



## Reasons to Amplify the Role of Parental Permission in Pediatric Treatment

Mark Christopher Navin & Jason Adam Wasserman

To cite this article: Mark Christopher Navin & Jason Adam Wasserman (2017) Reasons to Amplify the Role of Parental Permission in Pediatric Treatment, *The American Journal of Bioethics*, 17:11, 6-14, DOI: [10.1080/15265161.2017.1378752](https://doi.org/10.1080/15265161.2017.1378752)

To link to this article: <https://doi.org/10.1080/15265161.2017.1378752>



Published online: 07 Nov 2017.



Submit your article to this journal [↗](#)



Article views: 351



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 1 View citing articles [↗](#)

# Reasons to Amplify the Role of Parental Permission in Pediatric Treatment

Mark Christopher Navin, Oakland University

Jason Adam Wasserman, Oakland University William Beaumont School of Medicine

Two new documents from the Committee on Bioethics of the American Academy of Pediatrics (AAP) expand the terrain for parental decision making, suggesting that pediatricians may override only those parental requests that cross a harm threshold. These new documents introduce a broader set of considerations in favor of parental authority in pediatric care than previous AAP documents have embraced. While we find this to be a positive move, we argue that the 2016 AAP positions actually understate the importance of informed and voluntary parental involvement in pediatric decision making. This article provides a more expansive account of the value of parental permission. In particular, we suggest that an expansive role for parental permission may (1) reveal facts and values relevant to their child's treatment, (2) encourage resistance to suboptimal default practices, (3) improve adherence to treatment, (4) nurture children's autonomy, and (5) promote the interests of other family members.

**Keywords:** autonomy, informed consent, best interests standard, harm threshold, parental permission, pediatrics

In two recent documents—a policy statement and its accompanying technical report—the Committee on Bioethics of the American Academy of Pediatrics (AAP) identified a set of reasons for pediatricians to value parental permission in health care decision making for children (AAP Committee on Bioethics 2016; Katz, Webb, and AAP Committee on Bioethics 2016). These new documents expand on an earlier AAP statement that addressed the importance of parents in pediatric practice (AAP Committee on Bioethics 1995). In the earlier statement, the AAP argued that while pediatricians have a primary fiduciary responsibility to child patients, it was nonetheless important for parents to participate in health care decision making for their children. The AAP clarified that (what it named) “parental permission” was analogous to informed consent, insofar as it is an ongoing process of informed and voluntary participation in decision making. However, the AAP also clarified that parental permission is distinct from (and less morally important than) the informed consent of adult and mature adolescent patients, since parents are not the pediatrician's patients.

While the 1995 AAP statement was groundbreaking in its defense of the moral importance of parental participation in pediatric care, it also was ambiguous about the reasons parental permission matters. In particular, it contained an implicit assumption that parental involvement was mainly (or exclusively, depending on how one interprets some its ambiguities) of value for facilitating

treatments that physicians had already determined to be in a child's best interests. For example, the AAP statement concluded by observing that “physicians have an ethical (and legal) obligation to obtain parental permission to undertaken [sic] recommended medical interventions” (AAP Committee on Bioethics 1995, 317). While the 1995 statement advised due caution when overriding parental decisions about their children's health care, it gave physicians great latitude, since it identified a failure to promote a child's best interest as a reason for doing so.

The 2016 AAP statements are notable for establishing a clearer and more expansive terrain for parental decision making by concentrating the justification for acting against parental requests around a harm threshold. To be clear, these statements acknowledge that physicians should continue to promote the best interests of their child patients, even while walking back the latitude that physicians have for overriding parental permission, that is, from a best interest standard to the harm threshold. In doing so, the AAP statements introduce a broader set of considerations in favor of parental authority in pediatric care, and they acknowledge the possibility that physicians and parents may have reasonable disagreements about what is in a child patient's best interests.

Notably, the 2016 AAP documents come at a time when the ethical pendulum of clinical practice generally is swinging toward a new form of beneficent paternalism, after several decades of laissez-faire autonomy (Hans,

Dubé, and Wasserman 2015). Thus, to some degree, the 2016 AAP statements go against the grain of a transitioning culture of both clinical practice and medical ethics, which involves greater openness to forms of paternalism, expanded rights of physicians to dismiss noncompliant patients, increased resistance to family requests for medically inappropriate care, and a new openness to the ethical permissibility of nudging and other potentially autonomy-mitigating persuasive techniques. Of course, changes in medical decision-making practices have not been monotonal and are often context-dependent. For example, the recent emphasis on shared decision making acknowledges the importance of active roles for patients in clinical care, but it also emphasizes the authority of physicians, not just for identifying a menu of options, but for helping guide a patient's selections from that menu of options.

Given some of these recent shifts, it may seem out of place for the AAP to promote greater latitude for parental decision making. However, we argue that the 2016 AAP statements actually understate the importance of parental permission. While we agree with the main arguments, we believe there are additional reasons to care about parental permission in pediatric decision making that are not explored in those statements. Our purpose in this article, therefore, is to provide a more expansive account of the value of parental permission in pediatric decision making, which includes discussion of several frequently neglected considerations.

In what follows, we illustrate the importance of parental permission using cases of health care decision making for infants and young children. These sorts of cases allow us to focus narrowly on ways in which parental permission may contribute to a child's best interests, or in which parental permission may undermine a child's best interests in a morally permissible manner, that is, one that does not rise to the level of harm. Of course, parental permission matters in cases of medical decision making for older children, too, but those cases are often complicated by the fact that older children can assent to their treatments or provide informed consent. And while it is ultimately important to evaluate the relationship between parental permission and a child's assent or informed consent, this article aims at a necessarily prior task, namely, identifying the reasons why parental permission matters.

### **PARENTAL IDENTIFICATION OF A CHILD'S BEST INTERESTS**

Pediatricians are experts. They typically have far more experience with medical decision making than parents, and they have often dealt with the outcomes of significant pediatric health care interventions. In contrast, parents are usually making a particular health care decision for the first (and often last) time, and few will have prior experience with the outcomes of those decisions. Accordingly, physicians may seem to be in a better position than parents when it comes to assessing whether particular treatments

are in a child patient's best interests (Appel 2009; Emanuel 1991). This view was implicit in the 1995 policy statement, but it entails several troubling assumptions about the nature of children's "best interests." In particular, it contains an assumption that "best interests" is a relatively objective, predictable, and measurable outcome at which pediatric treatments ought to be aimed. One can narrow the scope of best interests in this way, of course, particularly by limiting the considerations of a treatment to the intervention itself and by limiting the outcomes of that intervention to its specific physiological effects. But when a pediatric patient's interests are considered more broadly, it becomes clear that parental permission should be seen as more than merely a conduit for (or blockade of) the treatment decisions physicians have made.

Even though pediatricians are experts, parents are sometimes better able to identify their child's interests in health care decision making. And efforts to cultivate parental permission for pediatric treatment may reveal knowledge that parents have about what is in the child patient's interests. This reason to value parental permission is briefly acknowledged in the 2016 AAP statements: "Parents generally are better situated than others to understand the unique needs of their children and family and make appropriate, caring decisions regarding their children's health care" (Katz, Webb, and AAP Committee on Bioethics 2016, e5; see also AAP Committee on Bioethics 2016, 5).

We agree, but we think it is important to distinguish two ways in which parents may be positioned to identify and protect their children's interests. On one hand, there are some facts and values relevant to a child's treatment that physicians rely on parents to reveal. In this case, physicians either cannot identify a child's best interests without parental participation, or they must rely on a reductive conception of a child's best interests. We think the 2016 AAP statements are likely pointing to this role for parents in medical decision making as a source of the value of parental permission. On the other hand, parents are often better able to identify and resist clearly suboptimal default practices in the health care setting. Even when it is clear to both parents and physicians that a practice is suboptimal—by which we mean simply that it is less than best medical practice—it may be easier for parents to see and respond to this fact because of their position as parents.<sup>1</sup> We see no indication that the 2016 AAP statements embrace this additional account of the valuable contributions parental permission can make to identifying a child's best interests.

---

1. Reasonable people can disagree about what constitutes best medical practice, and consequently, they can also disagree about what constitutes suboptimal practice. However, in the context of this section, we use "suboptimal" to characterize situations in which there is wide consensus about what course of action is best, and yet something other than this option is chosen, for example, with predictably worse outcomes or less efficacy than other options would have offered.

## Revealing New Information About a Child Patient's Interests

Parents can often provide physicians with information that is necessary for determining which health care interventions are in a child's interests. In these cases, active parental involvement in decision making—and respect for parental permission—promotes children's interests by revealing facts or values that alter the decision about what is best, particularly where consideration of that information or those values promotes a shift in the definition of best interest in ways that bring in considerations beyond the typical medical paradigm (Wilkinson and Nair 2016). The fact that parents can provide this sort of information when they are involved in pediatric decision making is a reason to value parental permission.

Parents have access to a set of facts about their children that it might be difficult or impossible for physicians to access without parental disclosure. This includes information about a child's medical history, symptoms, therapeutic adherence, and responses to treatment. For many diseases, a significant amount of diagnostic information must be self-reported (or, in pediatric care, parent-reported). This is especially the case for chronic and behavioral disorders, the symptoms of which are more diffuse and ambiguous, sometimes only intermittently visible, and typically not subject to laboratory screening (Holman and Lorig 2004). Parents therefore play a key role in reporting information used in the differential diagnosis. Because the presence or absence of particular symptoms can cause significant changes in the ultimate diagnosis, parents are important not just because they contribute to the physician's knowledge of the child patient, but because they are necessary to evaluate "fit" for a diagnostic proposition. In a real way, therefore, parents are often partners with physicians in determining appropriate medical care for their children. Given the importance of active parental involvement for fact-finding and evaluation of diagnoses in pediatric care, there is good reason to value parental permission in pediatric decision making.

Consider the example of attention-deficit/hyperactivity disorder (ADHD). An ADHD diagnosis requires longitudinal observation that is unlikely to be directly available to physicians, but will require parental input. For instance, DSM-V criteria for ADHD diagnosis include the observation of at least six kinds of behaviors, most of which occur at school, work, or home, and which must persist for at least 6 months (American Psychiatric Association 2013). ADHD diagnosis also rests on observations that include implicit normative judgments, that is, about whether a child's has such symptoms "to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities" (American Psychiatric Association 2013, 59). Even if a child patient could accurately report on her particular behaviors, parents are much more likely to be able to report whether these behaviors deviated from context-specific behavioral norms. Therefore, parental permission may have epistemic

benefits in diagnosis practices, even when children are old enough to report on their own experiences.

One might object that the fact that parents know a great deal about their children does not count in favor of parental permission, because gathering medical history comes before diagnostic testing or treatment, and because parental permission is germane only to acute diagnostic testing or treatment decisions. However, this objection has teeth only if parental permission is narrowly defined in terms of parental assent or dissent from recommendations made antecedently by physicians. But our use of "parental permission"—like the AAP's use of "parental permission"—denotes an ongoing process of informed and voluntary participation in medical decision making (something that echoes shared decision-making precepts). The process of parental permission involves parents throughout the diagnostic process. More broadly, a parent's decision to give or withhold observational information, and the extent to which parents are forthcoming about potentially relevant facts and values about their child, constitute a form of permission (or potentially passive resistance), such that parental permission clearly matters, at least implicitly, in the process of gathering a medical history.

Parents also possess unique value understandings that do not function solely as fuel for the standard clinical evaluation about the best thing to do for the child. Parents' knowledge regarding the values and lifestyles of their families can fund an expansion of what counts as "best interest," beyond typical clinical considerations. Specifically, parents know about the social, cultural, and religious contexts in which their children live, while physicians are frequently misinformed about patients' preferences and values (Mulley, Trimble, and Elwyn 2012), often because physicians wrongly assume that they share values and worldviews with their patients (Suarez-Almazor et al. 2001). For example, if parents have a commitment to "natural" lifestyles that involve the avoidance of "artificial" ingredients, and a reliance on diet and exercise for good health, then some interventions may (of their nature) undermine the child's interests in ways that are not obvious to the physician (Navin 2015). Also, parents may know that a particular medical choice would lead the child to experience guilt, or shunning, or loss of some community goods, as in the case of blood transfusions for children of Jehovah's Witnesses (Davis 1994). In these kinds of cases, involving parents in pediatric health care decision making—and valuing parental permission—can help to identify treatments that will best promote the child patient's interests, not only by supplying information used to calibrate diagnosis and treatment, but by promoting reflexive consideration about what constitutes a child's best interests. Of course, a physician's responsibility to defer to parental judgments about a child's best interests is limited by the harm threshold. So, for example, a physician may have sufficient reason to defer to parental judgments about whether non-lifesaving blood products are net benefits for a child raised in Jehovah's Witness community.

However, parental permission is clearly not sufficiently valuable to justify deference to a parental preference to refuse lifesaving blood products for their child, since acting on this preference would clearly cross the harm threshold.

### Resisting Suboptimal Defaults

When parents bring their children to be treated in the clinic or hospital, they are usually narrowly focused on promoting their children's interests. Of course, physicians usually profess and aspire to put their patients first, but they are often not able to be as narrowly focused on this goal. In particular, physicians practice against the background of clinic and hospital protocols and policies that, while perhaps optimal for patients in the aggregate, may fail to best promote a particular individual patient's interests at a particular time and under particular conditions. Complex institutions, like hospitals, use rules and procedures to coordinate the activity of their many interdependent personnel. Rules and procedures can promote great goods—including efficiency and predictability—and they can be better in the aggregate than a policy of case-by-case decision making by medical staff. But in any bureaucratic system, even the best general policies can provide suboptimal results in particular circumstances. Because parents are usually not focused on the aggregate goods at which clinic and hospital policies aim, but aim more narrowly at their children's interests, they are in a unique position to resist rules and procedures that may lead to suboptimal results for their child.

Consider a hospital policy to vaccinate all newborns against hepatitis B in the hours immediately after birth. There are excellent reasons for this general policy: Errors in testing or in reporting mothers' hepatitis B status are common, which means that some infected mothers will not be identified prior to childbirth. Since infected mothers are likely to transmit hepatitis B during childbirth, and since it can be difficult to diagnose hepatitis B in young infants (where it can cause serious liver damage and death if left untreated), the Centers for Disease Control and Prevention (CDC) recommends universal vaccination of neonates (Centers for Disease Control and Prevention 2006).

Even though universal neonatal hepatitis B vaccination likely has optimal aggregate outcomes, it is sometimes not in the interests of a particular infant to receive hepatitis B vaccine in the hours immediately after childbirth. Indeed, one of the authors and his wife refused this vaccine when hospital staff attempted to give it to their hours-old infant. This was because the infant's mother was HBsAg-negative, because the new baby was sleeping skin-to-skin with the mother when hospital staff entered the room, and because the parents knew their infant could easily receive the vaccine at an upcoming visit to the pediatrician. In this case, taking parental permission seriously led to a choice that what was best for their child. Parental permission promoted a child patient's interests (e.g., in rest, maternal bonding, establishing breastfeeding relationship) by

empowering parents to resist a generally justifiable policy that would have been suboptimal when applied under those particular conditions.

The machinations of the health care system are often not in particular patients' interests, even if they achieve optimal aggregate results. Therefore, an important reason to value parental permission is to empower parents to resist default practices under those conditions. Someone might object that the existence of this sort of case is not a reason to value parental permission, because physicians will always resist bureaucracies that fail to promote their patients' best interests. But this is too optimistic an account of the capacities of physicians to resist the default policies and protocols that shape their decisions. Physicians are human (even if they are generally very good humans), and it would take superhuman cognitive control for physicians to maintain a constant critical attitude toward not only the default policies of the clinic and hospital, but also their personal habituation to those practices. Physicians also have to balance the needs of many patients within systems in which resources can be scarce. These sorts of considerations also may also exercise influence on treatment decisions, even if their influence is not conscious to physicians. Prioritizing parental permission is a way to enlist parents to help physicians identify those times when deviating from bureaucratic protocols promotes particular patients' interests.

In practice, we suspect that most physicians are already promoting parental permission and that they are doing so for many of the reasons we articulate here (even if only implicitly). For example, it seems likely that most physicians engage in effective, empathetic, and nondefensive communication with parents who ask to deviate from standard policies and procedures. These physicians are, in practice, promoting parental permission in ways that may lead them to reject suboptimal clinic and hospital defaults. Our aim in this article is not to criticize physicians, nor to suggest that they are unaware of the ideas we have raised, but rather to provide a more explicit account of the ethical foundations of parental permission.

### THERAPEUTIC ADHERENCE

Parents may be more likely to complete treatment protocols when they take an active role in deciding on those protocols. There is evidence that this kind of shared decision making often leads to greater agreement about treatment and greater adherence to treatment plans (Joosten et al. 2008; Shay and Lafata 2015). Valuing parental permission is a means of encouraging greater shared decision making in pediatric practice. Therefore, parental permission is a means for achieving greater adherence to treatment plans, which is clearly in children's interests. We suspect that physicians are well aware that parental permission can encourage therapeutic adherence, but this potential upshot of parental permission is not explicitly accounted for in the 2016 AAP documents.

In some cases, valuing parental permission will lead parents to adhere to treatment plans that the physician agrees to be in the best interests of the child patient. More difficult (and more interesting) cases occur when parents will adhere only to treatment plans that the physician believes to be suboptimal. In this sort of case, it may seem as if valuing parental permission fails to promote children's interests, since there was a better treatment plan to which parents did not give their permission. But this is true only if, as discussed in the preceding, we subscribe to a narrowly scoped view of "best interest." When considered more broadly, it can sometimes be better overall for a child if their parents to adhere to a suboptimal plan than for parents to fail to comply with an optimal plan that a physician attempts to impose. For example, suppose there is a parent who will not agree to vaccinate on schedule, but will agree to an alternative "slowed-down" vaccination schedule (e.g., Sears 2007). In this case, valuing parental permission—and agreeing on the slowed-down schedule to which the parents will adhere—will have a net positive result, because the parent would not have adhered to the normal schedule. Even though following a slowed-down vaccination schedule will marginally increase a child's risks of acquiring vaccine-preventable diseases (since she will remain unvaccinated for a longer period than normally), physicians who can get parents to adhere to this schedule do better for their child patients than do physicians who insist on the normal schedule but fail to generate parental agreement and adherence.

Chronic conditions require intensive and long-term management. In pediatric health care, parents are responsible for providing much of the care for their children's chronic conditions. Therefore, when treatments are not simply interventional acts of physicians on pediatric patients, but rather require active involvement of parents, the fact that parental permission promotes treatment adherence makes parental permission especially important. More than ever before, the more complex dynamics of diagnostic processes (detailed earlier, in the second section) and treatment (articulated here) that attend the chronic illness era (Wasserman and Hinote 2011) position parents as medical providers for their children. Identifying and protecting an expanded role for parental permission is a means of recognizing that parents are effectively members of the health care team, particularly when their children have chronic illnesses. By amplifying the role of parental permission, we can foreground the necessity of parental buy-in on those diagnosis and treatment plans.

Of course, parents sometimes may only accept and adhere to treatment plans that physicians believe are so suboptimal that they ought not agree to them. These are cases in which treatment plans would cross the harm threshold. In this kind of case, we agree that physicians may attempt to overrule parents (and bypass parental permission) since doing so is necessary to avoid imposing significant risks of serious harms on child patients (AAP Committee on Bioethics 2016; Katz, Webb, and AAP Committee on Bioethics 2016). It is an important feature of the

2016 AAP documents that they expand the latitude of parental decisions, but that they limit that latitude with the harm threshold. In this way, the AAP has signaled that physicians should sometimes be willing to agree to treatments that they believe are suboptimal, if nonharmful suboptimality is the price of parental adherence.

## CONTRIBUTING TO THE AUTONOMY OF CHILDREN

Children have better outcomes for education, employment, income, and so on if their parents show them how to exercise authority in their social worlds, rather than encouraging children to be subservient and compliant (Joussemet et al. 2005). Thus, there may be benefits for children in watching their parents act autonomously. And these benefits sometimes may be significant enough to compensate for the fact that some parental pediatric health care decisions will not promote the child's best interests in other ways. These considerations are not explicit in the AAP 2016 statements, but they weigh in favor of an expanded role for parental permission.

The tendency of parental permission to promote a child's (future) autonomy likely emerges in specific and important ways within different social structural contexts. In particular, it may be especially beneficial when physicians encourage parents from historically disfranchised demographic groups to participate in informed decision making about their children's health care. Research suggests, for example, that there are stark differences between the ways in which working-class parents teach their children to interact with authority figures and the ways that middle- and upper-class parents pursue this task (Lareau 2003). While working-class parents encourage their children to be subservient and to practice private forms of resistance, better-off parents encourage their children to exercise autonomy in their relationships with authority figures. These class-based differences in deference to authority figures can be amplified when they intersect with other demographic differences, for example, of gender, race, or ethnicity. Of course, one might occupy any number of differently positioned social categories, some more or less advantageous than others. However, despite the fact that multiple intersecting social positions combine with individual factors to create an individualized experience for any particular patient, it is an important sociological consideration to characterize how parental permission may act as a countervailing factor to exercises of power, particularly for members of groups that tend to be disempowered.

In general, middle- and upper-class parents expect shared decision making with physicians about their children's health care choices. Two recent systematic reviews found that higher class patients asked more questions, made more opinionated statements, and were more expressive, while at the same time lower class patients received less information and less patient-centered communication (Verlinde et al. 2012; Willems et al. 2005). Relatively wealthier parents will tend to make sure that their

voices are heard, regardless of whether physicians consciously promote parental permission. Therefore, if physicians do not actively encourage parental permission, then working-class parents will likely have starkly different interactions with their children's physicians. If physicians want to avoid reproducing class-based differences in the ways in which parents (and, ultimately, children) interact with authority figures, then physicians ought to resist the default manner in which working-class parents interact with physicians. This is not to suggest that physicians can by themselves undo class-based differences or prevent parents from passing their class advantages to their children. But physicians can resist participating in the reproduction of class advantages, and one way to do that would be to value the permission of all parents in pediatric decision making. To be clear, we do not think that these efforts involve the use of children as tools in political struggle. Instead, our point is that parental permission may mitigate some of the ways in which children experience the harmful consequences of social inequalities that can manifest in clinical encounters.

Physicians who promote parental permission will not only resist the tendencies of some parents to be excessively deferential, but they will also resist their own tendencies to vary their behaviors based on their expectations about parents from different socioeconomic groups. In one classic study on this topic, Waitzkin (1985) found that when physicians interact with patients who have higher levels of education, they tend to spend more time and to explain things in multiple ways, including re-explaining technical statements in everyday language. More recently, a systematic review confirmed that patients from lower socioeconomic strata received not only less information, but physicians engaged them with a "more directive and less participatory consulting style" (Willems et al. 2005, 139). The fact that physicians vary their own behaviors in response to their expectations about patients' class membership provides further reason to think that physicians who proactively promote parental permission will resist troubling class-based differences in clinic interactions.

Promoting the development of autonomy in children also has important downstream consequences. Children who learn to exercise autonomy and actively participate in decision making are likely to become adult patients capable of doing so, not only as they are involved in their own health care, but as they contribute to the health care decision making of their own children and other relatives. For example, a child who learns to autonomously interact with medical professionals may, later in life, be a better surrogate decision maker for her infirm parents.

### **BENEFITS TO PARENTS AND OTHER FAMILY MEMBERS**

Up to this point in the article, we have focused our attention on the diverse ways that parental permission promotes a child patient's interests. The 2016 AAP statements also focus only on the ways in which parental permission

promotes the interests of the child patient. But the interests of the child are not the only source of reasons to value parental permission, even though it is common for people to characterize the value of parental permission in this narrow way (e.g., Birchley 2016). Another reason to care about parental permission is because it promotes the interests of parents and other family members. Of course, physicians have a primary responsibility to their child patients. But in some situations it may be ethically permissible to consider the interests of other people who are affected by treatment decisions, even at some cost to the interests of the child patient, if those costs do not rise to the level of harm.

Parents generally have wide discretion to act in ways that do not maximally promote their children's interests. For example, parents may buy their children video games, rather than violin lessons; or they can let their children play football rather than (the much safer) baseball (AAP Council On Sports Medicine And Fitness 2012). Parental discretion is not merely a legal right—a right that is justified, for example, because it is impractical for the state to coerce parents to maximize their children's interests. Instead, we think it is sometimes morally permissible for parents to make decisions for their children that do not promote their children's interests, as long as they do not cross the harm threshold.

When we protect a larger domain for parental discretion, as the revised AAP policy instructs physicians to do, we promote values—including intimacy, security, and spontaneity—that autonomous parenting relationships cultivate (Brighouse and Swift 2014). And it is important to promote these goods for parents, even at some cost to children's interests. The goods of autonomous parenting provide reasons to value parental discretion in decisions about children's health care decisions, in the same way that they count in favor of parental discretion in decisions about children's education, enrichment, and leisure (Wilkinson and Nair 2016, 117)

Trade-offs between the interests of parents and the interests of children should be familiar to parents, and they should be especially familiar to people who have divided parenting responsibilities with others. For example, both of the authors have sometimes disagreed with our spouses about what would be best for our children. And we have sometimes used the following sort of defense of our preferred parenting choices: "Even if you're right that it's not best for our child to watch that show / eat that food / stay up that late, it's still good for me to sometimes make my own parenting decisions, even at some cost to our child's interests." The experiences that these spousal confrontations aim to protect are often occasions of intimacy and bonding between the child and the parent asserting the particular decision. We may characterize the value of parental permission in pediatric care in a similar way: Even if a physician knows which treatment would be best for a child (an assumption that we should not easily grant, for reasons addressed in the preceding), the fact that parental discretion promotes a parent's interests sometimes counts in favor of letting parents make decisions,

even at some cost to the interests of the child patient. The fact that parental discretion is good for parents therefore counts in favor of parental permission in pediatric medicine, beyond considerations of the child's interests, though not rising above the threshold of harm.

Parents' interests have significant moral weight when pediatric health care decision making focuses on interventions that will impose great costs on parents. Consider the choice of whether to embrace comfort-focused care for a physically and cognitively disabled neonate who is suffering considerable pain, and who has no chance for significant improvement. Even if it were in this infant's interests to stay alive, it counts in favor of allowing a natural death if keeping the infant alive would seriously burden its parents. If parents lack the money, time, psychological fortitude, and so on to care for such an infant, then these facts about parents' interests count in favor of choosing comfort-focused care (Hardwig 1990). We may say something similar about interventions that reduce caregiving burdens for parents of severely disabled children. For example, consider the case of Ashley X, a severely disabled child who was subjected to growth attenuation, hysterectomy, and breast bud removal to make it easier for her parents to care for her. Some people, including her own parents, argued that those treatments were in Ashley X's best interests (Diekema and Fost 2010). However, we argue here that it would suffice to show that those treatments provided comparatively large benefits to her parents with comparatively small costs to Ashley X. Certainly, some argued that there were significant harms to Ashley X, which would cross the harm threshold, while others argued that the costs (if any) were comparatively small. However, we need not delve empirically into those claims to underscore our argument, according to which benefits to parents might be enough, under certain conditions and in sufficient proportions, to justify treatment decisions that are not in the best interests of a child (provided those decisions do not cross the harm threshold).<sup>2</sup> By taking parental permission seriously, physicians can make it more likely that parents' interests get the consideration they deserve in pediatric health care decision making (Blustein 2012; Salter 2012; Wilkinson and Nair 2016).

Our argument in this section takes for granted that it is sometimes possible to distinguish between the interests of the child patient and the interests of other members of the family. But in many cases this distinction may be difficult to draw, since the interests of family members are often intertwined. Children have interests in the flourishing of their families and in the well-being of their family members. Since families typically are not arbitrary sets of self-

interested individuals, but collective agents of solidarity and mutual commitment, the interests of a child are often inexorably bound up with the interests of the other members of her family (Nelson and Nelson 2014). Moreover, families form identities through their exercise of particular dispositions and patterns, and the development of these identities can strengthen relationships and promote interconnectedness among those families. In short, even parenting decisions that are suboptimal for a particular child from a medical standpoint could strengthen families both by promoting the interests of other family members or the family unit as a whole and by strengthening family bonds in ways that promote a deeper sense of identity.

### A BRIEF COMMENT ON OLDER CHILDREN

Throughout this article, we have bracketed questions about potential conflicts between parents and child patients regarding the facts, values, and judgments relevant to diagnosis and treatment. Our examples and discussion have focused on parental participation in the health care of their young children, that is, children who are usually unable to participate in their own health care decision making. However, parent-child conflicts are a reality of pediatric medical decision making, especially in the case of older children. Therefore, a more expansive account of the value of parental permission will have to characterize the relative values of parental permission and a child patient's assent or informed consent, especially in situations in which these conflict with each other. While it is beyond the scope of this article to address these kinds of conflicts, it may be helpful to make a few comments on the value of parental permission in cases of parent-child conflicts.

Parental permission matters in cases of pediatric decision making for older children for the same reasons it matters in cases of pediatric decision making for younger children. Even in cases involving older children, parental permission can reveal facts and values relevant to their child's treatment, encourage resistance to suboptimal default practices, improve adherence to treatment, nurture children's autonomy, and promote the interests of other family members. However, the presence of conflicts between parents and older children complicates questions about how much weight to give to parental permission, and will require attention to the details of particular cases. For example, parents are sometimes able to provide information and normative judgments that are inaccessible to older child patients, as in the case of ADHD diagnosis we discussed earlier. In this sort of case, physicians should place great weight on parental permission, even in the face of contradictory fact claims and value judgments from older child patients. For another example, the fact that parental permission is an effective means for protecting the interests of other family members is a reason to give parental permission significant weight, even when older children do not assent to the treatments that parents have

---

2. It is worth noting that our argument seems to go a step further than the one offered by Liao, Savulescu, and Sheehan (2007), according to which pediatric treatment decisions that benefit parents can be justified, even if they do not promote the child patient's best interests, on the grounds that parents should not be forced to make unreasonable sacrifices to promote their children's best interests.

endorsed. Of course, the harm threshold identifies an absolute limit for parental permission in this sort of case, as it does in all cases. Finally, if an older adolescent patient (who is capable of informed consent) fails to provide informed consent to a procedure, this will usually be a sufficient reason to override parental permission, regardless of the values that parental permission might serve in this sort of case. Physicians should still seek parental permission in cases involving older adolescent children, for the reasons we discuss throughout this article, but the autonomy of the older adolescent patient should generally trump parental preferences in cases of conflict.

## CONCLUSION

The central thesis of this article is straightforward: There are reasons to value parental permission that warrant giving wider latitude to parental decision making than the best interest standard arguably allows. In light of this thesis, we conclude that the new AAP statements on parental permission in pediatric care provide an ethically defensible and sociologically aware stance for pediatric ethics, particularly where they invoke a harm threshold to identify limits on permissible physician override of parental permission (AAP Committee on Bioethics 2016; Katz, Webb, and AAP Committee on Bioethics 2016). While we embrace the AAP's newly expansive conception of the value of parental permission, this article has introduced and defended numerous additional reasons to value informed and voluntary parental participation in pediatric decision making.

Clearly, physicians possess a great deal of knowledge about health and illness. But from the perspective of the average person, who faces so many ambiguous chronic disease threats today, along with a constant stream of fatiguing "medical reversals" (Prasad and Cifu 2015), questions about how to be healthy have become more perplexing, and people increasingly navigate medical decision making by relying on their own values and concepts of self. In this context, it is outdated to conceive of parental involvement in pediatric care as merely a conduit for the implementation of treatment plans that pediatricians have identified. The point at which we set the trigger for allowing physicians to subvert parental values or ignore parental permission must be reflexively considered in light of this shifting landscape. Centering physician override of parental authority around a harm threshold appears to set the most reasonable bright line. It provides an appropriate accommodation to the rights of parents to involve their values and identities in treatment decisions for their children—which promotes the array of advantages discussed throughout this article—while protecting children against serious harm. ■

## REFERENCES

AAP Committee on Bioethics. 1995. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 95 (2):314–17.

AAP Committee on Bioethics. 2016. Informed consent in decision-making in pediatric practice. *Pediatrics* 138 (2):July:e20161484.

AAP Council on Sports Medicine and Fitness. 2012. Baseball and softball. *Pediatrics* 129 (3):e842–56. <https://doi.org/10.1542/peds.2011-3593>

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders*, 5th ed. Washington, DC: American Psychiatric Publishing.

Appel, Jacob M. 2009. Neonatal euthanasia: Why require parental consent? *Journal of Bioethical Inquiry* 6 (4):477–82. <https://doi.org/10.1007/s11673-009-9156-3>

Birchley, G. 2016. The harm threshold and parents' obligation to benefit their children. *Journal of Medical Ethics* 42 (2):123–26. <https://doi.org/10.1136/medethics-2015-103283>

Blustein, J. 2012. Doing the best for one's child: Satisficing versus optimizing parentalism. *Theoretical Medicine and Bioethics* 33 (3):199–205. <https://doi.org/10.1007/s11017-012-9222-4>

Brighouse, H., and A. Swift. 2014. *Family values: The ethics of parent-child relationships*. Princeton, NJ: Princeton University Press.

Centers for Disease Control and Prevention. 2006. A comprehensive immunization strategy to eliminate transmission of hepatitis B virus infection in the United States. *Morbidity and Mortality Weekly Report* 55:RR-16. <http://www.cdc.gov/mmwr/pdf/rr/rr5516.pdf>.

Davis, D. S. 1994. Does 'no' mean 'yes'? The continuing problem of Jehovah's Witnesses and refusal of blood products. *Second Opinion (Park Ridge, Ill.)* 19 (3):34.

Diekema, D. S., and N. Fost. 2010. Ashley revisited: A response to the critics. *American Journal of Bioethics* 10(1):30–44. <https://doi.org/10.1080/15265160903469336>

Emanuel, L. 1991. PSDA in the clinic. *Hastings Center Report* 21 (5):S7. <https://doi.org/10.2307/3562901>

Hans, D. R., P. Dubé, and J. A. Wasserman. 2015. Experimental evidence showing that physician guidance promotes perceptions of physician empathy. *AJOB Empirical Bioethics* 7:135–39. <https://doi.org/10.1080/23294515.2015.1047474>

Hardwig, J. 1990. What about the family? *Hastings Center Report* 20 (2):5–10. <https://doi.org/10.2307/3562603>

Holman, H., and K. Lorig. 2004. Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports* 119 (3):239. <https://doi.org/10.1016/j.phr.2004.04.002>

Joosten, E. A. G., L. DeFuentes-Merillas, G. H. De Weert, T. Sensky, C. P. F. Van Der Staak, and C. A. J. de Jong. 2008. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy and Psychosomatics* 77 (4):219–26. <https://doi.org/10.1159/000126073>

Joussemet, M., R. Koestner, N. Leke, and R. Landry. 2005. A longitudinal study of the relationship of maternal autonomy support to children's adjustment and achievement in school. *Journal of Personality* 73 (5):1215–36. <https://doi.org/10.1111/j.1467-6494.2005.00347.x>

Katz, A. L., S. A. Webb, and AAP Committee on Bioethics. 2016. Informed consent in decision-making in pediatric practice. *Pediatrics* 138 (2):July:e20161485. <https://doi.org/10.1542/peds.2016-1485>

- Lareau, A. 2003. *Unequal childhoods: Class, race, and family life*. Berkeley, CA: University of California Press.
- Liao, S., J. Savulescu, and M. Sheehan. 2007. The Ashley treatment: Best interests, convenience, and parental decision-making. *Hastings Center Report* 37 (2):16–20. <https://doi.org/10.1353/hcr.2007.0027>
- Mulley, A. G., C.s Trimble, and G. Elwyn. 2012. Stop the silent misdiagnosis: Patients' preferences matter. *British Medical Journal* 345 (1):e6572.
- Navin, M. 2015. *Values and vaccine refusal: hard questions in ethics, epistemology and health care*. New York, NY: Routledge.
- Nelson, H. L., and J. L. Nelson. 2014. *The patient in the family: An ethics of medicine and families*. Boca Raton, FL: Routledge.
- Prasad, V. K., and A. S. Cifu. 2015. *Ending medical reversal: Improving outcomes, saving lives*. Baltimore, MD: Johns Hopkins University Press.
- Salter, E. K. 2012. Deciding for a child: A comprehensive analysis of the best interest standard. *Theoretical Medicine and Bioethics* 33 (3):179–98. <https://doi.org/10.1007/s11017-012-9219-z>
- Sears, R. 2007. *The vaccine book: Making the right decision for your child*. Boston, MA: Little, Brown.
- Shay, L. A., and J. E. Lafata. 2015. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making* 35 (1):114–31. <https://doi.org/10.1177/0272989X14551638>
- Suarez-Almazor, M. E., B. Conner-Spady, C. J. Kendall, A. S. Russell, and K. Skeith. 2001. Lack of congruence in the ratings of patients' health status by patients and their physicians. *Medical Decision Making* 21 (2):113–21. <https://doi.org/10.1177/02729890122062361>
- Verlinde, E., N. De Laender, S. De Maesschalck, M. Deveugele, and S. Willems. 2012. The social gradient in doctor–patient communication. *International Journal for Equity in Health* 11:12. <https://doi.org/10.1186/1475-9276-11-12>
- Waitzkin, H. 1985. Information giving in medical care. *Journal of Health and Social Behavior* 26:81–101. <https://doi.org/10.2307/2136599>
- Wasserman, J. A., and B. P. Hinote. 2011. Chronic illness as incalculable risk: Scientific uncertainty and social transformations in medicine. *Social Theory & Health* 9 (1):41–58. <https://doi.org/10.1057/sth.2010.4>
- Wilkinson, D., and T. Nair. 2016. Harm isn't all you need: Parental discretion and medical decisions for a child. *Journal of Medical Ethics* 42:116–18. <https://doi.org/10.1136/medethics-2015-103265>
- Willems, S., S. De Maesschalck, M. Deveugele, A. Derese, and J. De Maeseneer. 2005. Socio-economic status of the patient and doctor–patient communication: Does it make a difference? *Patient Education and Counseling* 56 (2):139–46. <https://doi.org/10.1016/j.pec.2004.02.011>