging the child’s developing self as well as the trusting relationship between the child, his parents, and the physician.

B. Determining the Validity of a Child’s Decision

For a medical decision to be valid, it must be voluntary and informed. Decisional capacity matures along a continuum dependent on time and experience; as such, children possess varying degrees of decision-making capacity, which is determined primarily by the type of decision and the risks and benefits involved. The threshold level of capacity is a useful model to assist in determining if a particular child may make a given decision. For high-risk decisions (e.g., refusal of a life-saving intervention), a higher threshold of decision-making capacity is necessary; for low-risk decisions (e.g., choosing between two equally efficacious medications), a lower threshold is appropriate.

Historically, assessment of decision-making capacity has focused on understanding, an important component of decision-making capacity. Yet, in practice, evaluating understanding is a difficult task. Part of the problem relates to the definition of understanding, which is multidimensional (i.e., elements of understanding include, but are not limited to, comprehension, knowledge, and awareness). Additionally, few validated tools exist for assessing understanding, and most are designed for adults, not children. What is clear is that three factors must exist for a child to possess decision-making capacity: (1) a child’s choice must be voluntary; (2) his or her choice must be both reasonable and rational; and (3) the child must understand information that is relevant to his choice. Although evaluating a child’s understanding remains an essential element of assent, it alone is insufficient in assuring that assent is significant and meaningful. As appreciated by the American Academy of Pediatrics (AAP), the process of obtaining a child’s assent requires several steps: the physician must (1) help the patient achieve awareness of his or her condition; (2) tell the patient what he or she can expect regarding diagnosis and treatment; (3) assess the patient’s understanding; (4) assess factors influencing patient responses (i.e., undue pressure); and (5) solicit the patient’s willingness to accept care.

C. Societal and Legal Attitudes Towards Assent

Sufficient evidence supports a role for children’s involvement in decisions related to their care and research involvement. In addition to promoting a child’s developing sense of autonomy and personal responsibility, participation in decision making may in fact improve a child’s response to treatment. Nevertheless, there is reluctance on the part of legal institutions and the public at large to include children in certain treatment-and research-related decisions.

Part of this reluctance concerns the potential for child-parent conflict as it relates to the appropriate moral weight to assign to children’s assent or dissent. As appreciated by Baylis and colleagues, this is particularly germane to children’s involvement in research settings yet it is relevant in the clinical arena as well. If a child’s decisions carry the same power as the decisions of his parents, then from a moral and ethical perspective the child may veto the parents’ decision if and when he disagrees about research involvement or a particular clinical decision. Purely from an enforcement perspective, the difficulty with this scenario is primarily a legal one. While morally a child’s decisions may be no different from those of his parents, the difficult question that arises in such a situation is: should the decisions of a child who lacks legal standing be as authoritative as those of his parents? Baylis et al. argue that concepts of assent (for research), which rely on decisional authority, are too narrow and instead need to be expanded in its focus and consider to what extent a child may participate as “assenter or disserter.” Thus, a child may still have a valuable contribution even if he lacks decisional
authority. Baylis et al. describe this as a “receptive role” rather than a “decisional role.”

###

III. Finding a balance

The need for direct communication between parents, physicians, and children with life-limiting illnesses is increasingly apparent. This communication includes discussions relating to prognosis and even death. Hinds and colleagues found that children with life-limiting cancer between ages ten and twenty were capable of participating in end-of-life decision making. Children typically want to be involved in decisions that concern their bodies and health. They also generally recognize their role in decision-making as intertwined with that of their parents and appreciate and respect their parents’ input, particularly when they perceive a situation to be more risky. Most children do not expect to make decisions on their own but wish to be involved in the process and have their opinions respected. Shared decision making enables children to clarify their own values and preferences. Assent should not be viewed as a challenge to parental authority and parental decision making. Assent and parental permission are not mutually exclusive; instead, the two complement one another and result in a more collaborative and substantive shared decision-making model. As appreciated by the AAP, meaningful assent is best viewed as a process wherein children, parents, and physicians participate in joint decision making. Importantly, this process is individualized based on the unique capabilities of the child.

Mack and colleagues surveyed parents of children with cancer and found that parents rated the quality of care provided by physicians more favorably when physicians communicated directly with their children (when appropriate). Similarly, in a survey of over 400 Swedish parents of children who died of cancer, Kreicbergs et al. found that none of the parents who spoke with their child about death regretted doing so, whereas more than one quarter of parents who did not speak with their child regretted not doing so. The latter parent group had higher levels of anxiety and depression than parents who spoke to their children.

Parents are not alone in valuing the importance of direct communication between children and physicians. Recent research has shown that children with cancer consider direct communication between doctors and children more important than any other aspect of improving adolescent decision making. Nearly forty years ago, following parental approval, Nitschke et al., began including children with cancer, ages five and older, who were near death, in end-of-life discussions. They found that the majority of children and parents found the child’s inclusion a positive experience. They also reported that some children from whom information was withheld experienced fear and isolation prior to dying. Pediatricians are in a unique position to help children and parents with appreciating and developing their own practical approach to shared decision making. When a child is ill, parents seek to protect and to isolate their child from harms. Many parents perceive decision making itself as burdensome and in an effort to shield their child, assume full decision-making responsibility. Clinicians need to be aware of this phenomenon. As a trusted caretaker, pediatricians can, and should, help parents develop the skills to allow their children to think independently. Children, especially ill children, need to know that they can depend on their parents to support them as they learn to make appropriate decisions. Including children in decision making empowers children. It provides them with a sense of purpose and control and promotes improved future choices.

Collaborative decision making does not require that children’s, parents’, and physician’s decisions carry equal weight. Rather, all parties should be able to respectfully state their desires and concerns. Thus, parents should allow children to speak freely; they must honestly and thoughtfully listen to and acknowledge what their child has to say. Children need to know that while their preferences will be heard and considered, decision making is a joint endeavor, and ultimately, their decision may be overturned. As the child’s advocate, pediatricians are ideally situated to serve as a bridge between the child and his parents, easing some of the burden, mediating...
disagreements, and assisting both sides in reaching a reasonable decision—one that is acceptable to all stakeholders.

**IV. Recommendations for a Practical Decision-Making Model**

As appreciated by others, a tangible model of assent gives choices to children of all ages. The type and extent of acceptable choices are unique to each child and contingent upon the child’s maturity level, history of decision making, and familial values. As children gain an appreciation for and awareness of the decision-making process, they should be granted greater responsibility and allowed a higher threshold for decision making.

Applying this model to the case study presented at the beginning of this article, Michael, as a fifteen-year-old, is sufficiently mature to understand the issues related to his treatment and to participate in decision making. His experience with his disease and past treatment regimens has also resulted in a level of maturity that exceeds his age. Michael understands the nature of the proposed treatment, including its risks and expected benefits. He has voiced the opinion that he does not wish to proceed with an experimental regimen, an opinion not shared by his mother. Given his level of maturity, failure to respect his wishes, especially regarding an experimental treatment regimen that is unlikely to significantly alter the course of his illness, would be profoundly disrespectful and potentially harmful. Ignoring his wishes may also lead to feelings of isolation and distress.

Situations like Michael’s do not lend themselves to easy solutions. By helping to facilitate, clarify, and resolve areas of contention, pediatricians can be extremely helpful. The challenge for pediatricians is to do so in a way that is both sensitive and respectful of the conflicting needs of the child, parents, and providers. In many cases, simply providing a space where Michael and his mother can speak freely about their choices and the reasons for those choices will lead to a solution that is acceptable to both. Michael needs his mother to hear what he is saying, and the physician’s role in this case is not simply to override his desires but to facilitate the opportunity for his mother to understand what he needs in this difficult situation.

---

1 Division of Pediatric Hematology/Oncology, The Herman and Walter Samuleson Children’s Hospital at Sinai; Berman Institute of Bioethics Johns Hopkins University.


2 See 45 C.F.R. §§ 46.401-.407 (2010) (establishing that a physician must solicit a child’s assent and a parent’s permission for a child to participate in a clinical research study); see also Comm. on Bioethics, Informed Consent, Parental Permission, and Assent in Pediatric Practice, 95 Pediatrics 314, 317 (1995) (noting that, in addition to obtaining parental permission, physicians should, in most cases, obtain patient assent as well).

***


9 See id. at 135-36 (noting that children less than seven-years-old are considered incapable of providing assent, and among children aged seven to fourteen, assent can be easily compromised by the power relationship between parents and children).

10 See Lawrence Schlam & Joseph P. Wood, Informed Consent to the Medical Treatment of Minors: Law and Practice, 10 Health Matrix 141, 149-50 (2000) (noting the belief that children lack the “maturity, experience, and capacity”
necessary to make difficult decisions and are therefore incapable of making medical decisions and need to be protected from themselves).


See Tara L. Kuther, Medical Decision-Making and Minors: Issues of Consent and Assent, 38 Adolescence 343, 345 (2003) (noting that physicians are largely responsible for determining whether a minor has the capacity to consent to specific treatment based partly on the minor’s comprehension of the procedure and the possible outcomes).

Id. at 351 (describing that minors may not be capable of autonomous decision making in all circumstances, but that it is still appropriate to involve them in the decision-making process).

Id.

Id.


Id. at 360.

Id. at 360-61.

See id. (noting that the multiple elements of assent recognize the child’s developmental maturity and inclinations).

Yoram Unguru et al., Rethinking Pediatric Assent: From Requirement to Ideal, 55 Pediatric Clinics N. Am. 211, 217 (2008).

Id. at 217-18.


Id. at 509-10, 513.

Id. at 511 (explaining that family factors may determine a child’s level of involvement in the decision-making process).

Id. at 509.

Cardwell v. Bechtol, 724 S.W.2d 739, 744-45 (Tenn. 1987) (noting the common law recognition of varying degrees of decision-making capacity in minors).

Id. at 745.

Id.

32 See Rossi et al., supra note 8, at 132 (noting that age, maturity, and psychological state are all factors that should be considered when determining a minor’s capacity); see also Robert Bennett, Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis, 62 Va. L. Rev. 285, 309 (1976) (noting that experience will change a child’s decision-making capacity).

33 See Geller et al., supra note 23, at 269 (noting that both children and parents value shared medical decision making).

34 See COG Task Force Guidelines, supra note 11, at 7 (recognizing that fundamental disagreements between parents and children, with regard to research participation, are rare).

35 See Kuther, supra note 12, at 354-55 (describing the ways in which disagreements occur and how to proceed despite the disagreement of the parties).

36 Id. at 344, 356.

37 Id. at 344.

38 Id. at 344, 355-56.

39 Id. at 352-53 (noting that physicians should always be up-front with minor patients about how the patient’s values and preferences will be incorporated into the decision-making process).

40 See Francoise Baylis et al., Children and Decisionmaking in Health Research, 21 IRB, July-Aug. 1999, at 5, 8 (stating that children may be “seriously harmed by having something done to them without their knowledge or understanding”).

41 Kuther, supra note 12, at 344.

42 McCabe, supra note 24, at 507-10.

43 Id. at 509-10 (describing the varying levels of situations and factors that influence a minor’s capacity to make competent decisions).


45 Cf. Kuther, supra note 12, at 354 (opining that a physician should respect a minor’s decision with regard to elective treatments but “probe further” where a minor is refusing treatment with benefits that outweigh the risks).

46 See, e.g., Protection of Human Subjects, Research Involving Children: Report and Recommendations of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 43 Fed. Reg. 2084, 2098 (Jan. 13, 1978) (emphasizing that pediatric researchers should make sure minors of a certain age have the requisite understanding about their involvement).

47 See Kuther, supra note 12, at 346 (noting that there is a lack of clear guidelines in determining a minor’s maturity or decision-making capacity).


49 Cf. Buchanan, supra note 44, at 415-16 (applying the threshold level of capacity theory to adult patients); Cathy Charles et al., Shared Decision-Making in the Medical Encounter: What Does It Mean? (or It Takes at Least Two to Tango), 44 Soc. Sci. & Med. 681, 682 (1997) (applying shared decision-making theory to adult decision making with regard to medical treatment).

50 See Kuther, supra note 12, at 344.
See Comm. on Bioethics, supra note 2, at 315-16 (outlining the multiple elements required for obtaining assent, including understanding).

Id.

Id.

See Kuther, supra note 12, at 348-50 (showing that adolescents and adults have similar decision-making capacities for certain types of decisions).

Cf. Rochelle T. Bastien & Howard S. Adelman, Noncompulsory Versus Legally Mandated Placement, Perceived Choice, and Response to Treatment Among Adolescents, 52 J. Consulting & Clinical Psychol. 171, 172 (1984) (citing a study on an elderly population which demonstrated that those seniors who had control over their decisions were happier and healthier than those who did not have any control).

Baylis et al., supra note 40, at 6.

Id.

Id. at 5.

See generally id. (discussing the involvement of children in the research decision-making process).


See Baylis et al., supra note 40, at 6 (noting the difficulty in determining the amount of decision-making power that children should have in the medical setting).

Id. at 9 (discussing that parents are entrusted with the responsibility of making decisions on behalf of their children because it is believed that they will act in the child’s best interests, and if not, can sometimes suffer legal repercussions).

See id. at 8 (establishing the difficulty in determining when children have the necessary capacity to make decisions for themselves).

Id. at 8.

See id. (referencing a child’s ability to participate without actually having the final decision-making authority).

Id.

***

Ctr. for Bioethics, Univ. of Minn., End of Life Care: An Ethical Overview 48 (2005) (discussing the importance of involving a dying child in treatment and health care discussions).


Pamela S. Hinds et al., End-of-Life Care Preferences of Pediatric Patients with Cancer, 23 J. Clinical Oncology 9146, 9153 (2005).

See, e.g., Geller et al., supra note 23, at 264 (noting that children generally felt it was their decision of whether to participate in genetic research).
Rossi et al., supra note 8, at 139; see also Geller et al., supra note 23, at 264; Yoram Unguru et al., The Experiences of Children Enrolled in Pediatric Oncology Research: Implications for Assent, 125 Pediatrics e876, e880 (2010).

Geller et al., supra note 23, at 265-66.

Id.

Id. at 270.

Cf. Comm. on Bioethics, supra note 2, at 315 (noting that while advocating the solicitation of assent from a child, practitioners still need the “informed permission” from the parents for medical interventions).

See Geller et al., supra note 23, at 269 (arguing that a shared-decision process, which includes both children and parents, can enhance cooperation).

Comm. on Bioethics, supra note 2, at 315.

Baylis et al., supra note 40, at 7 (describing the four criteria for making an individualized assessment of a child’s decision-making capacity in research participation).


Id. at 1184.

Ctr. for Bioethics, Univ. of Minn., supra note 75, at 48.

See Unguru et al., supra note 79, at e880 (advancing a study on children with cancer about their understanding of research and treatment, which demonstrated that 39% of those children surveyed wanted more discussions directly with doctors); see also Mack et al., supra note 87, at 9160 (noting the importance of communication with children, especially near the end of their life).


See id. at 269 (stating that regardless of the child’s therapeutic choice, fewer than one-third of the children reacted with sadness, anxiety and anger when included in the final stage conference to discuss their unresponsiveness to further therapy).

Id.

See McCabe, supra note 24, at 511-12 (explaining how a decision-making situation may be difficult and burdensome for a child); Alan Meisel, The “Exceptions” to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking, 1979 Wis. L. Rev. 413, 423 (1979) (stating that, in general, family and friends are interested in a loved one’s medical decision because of the desire to relieve the patient’s pain and suffering).


See Bartholome, supra note 17, at 358 (noting the general fragility of children and the need for encouragement and reinforcement by parents in the context of giving medical consent).
See Comm. on Bioethics, supra note 2, at 315 (stating that including children in medical decision making empowers the child and can “improve long-term health outcomes”).

See McCabe, supra note 24, at 508-09 (noting the varying levels of child, parent and caregiver involvement in medical decision making).

See Geller et al., supra note 23, at 269 (discussing the importance of shared decision making between parents and children which inherently involves both parties voicing their opinions); see also Myra Bluebond-Langer et al., “I Want to Live, Until I don’t Want to Live Anymore”: Involving Children with Life-Threatening and Life-Shortening Illnesses in Decision Making About Care and Treatment, 45 Nursing Clinics N. Am. 329, 336-40 (2010) (discussing the issues that must be considered when involving children in medical decision making as well as suggesting an approach for involving children).

See Kuther, supra note 12, at 351-52 (noting the importance of including minors in discussions about their medical treatment).

Comm. on Bioethics, supra note 2, at 315-16.


See id. at 12, 13 (stating that when determining a child’s capacity to make decisions, physicians and parents should examine several factors, including age, intellect, past decisions, and familial values).

Comm. on Bioethics, supra note 2, at 316.

Bartholome, supra note 17, at 358.

See Kuther, supra note 12, at 343 (“The information provided by physicians about illness and treatment options is vital to patients’ decision making and influences their psychological well-being.”).

See King & Cross, supra note 103, at 16 (arguing that it is important for physicians to recognize and balance the conflicting needs of the child-patient and parents).
Informed Consent, Parental Permission, and Assent in Pediatric Practice

Committee on Bioethics

Pediatrics 1995;95;314

The online version of this article, along with updated information and services, is located on the World Wide Web at:

http://pediatrics.aappublications.org/content/95/2/314
Informed Consent, Parental Permission, and Assent in Pediatric Practice

Committee on Bioethics

The statement on informed consent, parental permission, and patient assent has a long and extraordinary history. The first draft of this document, prepared by William G. Bartholome, MD, was presented to the original American Academy of Pediatrics (AAP) Committee on Bioethics in 1985. Bill put his soul into the manuscript and has watched over it carefully ever since. Now, a decade later, those who have worked on its continued development and urged its adoption as Academy policy applaud its publication. No one is more gratified than its primary author and champion. Those who have had the privilege to know Dr Bartholome share his sense of accomplishment, but cannot help but experience a cruel sense of irony. Just as the work Bill considers his most important contribution has become available for public appreciation, Dr Bartholome suffers from a serious illness that threatens his life.

Bill always wanted “the experience, perspective, and power of children” to be taken most seriously. Through the years of the statement’s revisions and re-presentation within the Academy, Bill “had faith in the power of the text and the ideas it contained, . . . that its time would come.” The statement embodies Bill Bartholome’s dedication to children. Throughout his career, he worked to make medicine and medical research safer and more friendly for children. The AAP and its Committee on Bioethics, on behalf of all our colleagues, extend heartfelt thanks to Dr William G. Bartholome for helping us more fully appreciate that children are in the process of becoming, in his words, “intelligent, observant, capable, and responsible persons” who deserve our utmost respect.

AN OVERVIEW

Since the 1976 publication of an AAP policy statement on the legal concept of informed consent in pediatric practice, the concept has evolved and become more formal.1 A better understanding now exists as to how physicians should collaborate with patients and parents in making these decisions. Patients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable. Parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons. Indeed, some patients have specific legal entitlements to either consent or to refuse medical intervention. Although physicians should seek parental permission in most situations, they must focus on the goal of providing appropriate care and be prepared to seek legal intervention when parental refusal places the patient at clear and substantial risk.2 In cases of serious conflict, physicians and families should seek consultative assistance and only in rare circumstances look to judicial determinations.

We now realize that the doctrine of “informed consent” has only limited direct application in pediatrics. Only patients who have appropriate decisional capacity and legal empowerment can give their informed consent to medical care. In all other situations, parents or other surrogates provide informed permission for diagnosis and treatment of children with the assent of the child whenever appropriate.

In this statement, the AAP provides an updated analysis of 1) the concept of informed consent; 2) the ethics of informed consent and the concept of the right to refuse treatment; 3) the concept of “proxy consent”; 4) the concepts of parental permission and child assent; and 5) informed consent of adolescents.

CHANGES IN MEDICAL DECISION-MAKING

The authority to make medical decisions used to lie squarely in the hands of physicians. However, complex social changes have resulted in acceptance of the idea that patients have a right to know about their health, to know about available diagnostic and treatment options and their risks and probable benefits, and to choose among the alternatives.3 Many now regard traditional practices based on the theory that “doctor knows best” as unacceptably paternalistic.4 Society recognizes that patients or their surrogates have a right to decide, in consultation with their physicians, which proposed medical interventions they will or will not accept. Decision-making power or authority is increasingly seen as something to be shared by equal partners in the physician-patient or physician-surrogate relationship. For many patients and family members, personal values affect health care decisions, and physicians have a duty to respect the autonomy, rights, and preferences of their patients and their surrogates.5

ETHICS AND INFORMED CONSENT

The doctrine of informed consent reminds us to respect persons by fully and accurately providing information relevant to exercising their decision-making rights. Experts on informed consent include
at least the following elements in their discussions of the concept: 6

1. Provision of information: patients should have explanations, in understandable language, of the nature of the ailment or condition; the nature of proposed diagnostic steps and/or treatment(s) and the probability of their success; the existence and nature of the risks involved; and the existence, potential benefits, and risks of recommended alternative treatments (including the choice of no treatment).

2. Assessment of the patient’s understanding of the above information.

3. Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s).

4. Assurance, insofar as is possible, that the patient has the freedom to choose among the medical alternatives without coercion or manipulation.

The goals of this consent process include the development of the patient’s comprehensive understanding of the clinical situation, and the timely exercise, by the patient, of active choices regarding the circumstances. 7,8

INFORMED CONSENT AND THE RIGHT TO REFUSE TREATMENT

Health care providers should engage in the process of informed consent with patients before undertaking any medical intervention. Patients generally have a moral and legal right to refuse proposed medical intervention, except when the patient has diminished decision-making capacity or must undergo legally authorized “involuntary” treatment. Respect for competent patients’ autonomy ordinarily extends even to the refusal or discontinuation of their own life-sustaining treatment. 9

PROBLEMS WITH THE CONCEPT OF “CONSENT” BY PROXY

In attempting to adapt the concept of informed consent to pediatrics, many believe that the child’s parents or guardians have the authority or “right” to give consent by proxy. Most parents seek to safeguard the welfare and best interests of their children with regard to health care, and as a result, proxy consent has seemed to work reasonably well.

However, the concept encompasses many ambiguities. Consent embodies judgments about proposed interventions and, more importantly, consent (literally “to feel or sense with”) expresses something for one’s self: a person who consents responds based on unique personal beliefs, values, and goals.

Thus “proxy consent” poses serious problems for pediatric health care providers. Such providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses. Although impasses regarding the interests of minors and the expressed wishes of their parents or guardians are rare, the pediatrician’s responsibilities to his or her patient exist independent of parental desires or proxy consent. 10

PARENTAL PERMISSION AND SHARED RESPONSIBILITY

Decision-making involving the health care of young patients should flow from responsibility shared by physicians and parents. Practitioners should seek the informed permission of parents before medical interventions (except in emergencies when parents cannot be contacted). The informed permission of parents includes all of the elements of standard informed consent, as outlined previously.

Usually, parental permission articulates what most agree represents the “best interests of the child.” However, the Academy acknowledges that this standard of decision-making does not always prove easy to define. In a pluralistic society, one can find many religious, social, cultural, and philosophic positions on what constitutes acceptable child rearing and child welfare. The law generally provides parents with wide discretionary authority in raising their children. 11 Nonetheless, the need for child abuse and neglect laws and procedures makes it clear that parents sometimes breach their obligations toward their children. Providers of care and services to children have to carefully justify the invasion of privacy and psychologic disruption that come with taking legal steps to override parental prerogatives.

THE DEVELOPMENT OF THE CHILD AS PERSON AND THE CONCEPT OF ASSENT

Decision-making involving the health care of older children and adolescents should include, to the greatest extent feasible, the assent of the patient as well as the participation of the parents and the physician. Pediatricians should not necessarily treat children as rational, autonomous decision makers, but they should give serious consideration to each patient’s developing capacities for participating in decision-making, including rationality and autonomy. If physicians recognize the importance of assent, they empower children to the extent of their capacity. 12 Even in situations in which one should not and does not solicit the agreement or opinion of patients, involving them in discussions about their health care may foster trust and a better physician-patient relationship, and perhaps improve long-term health outcomes.

Assent should include at least the following elements:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.

2. Telling the patient what he or she can expect with tests and treatment(s).

3. Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).

4. Soliciting an expression of the patient’s willingness to accept the proposed care. Regarding this
final point, we note that no one should solicit a patient’s views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived.

As children develop, they should gradually become the primary guardians of personal health and the primary partners in medical decision-making, assuming responsibility from their parents.

Just as is the case with informed consent, the emphasis on obtaining assent should be on the interactive process in which information and values are shared and joint decisions are made. The Academy does not in any way recommend the development of new bureaucratic mechanisms, such as “assent forms,” which could never substitute for the relational aspects of consent or assent.

THE PATIENT’S REFUSAL TO ASSENT (DISSENT)

There are clinical situations in which a persistent refusal to assent (i.e., dissent) may be ethically binding. This seems most obvious in the context of research (particularly that which has no potential to directly benefit the patient). A patient’s reluctance or refusal to assent should also carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be deferred without substantial risk.

Medical personnel should respect the wishes of patients who withhold or temporarily refuse assent in order to gain a better understanding of their situation or to come to terms with fears or other concerns regarding proposed care. Coercion in diagnosis or treatment is a last resort.

ETHICAL CONFLICT AND ITS RESOLUTION

Social forces tend to concentrate authority for health care decisions in the hands of physicians and parents and this tendency diminishes the moral status of children. Thus, those who care for children need to provide for measures to solicit assent and to attend to possible abuses of “raw” power over children when ethical conflicts occur. This is particularly important regarding the initiation, withholding, or withdrawing of life-sustaining treatment. Examples of mechanisms to resolve ethical conflicts include additional medical consultation(s); short-term counseling or psychiatric consultation for patient and/or family; “case management” or similar multidisciplinary conference(s); and/or consultation with individuals trained in clinical ethics or a hospital-based ethics committee. In rare cases of refractory disagreement, formal legal adjudication may be necessary.

LEGAL EMANCIPATION AND INFORMED CONSENT

The traditional notion of informed consent clearly applies to patients who have reached the legal age of majority, except when the patient has been determined to be incompetent. In addition, laws designate two settings in which minors have sole authority to make health care decisions. First, certain minors are deemed “emancipated” and treated as adults for all purposes. Definitions of the emancipated minor include those who are: 1) self-supporting and/or not living at home; 2) married; 3) pregnant or a parent; 4) in the military; or 5) declared to be emancipated by a court. Second, many states give decision-making authority (without the need for parental involvement) to some minors who are otherwise unemancipated but who have decision-making capacity (“mature minors”) or who are seeking treatment for certain medical conditions, such as sexually transmitted diseases, pregnancy, and drug or alcohol abuse. The situations in which minors are deemed to be totally or partially emancipated are defined by statute and case law and may vary from state to state. Legal emancipation recognizes a special status (e.g., independent living) or serious public and/or individual health problems that might not otherwise receive appropriate attention (e.g., sexually transmitted disease).

PRACTICAL APPLICATIONS

The following illustrations may help practitioners when applying the concepts developed above. These examples are intended to provide a focus for discussion and clarification and do not suggest new legal standards for pediatric practice.

In cases involving the following kinds of medical care for infants and young children, the Academy encourages physicians to seek the informed permission of the parents before: 1) providing immunizations; 2) performing invasive diagnostic testing for a congenital cardiac defect; 3) beginning long-term anticonvulsant therapy to control a seizure disorder; 4) initiating serial casting to correct congenital “clubfoot”; or 5) undertaking surgical removal of a “suspicious” neck mass.

Even in pressing situations, informed permission should be sought for actions such as performing a lumbar puncture to evaluate the possibility of meningitis. (In this situation, if parents deny permission for the procedure, one should obtain permission from the parents to initiate treatment based on reasonable clinical judgment, rather than delaying care or risking liability for performing the lumbar puncture without appropriate authorization).

In cases involving the following kinds of medical care for older school-age children, the Academy encourages physicians to seek the assent of the patient as well as the informed permission of the parents: 1) venipuncture for a diagnostic study in a nine-year-old; 2) diagnostic testing for recurrent abdominal pain in a 10-year-old; 3) psychotropic medication to control an attention-deficit disorder in a third grader; 4) an orthopedic device to manage scoliosis in an 11-year-old; 5) an “alarm” system to treat nocturnal enuresis in an eight-year-old; or 6) surgical repair of a malformed ear in a 12-year-old. In some cases, treatment may proceed over the objection of the patient. However, physicians and parents should realize that overruling the child may undermine their relationship(s) with the child.

In situations such as the following that involve
adolescents and young adults, the Academy encourages physicians to obtain the informed consent of the patient, in most instances: 1) performance of a pelvic examination in a 16-year-old; 2) diagnostic evaluation of recurrent headache in an 18-year-old; 3) a request for oral contraceptives for fertility control in a 17-year-old; 4) proposed long-term oral antibiotics administration for severe acne in a 15-year-old; or 5) surgical intervention for a bone tumor in a 19-year-old. Such patients frequently have decision-making capacity and the legal authority to accept or reject interventions, and, in that event, no additional requirement to obtain parental permission exists. However, the Academy encourages parental involvement in such cases, as appropriate.

Review of the limited relevant empirical data suggests that adolescents, especially those age 14 and older, may have as well developed decisional skills as adults for making informed health care decisions.20–22 Ethical and legal factors, (ie, confidentiality and/or privacy), suggest that the physician involve parents after appropriate discussion with the adolescent elicits his or her permission to do so. In some cases in which the patient has no legal entitlement to authorize treatment, the physician may have a legal obligation in some jurisdictions to obtain parental permission or to notify parents in addition to obtaining the patient’s consent. An adolescent’s refusal of consent in cases such as these may well be legally (and ethically) binding. If “conflict resolution” fails, formal legal adjudication may be needed.

CONCLUSION

A re-analysis of informed consent leads to the identification of important limitations and problems in its application to pediatric practice. Two additional concepts are needed: parental permission and patient assent. The American Academy of Pediatrics believes that in most cases, physicians have an ethical (and legal) obligation to obtain parental permission to undertake recommended medical interventions. In many circumstances, physicians should also solicit a patient assent when developmentally appropriate. In cases involving emancipated or mature minors with adequate decision-making capacity, or when otherwise permitted by law, physicians should seek informed consent directly from patients.

COMMITTEE ON BIOETHICS, 1993 TO 1994
Arthur Kohrman, MD, Chair
Ellen Wright Clayton, MD
Joel E. Frader, MD
Michael A. Grodin, MD
Kathryn L. Moseley, MD
Ian H. Porter, MD
Virginia M. Wagner, MD

LIASON REPRESENTATIVES
Elena A. Gates, MD
American College of Obstetricians and Gynecologists
Serge Melancon, MD
Canadian Paediatric Society

SECTION CHAIRS
Anthony Shaw, MD
Section on Surgery

CONSULTANTS
William Gibson Bartholome, MD
Rebecca Dresser, JD

REFERENCES
15. Shield JPH, Baum JD. Children’s consent to treatment: listen to the children—they will have to live with the decision. Br Med J. 1994;308:1182–1183