

Navigating Decisional Discord: The Pediatrician's Role When Child and Parents Disagree

Bryan A. Sisk, MD,^a James DuBois, DSc, PhD,^b Eric Kodish, MD,^c Joanne Wolfe, MD, MPH,^d Chris Feudtner, MD, PhD, MPH^e

From the time when children enter the preteen years onward, pediatric medical decision-making can entail a complex interaction between child, parents, and pediatrician. When the child and parents disagree regarding medical decisions, the pediatrician has the challenging task of guiding the family to a final decision. Unresolved discord can affect family cohesiveness, patient adherence, and patient self-management. In this article, we outline 3 models for the pediatrician's role in the setting of decisional discord: deference, advocative, and arbitrativ. In the deference model, the pediatrician prioritizes parental decision-making authority. In the advocative model, the pediatrician advocates for the child's preference in decision-making so long as the child's decision is medically reasonable. In the arbitrativ model, the pediatrician works to resolve the conflict in a balanced fashion. Although each model has advantages and disadvantages, the arbitrativ model should serve as the initial model in nearly all settings. The arbitrativ model is likely to reach the most beneficial decision in a manner that maintains family cohesiveness by respecting the authority of parents and the developing autonomy of children. We also highlight, however, occasions when the deference or advocative models may be more appropriate. Physicians should keep all 3 models available in their professional toolkit and develop the wisdom to deploy the right model for each particular clinical situation.

"Sarah" is a mature 11-year-old girl admitted to the hospital with an ulcerative colitis flare. Despite intensive outpatient medical management including biologic therapies and immunosuppression, she continues to experience frequent flares. Each flare requires hospitalization and a course of steroids. These hospitalizations led her to miss more than 30 days of school last year. Her gastroenterologist is concerned about her disease trajectory, and he maps out 2 treatment options. The first is to continue with current therapies in hopes of an improvement in the trajectory of the disease course. The second option would be referral to a surgeon for total colectomy. Although this intervention would eliminate any symptoms directly related to ulcerative colitis, she would then have to manage possible long-term complications of the

surgery, including frequent loose stools, the need for additional surgeries, and a temporary ostomy. After hearing the options, her parents favor the colectomy. Sarah disagrees and tells the physician, "I don't want to have surgery."

Decision-making in pediatrics is a complex interaction involving the pediatrician, the child, and the parents. Most pediatricians adhere to the paradigm of shared decision-making, in which decisional authority and decisional burden are distributed in varying degrees among the child, parents, and pediatrician. The particular nuances of pediatric decision-making, however, pose several challenges to this paradigm.¹

abstract



^aDepartment of Pediatrics, St Louis Children's Hospital, St Louis, Missouri; ^bDepartment of Medicine, Washington University School of Medicine, St Louis, Missouri; ^cPediatrics Institute and Department of Bioethics, Lerner College of Medicine, Cleveland Clinic, Cleveland, Ohio; ^dDepartment of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute and Department of Medicine, Boston Children's Hospital, Boston, Massachusetts; and ^eDepartment of Medical Ethics, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania

Dr Sisk conceptualized the manuscript, performed a literature review, and drafted the initial manuscript; Drs DuBois, Kodish, Wolfe, and Feudtner provided guidance for conceptualization of the manuscript and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: 10.1542/peds.2017-0234

Accepted for publication Mar 9, 2017

Address correspondence to Bryan A. Sisk, MD, Department of Pediatrics, St Louis Children's Hospital, 1 Children's Place, 3S34, St Louis, MO 63110. E-mail: sisk_b@kids.wustl.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2017 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Dr DuBois was supported in part by National Center for Advancing Translational Sciences (UL1TR000448). Funded by the National Institutes of Health (NIH).

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Sisk BA, DuBois J, Kodish E, et al. Navigating Decisional Discord: The Pediatrician's Role When Child and Parents Disagree. *Pediatrics*. 2017; 139(6):e20170234

Whereas the ethical basis of adult decision-making is derived from the doctrine of informed consent, many children do not have full capacity to provide consent.

The elements of informed consent are²:

- Competence
- Disclosure of information
- Understanding of material information
- Voluntariness
- Consent and authorization of a plan

Pediatric decision-making is therefore better understood as a combination of parental permission and child assent.³ Assent does not have a broadly agreed on definition, but generally “child assent refers to affirmative agreement of a minor who is to take part in the informed consent procedure in a way adapted to his or her capabilities, while their legal representative has the formal role of consenting”.⁴

The American Academy of Pediatrics elements of assent are³:

- Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
- Telling the patient what he or she can expect with tests and treatment(s).
- 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).
- Soliciting an expression of the patient’s willingness to accept the proposed care. Regarding this final point, [the committee members] 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

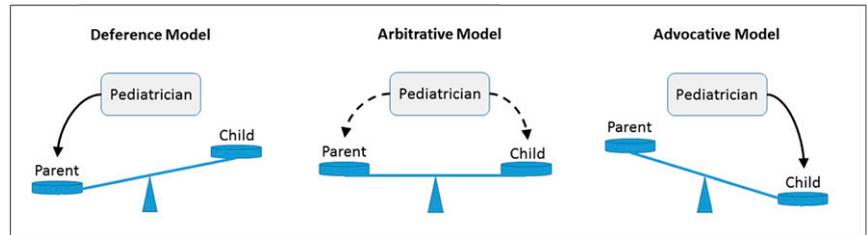


FIGURE 1 Models of the pediatrician’s role when pediatric patient and parent disagree about treatment.

patient should be told that fact and should not be deceived.

This model of permission and assent works well when parents and the child agree, but persistent disagreement between the parent and child can place the pediatrician in a difficult position. Although physicians can support the resolution of many disagreements by helping parents and children to articulate their values and goals, some disagreements will persist.

This decisional discord can go in either direction relative to a given treatment option: the parents may want to pursue a specific treatment and the child patient does not, refusing to provide assent or actively dissenting; or vice versa, the child may want to pursue a treatment option but the parents object. In the setting of either form of discord, the pediatrician should have 2 goals: to help the patient and family reach a decision that is in the best interests of the child, and to reach a decision that parents and the child can agree on and can collaboratively enact. Persistent decisional discord can have a negative impact on family cohesiveness, patient adherence, and patient self-management.⁵ In this article, we describe 3 models for facilitating decision-making in the setting of persistent decisional discord, highlighting circumstances in which each model may be appropriate. Each model is nested within the paradigm of shared decision-making, describing the degree to which decisional authority

is distributed between parents and children.

THREE MODELS OF PHYSICIAN ROLE IN CHILD-PARENT DISAGREEMENT

When a pediatrician encounters decisional discord between a child and parents, there are 3 basic models by which the pediatrician can respond: the deference model, the advocative model, and the arbitrative model (Fig 1). These models apply to disagreements along the full spectrum of medical decisions, including the performance of routine procedures (such as injectable immunization), life-changing interventions (such as treatments to cause pubertal delay in a transsexual child), and end-of-life decisions (such as whether to perform cardiopulmonary resuscitation). In this article, we will explore these models by using the initial case of medical versus surgical management of Sarah’s ulcerative colitis, which represents a decision between 2 clinically reasonable options that will nonetheless have significant life-altering consequences. To examine these models more thoroughly, we will explore how key changes to the scenario highlight the value of each model.

Deference Model

In the deference model, the pediatrician prioritizes parental decision-making authority when there is discord. The deference model is supported by the concept of parental authority, which rests on several justifications: (1) Parents

are responsible for raising their children, and this responsibility necessitates that parents are allowed a reasonable amount of decision-making prerogative; (2) Parents have to live with the consequences of their decisions and provide support for their children; (3) Parents best know their children and are presumed to make decisions in accordance with their children's best interests.^{6,7} When children are young, the deference model is dominant, because the objections of young children to receiving medical treatments are routinely overridden. Some adherents of the deference model also support its application in the care of adolescents, citing data on adolescent impulsiveness, which has been attributed to a "heightened responsiveness to incentives while impulse control is still relatively immature during this period."⁸ (Indeed, in *Roper v Simmons* the Supreme Court specifically identified adolescent impetuosity and susceptibility to outside pressure when making decisions as reasons to abolish the juvenile death penalty.⁹) Some have argued that adolescents do not have the ability to make informed, forward-thinking decisions, and therefore are incapable of making the best decisions.^{10,11} From this point of view, increased parental authority is necessary to protect the child from poor decisions and to teach the adolescent to become a better decision-maker in the future.^{10,12}

The deference model, however, has many opponents. The basis for this opposition arises from a respect for the child's developing autonomy and ability to provide assent.¹³ Although mandated in clinical research,^{14–18} assent in medical decision-making is encouraged but not required.¹⁹ Many argue, however, that assent remains an appropriate goal for all treatment decisions,³ although honoring the child's ability to assent leads to the challenging possibility of dissent.

Additionally, others argue that if parents make decisions on behalf of a child that have long-lasting effects, they may be limiting the child's "right to an open future,"²⁰ a right that "protects the child against having important life choices determined by others before she has the ability to make them for herself."²¹

The deference model may nevertheless be appropriate when the child is unable to demonstrate capacity to engage in the decision-making process. In our initial case, if Sarah had mild cognitive impairments due to an underlying condition, deferring to parental wishes may be more appropriate. Similarly, the deference model may be warranted in the setting of high acuity illness when the decision is time-sensitive, or when the child's decision is not medically appropriate. For example, if Sarah were admitted with acute appendicitis and peritonitis, the physician should support the parents' preferences for surgery despite the child's dissent.

A pediatrician employing the deference model would initially propose diagnostic or treatment options to both the parent and the child and elicit their preferences. When discord becomes apparent, the pediatrician would work with the parents to explain to the child the necessity of the intervention. For our patient with ulcerative colitis, the pediatrician might start by asking the patient, "What worries you about surgery?" Next, the pediatrician might say, "I understand why you are worried. This type of surgery can be scary, but your parents and I feel strongly that this is best for you. We think surgery will help you to live a healthier life and help to keep you out of the hospital. You missed so much school last year and have been away from your friends for so long. There are some downsides to surgery, but we really believe the downsides are outweighed by the long-term benefits."

Advocative Model

In the advocative model, the pediatrician advocates strongly for the older child or adolescent's preference in decision-making so long as the patient's decision is medically reasonable. This model is based on the child's developing autonomy and the benefits of incorporating children in decision-making.

Involving children in decision-making is beneficial in the following ways (adapted from McCabe)⁵:

- Demonstrates respect for children's developing capacities, and may foster further development.
- Supported by ethical principle of patient self-determination, especially as children further develop decision-making capacity.²²
- Improves open communication among physicians, children, and parents, and this communication is fundamental to both children's and parents' satisfaction with medical care.²³ Satisfaction is associated with improved compliance.
- Facilitates the child's cooperation with treatment.²⁴
- Promotes a sense of control for the child.^{25,26}

In support of this model, 1 author argued that "we need to support minors' involvement in decision-making, particularly... where treatment preferences are based upon personal values and 'quality of life' issues."⁵ Additionally, the Children's Oncology Group guidelines state that oncologists should encourage and support the involvement of children in decision-making.^{14,27} Bartholome,²⁸ who pioneered the concept of pediatric assent, went further to state that "children and adolescents should *always* be included in health care decision-making to the extent of their capacity and willingness to do so."

Implicit in these arguments is the premise that many children are capable of making informed, meaningful decisions related to their health. Historically, research on decision-making capacity in children has varied widely in methodology and has often resulted in conflicting results with regard to age and previous experiences.¹⁹ Some studies have suggested, however, that children as young as 9 years can begin to make informed decisions, and may have developed adequate decision-making capacity by adolescence.^{29,30} Others have suggested that children reach adult capacity for abstract thought between 14 and 16 years of age.³¹ Putting the argument into more concrete terms, 1 expert has asserted that “our paradigm should become that adolescents are capable of consent and those wishing to prove otherwise have the burden of proof.”³²

A more recent study used a standardized instrument to assess the capacity of children based on their ability to comprehend and make rational decisions.⁴ These authors concluded that children older than 12 years are generally competent to make rational decisions. They therefore recommended a dual-consent model in which children who demonstrate capacity must provide consent in addition to their parents before a physician can proceed with treatments or procedures. This dual-consent model is used in some European countries,⁴ but has no legal basis in the United States.

Opponents of the advocative model point out that having capacity to reason abstractly may not be sufficient to mandate the child’s preeminence in decision-making. Although the previously mentioned study found evidence of capacity in children as young as 12 years of age, they also acknowledged that “children may differ from adults by not having developed yet stable long

term goals and values in life, meaning that children may procedurally be classified as competent although their decisions are based on values that might change.”⁴ If children are allowed to make decisions, they may make ill-advised choices that they will regret in the future.

Just as the deference model declines in use as patients grow older, the advocative model is increasingly appropriate as children age and demonstrate expanded capacity to engage in the decision-making process. If Sarah were 16 years old, for instance, physicians would likely be less keen to promote surgery against the patient’s wishes. Even at younger ages, the advocative model may be appropriate for decisions that have minimal consequences. For example, pediatricians would appropriately advocate for Sarah’s ability to dissent if she were refusing medication for seasonal allergies.

In practicing the advocative model, the pediatrician would similarly propose options and solicit insights from the child and parents. When discord is appreciated, the physician would support the child’s decision, assuming the child displays sufficient capacity to provide assent or dissent. The pediatrician might say to Sarah’s parents, “I understand your concerns, and I appreciate that you want what is best for your child. That is what any loving parent would want. But I cannot recommend pursuing surgery if Sarah is against it. This is her body and I truly believe we need to respect her decision. I recommend we continue with medical management for now. We can always see how things develop over time.” The pediatrician can also draw out the negative repercussions of overriding Sarah’s dissent: “Furthermore, Sarah is going to have to grow into the self-manager of her IBD for the rest of her life. If we force her to have the surgery, we might win a short-term struggle but really suffer a setback

for our long-term goal of helping her take charge of her own health.”

Arbitrative Model

The arbitrative model resides between the advocative and deference models. In this model, the pediatrician works to resolve the conflict in a balanced fashion, essentially working out a deal that the patient and the parents find acceptable. If an agreement cannot be reached, then the pediatrician would take a tiered approach by (1) further assessing the reasons for discord and facilitating communication between parents and child, (2) discussing the case with a trusted colleague for additional insights, and (3) considering an ethics consultation.

The arbitrative model is based on the principle that parents and children both share decisional authority and both have important insights that should impact the final decision. One way to implement the arbitrative model is by use of “shuttle diplomacy.”³³ As described by Bluebond-Langner et al,³³ the physician employing shuttle diplomacy first meets with the parents to ascertain what options they are amenable to discussing with the child. The physician subsequently meets with the child, either alone or with the parents, to further understand motives, values, and interest in participating. Through a collaborative process, a final decision is made. As noted by the authors, “physicians also must make clear in the meetings alone with a child and in meetings with the parents and child present that although the child will be listened to by the parents and physician, and the child’s wishes taken into account, the decision is not the child’s alone to make.”³³ This diplomatic approach allows all parties to have their voices heard and provides an avenue to deeper understanding of the family unit. Furthermore, this approach protects

the child from shouldering the full burden of decisional authority.

Opponents of the arbitratative model question the value of seeking assent if dissent is not an acceptable outcome.³⁴ Some have further argued that not accepting dissent as a potential outcome of decision-making “makes a mockery of the whole idea of assent.”²⁸ Without the ability to say “yes” or “no,” assent becomes “merely a formality without any true respect for the burgeoning autonomy of the minor patient.”³⁴ In response to the challenge of dissent, the AAP Committee on Bioethics stated: “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.”³ If a child’s opinion is sought but not heeded, the child may feel alienated and the relationship in the family may be further strained.

Some of the techniques used in ethics consultations may further the aims of the arbitratative model, including allowing time for adolescents to absorb information (such as information about surgical side effects, which may be initially experienced as threatening) and proposing time-limited trials (such as continuing medical management for another 6 weeks before revisiting the decision).³⁵ Sometimes conditional commitments (“Would you agree to surgery if medical management does not produce improvements in the next 2 months?”) are easier to negotiate than immediate commitments.

We propose that the arbitratative model should serve as the initial approach to decisional discord in nearly all situations, although as highlighted above, physicians may need to deviate from this model at times. This model is especially appropriate when it is uncertain which decision will yield the

most medical benefit, or if the potential intervention is invasive or has significant consequences. Furthermore, the arbitratative model is most useful when decisions are less time-sensitive. Our initial case represents such a scenario, because Sarah presumably has shown capacity to provide assent (or dissent) and the nonemergent surgery would be permanently life-altering. This model would not be appropriate, however, for situations in which children have a legal right to confidentiality from their parents. For example, many states have legislation that protects the minor’s privacy related to reproductive health and substance abuse, precluding the pediatrician from engaging the parents in discussion without the minor’s approval.³⁶

The pediatrician applying the arbitratative model would first propose diagnostic or treatment options, then seek out the values and motives that drive the decision-making process for the child and parents. The pediatrician would then try to identify which aspects of the decision are negotiable versus nonnegotiable, saying to the parents, “You seem to be most worried about your child’s quality of life and long-term health. After talking with your daughter, she does not feel that her quality of life is greatly suffering right now, and she is frightened of the surgery. Perhaps we could plan to revisit the option of surgery later? In the meantime, we could arrange for her to meet some of our teenagers who have had similar surgeries. They can help her to see what life is like after a colectomy. She may just need more time to process all of this information.”

THE PEDIATRICIAN AND THE ROLE OF EXPERIENTIAL EXPERTISE

Although these 3 models present different notions of how pediatricians should respond to decisional discord between child and parents,

pediatricians have a role across all 3 models as expert that warrants consideration. Some pediatricians may strive to base all treatment recommendations solely on objective data, but this is often impracticable given the unfortunate lack of high-quality data to guide many medical decisions. In addition, we suggest that parents and children do not want a strictly objective recommendation. When seeking the expertise of a pediatrician, they are looking not only for technical expertise, but also the pediatrician’s expertise based on breadth of previous experience caring for patients and families in similar situations. In fact, some families will nudge physicians beyond purely objective answers by asking, “What would you do in my situation?” or, “What would you do if this were your child?” The pediatrician should certainly work to elicit the child’s and parents’ values and goals related to the decision, but this should be followed by a recommendation based on the physician’s expertise in combination with the family’s elicited values.

The recommendations for eliciting priorities and values in discussions with patients and families are:

- Use open-ended questions, and allow the child or parent sufficient time to talk: “What do you really enjoy doing?” “How has this disease affected you and your family?” “Has your illness prevented you from being able to do things that you want to do?” “What are you hoping for?” “What is your biggest worry about the different treatment options?”
- Reflect back the values demonstrated in their responses: “It sounds like you really miss playing on your basketball team.” “It sounds like you are really worried about your friends seeing you with an ostomy.”
- Summarize the conversation: “So, what I am hearing is...”

- At the conclusion of the discussion, provide a recommendation based on your knowledge and experience, and the values expressed by the child and parents. “In light of what we discussed, I would recommend that we...”
- If the decision is not time-sensitive, allow the patient and parents time to process information. Then reengage and help to work toward a decision.

The physician’s combined technical and experiential expertise, therefore, serves as a starting point for decision-making in pediatrics. For parents and patients to make truly informed decisions, the pediatrician must be reflective and transparent about the process by which he or she develops recommendations. Every physician has personal values, preferences, and beliefs that impact the options presented, the manner in which they are presented, and the recommended course of treatment. Such transparency and reflection can help the physician to refocus on the values, goals, and needs of the patient and family. Without this effort, pediatricians run the risk of subverting parental authority and patient autonomy. For example, in 1 study of pediatric gastroenterology and rheumatology patients and parents considering treatment with biologics, providers offered detailed information about their preferred option, but provided less information about other options. “There was minimal elicitation of preferences, treatment goals, or prior knowledge.”³⁷ In one-third of cases, no explicit decision was made, yet the provider took steps to implement his or her preferred treatment. In another recent study, researchers observed physicians during the informed consent conversation (ICC) for enrollment in pediatric Phase I oncology trials with parents and children. In this study, “physicians failed to mention no treatment and/or palliative care as options in

68% of ICCs and that the disease was incurable in 85% of ICCs.”³⁸ Reflective self-management by the pediatrician is essential to creating an environment that supports truly shared decision-making.

CLINICAL USE OF MODELS

When faced with decisional discord, pediatricians must decide how to respond in a way that leads to the best decision for an individual patient and family. Each of the decision-making models described above has different limitations and raises different concerns. Critics of the deference model argue that it fails to fully support or respect the developing autonomy of the child. Opponents of the advocative model posit that many children are incapable of fully appreciating long-term effects of their decisions. Those who are concerned about the arbitratve model question the validity of asking for assent if the pediatrician is unwilling or unable to honor the child’s dissent. Similarly, some state laws preclude the pediatrician’s ability to engage parents on certain topics without the child’s approval. Reviewing these counterarguments shows the challenging situation that pediatricians face when parent and child disagree. Importantly, several other factors can affect this decision-making process. For example, parental discord and chronic family stress are other important barriers to consider. Similarly, culture, religion, mental health issues, and financial constraints also may affect the role of children in the decision-making process. The impact of these factors should also be taken into account by pediatricians as they navigate decisional discord.

CONCLUSIONS

Each decision-making model has value depending on the clinical

situation. We recommend that physicians initially employ the arbitratve model when confronted with decisional discord because this model is most likely to lead to a decision that respects the child’s developing autonomy while also supporting the needs of the whole family. Additionally, this model further reinforces the pediatrician’s mandate to more fully understand the motives and beliefs of the child and parent. Even if compromise remains elusive, the child will know that his or her voice was heard and valued by the pediatrician. When the arbitratve model is either inappropriate or has failed, we recommend that physicians reassess the child’s ability to engage in decision-making, the degree to which the treatment options have equivalent benefit-to-risk profiles, and the invasiveness or permanence of the proposed interventions to determine if the advocative or deference models are appropriate. Pediatricians should strive to keep all 3 models in their professional toolkit, employing the most appropriate model for each individual situation.

ABBREVIATION

ICC: informed consent conversation

REFERENCES

1. Opel DJ. A push for progress with shared decision-making in pediatrics. *Pediatrics*. 2017;139(2):e20162526
2. Nelson RM, Beauchamp T, Miller VA, Reynolds W, Ittenbach RF, Luce MF. The concept of voluntary consent. *Am J Bioeth*. 2011;11(8):6–16
3. Committee on Bioethics; American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314–317
4. Hein IM, De Vries MC, Troost PW, Meynen G, Van Goudoever JB, Lindauer

- RJ. Informed consent instead of assent is appropriate in children from the age of twelve: policy implications of new findings on children's competence to consent to clinical research. *BMC Med Ethics*. 2015;16(1):76
5. McCabe MA. Involving children and adolescents in medical decision making: developmental and clinical considerations. *J Pediatr Psychol*. 1996;21(4):505–516
 6. Schoeman F. Children's competence and children's rights. *IRB*. 1982;4(6):1–6
 7. Cummings CL, Mercurio MR. Ethics for the pediatrician: autonomy, beneficence, and rights. *Pediatr Rev*. 2010;31(6):252–255
 8. Casey BJ, Getz S, Galvan A. The adolescent brain. *Dev Rev*. 2008;28(1):62–77
 9. *Roper v Simmons*, 543 U.S. 551 (2005)
 10. Partridge B. Adolescent pediatric decision-making: a critical reconsideration in the light of the data. *HEC Forum*. 2014;26(4):299–308
 11. Partridge BC. The mature minor: some critical psychological reflections on the empirical bases. *J Med Philos*. 2013;38(3):283–299
 12. Partridge BC. Adolescent psychological development, parenting styles, and pediatric decision making. *J Med Philos*. 2010;35(5):518–525
 13. King NM, Cross AW. Children as decision makers: guidelines for pediatricians. *J Pediatr*. 1989;115(1):10–16
 14. Unguru Y, Coppes MJ, Kamani N. Rethinking pediatric assent: from requirement to ideal. *Pediatr Clin North Am*. 2008;55(1):211–222, xii
 15. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Research Involving Children: Report and Recommendations Publication No. (OS) 77-0044*. Washington, DC: DHEW; 1977
 16. Levine RJ. Research involving children: an interpretation of the new regulations. *IRB*. 1983;5(4):1–5
 17. U.S. Department of Health and Human Services. 45 CFR 46. Subpart D—additional protections for children involved as subjects in research. *Fed Regist*. 1983;48:9818
 18. Kodish E. Informed consent for pediatric research: is it really possible? *J Pediatr*. 2003;142(2):89–90
 19. Miller VA, Drotar D, Kodish E. Children's competence for assent and consent: a review of empirical findings. *Ethics Behav*. 2004;14(3):255–295
 20. Feinberg J. The child's right to an open future. In: Aiken W, LaFollette H, eds. *Whose Child?* Totowa, NJ: Rowman & Littlefield; 1980:124–153
 21. Millum J. The foundation of the child's right to an open future. *J Soc Philos*. 2014;45(4):522–538
 22. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 6th ed. New York, NY: Oxford University Press; 2009
 23. Korsch BM, Gozzi EK, Francis V. Gaps in doctor-patient communication. 1. Doctor-patient interaction and patient satisfaction. *Pediatrics*. 1968;42(5):855–871
 24. Putnam DE, Finney JW, Barkley PL, Bonner MJ. Enhancing commitment improves adherence to a medical regimen. *J Consult Clin Psychol*. 1994;62(1):191–194
 25. Nannis ED, Susman EJ, Strobe BE, et al. Correlates of control in pediatric cancer patients and their families. *J Pediatr Psychol*. 1982;7(1):75–84
 26. Weisz JR, Stipek DJ. Competence, contingency, and the development of perceived control. *Hum Dev*. 1982;25(4):250–281
 27. Joffe S, Fernandez CV, Pentz RD, et al. Involving children with cancer in decision-making about research participation. *J Pediatr*. 2006;149(6):862–868
 28. Bartholome WG. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;96(5 pt 1):981–982
 29. Reyna VF, Farley F. Risk and rationality in adolescent decision making: implications for theory, practice, and public policy. *Psychol Sci Public Interest*. 2006;7(1):1–44
 30. Weithorn LA, Campbell SB. The competency of children and adolescents to make informed treatment decisions. *Child Dev*. 1982;53(6):1589–1598
 31. Kurz R, Gill D, Mjones S; Ethics Working Group of Confederation of European Specialists in Paediatrics. Ethical issues in the daily medical care of children. *Eur J Pediatr*. 2006;165(2):83–86
 32. Zinner SE. The elusive goal of informed consent by adolescents. *Theor Med*. 1995;16(4):323–331
 33. Bluebond-Langner M, Belasco JB, DeMesquita Wander M. "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. *Nurs Clin North Am*. 2010;45(3):329–343
 34. Sinclair SJ. Involvement of adolescents in decision making for heart transplants. *MCN Am J Matern Child Nurs*. 2009;34(5):276–281; quiz 282–273
 35. Lo B. *Resolving Ethical Dilemmas. A Guide for Clinicians*. 5th ed. New York, NY: Wolters Kluwer; 2013
 36. Morreale M, Stinnett A, Dowling EE. *Policy Compendium on Confidential Health Services for Adolescents*. 2nd ed. Chapel, NC: Center for Adolescent Health & the Law; 2005. Available at: www.cahl.org/PDFs/PolicyCompendium/PolicyCompendium.pdf. Accessed March 1, 2017
 37. Lipstein EA, Dodds CM, Britto MT. Real life clinic visits do not match the ideals of shared decision making. *J Pediatr*. 2014;165(1):178–183.e1
 38. Miller VA, Cousino M, Leek AC, Kodish ED. Hope and persuasion by physicians during informed consent. *J Clin Oncol*. 2014;32(29):3229–3235

Navigating Decisional Discord: The Pediatrician's Role When Child and Parents Disagree

Bryan A. Sisk, James DuBois, Eric Kodish, Joanne Wolfe and Chris Feudtner
Pediatrics 2017;139;

DOI: 10.1542/peds.2017-0234 originally published online May 12, 2017;

Updated Information & Services	including high resolution figures, can be found at: http://pediatrics.aappublications.org/content/139/6/e20170234
References	This article cites 32 articles, 6 of which you can access for free at: http://pediatrics.aappublications.org/content/139/6/e20170234#BIBL
Subspecialty Collections	This article, along with others on similar topics, appears in the following collection(s): Ethics/Bioethics http://www.aappublications.org/cgi/collection/ethics:bioethics_sub
Permissions & Licensing	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: http://www.aappublications.org/site/misc/Permissions.xhtml
Reprints	Information about ordering reprints can be found online: http://www.aappublications.org/site/misc/reprints.xhtml

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Navigating Decisional Discord: The Pediatrician's Role When Child and Parents Disagree

Bryan A. Sisk, James DuBois, Eric Kodish, Joanne Wolfe and Chris Feudtner
Pediatrics 2017;139;

DOI: 10.1542/peds.2017-0234 originally published online May 12, 2017;

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/139/6/e20170234>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2017 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

