

# REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 8-I-07

Subject: Pediatric Decision-Making

Presented by: Mark A. Levine, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Jane C.K. Fitch, MD, Chair)

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## 1 INTRODUCTION

2  
3 Recent events challenging parents' authority to make health care decisions for their children have  
4 received considerable national media attention.<sup>1,3</sup> Generally, pediatric patients are unable to make  
5 informed health care decisions for themselves, so their parents or guardians have this responsibility  
6 under common law and the statutes of most states. The decision-making process for pediatric  
7 patients can be complicated. For example, parents and the treating physician may disagree on the  
8 care of a young child. An older minor patient may disagree with the decision, and parents may  
9 disagree among themselves.

10  
11 This report examines the ethics of medical decision-making for pediatric patients, especially when  
12 disagreements arise among physicians, parents, and sometimes the patients themselves. In this  
13 report, "pediatric patients" refers to patients in early childhood through adolescence, to the age of  
14 majority. The scope of this report does not include the fetus or the neonate because the AMA's  
15 *Code of Medical Ethics* already contains relevant guidance (see Opinion E-2.215, "Treatment  
16 Decisions for Seriously Ill Newborns").

## 17 BACKGROUND

18  
19  
20 Parents make decisions regarding a child's rearing, including decisions related to the child's  
21 welfare and health care. This authority is well established in law, and grants parents or legal  
22 guardians the responsibility to consent to the medical treatment of minors.

23  
24 The statement of the Committee on Bioethics of the American Academy of Pediatrics (AAP) on  
25 "Informed consent, parental permission, and assent in pediatric practice," similarly affirms that  
26 physicians have an ethical, as well as legal, obligation to obtain parental permission to perform a  
27 recommended medical intervention on a pediatric patient.<sup>4</sup> Likewise, the Code of Ethics of the  
28 American Academy of Child and Adolescent Psychiatry (AACAP) states that a parent or legal

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1 guardian is responsible for a minor’s health care decision-making and that a psychiatrist may not  
2 need to obtain agreement of a child or adolescent patient to pursue “evaluation, treatment, or  
3 prevention efforts.”<sup>5</sup> The guidelines from both the AAP and the AACAP further suggest that  
4 young patients be informed of a medical treatment plan and that assent be obtained directly from  
5 the patient when developmentally appropriate.<sup>4,5</sup>

6 The authority to consent to medical treatments implies that parents may also refuse treatment for  
7 almost any reason, including on the basis of religious beliefs; however, this authority may be  
8 limited when the life of the minor is at risk or when there is a threat to community health. If  
9 parents refuse life-saving treatment and members of the health care team believe the decision is  
10 placing the child at significant risk of serious harm, the matter can be brought before the courts or  
11 other welfare agencies, which may overturn parents’ decisions.<sup>6</sup>

12  
13 Parties other than parents may make health care decisions. If a parent is not available to approve a  
14 medical intervention in an emergency situation, it is legally and ethically permissible to provide  
15 emergent care with presumed parental consent as the duty to preserve the health and life of the  
16 pediatric patient is paramount.<sup>6</sup>

17  
18 In some circumstances, a pediatric patient can be deemed a mature decision-maker, legally  
19 authorized to make medical decisions. A court may make a decision to this effect based on the age  
20 of the patient, the patient’s understanding of the relevant medical procedure and potential  
21 outcomes, as well as the degree of risk of the intended treatment. Also, emancipated minors—  
22 minors who are living on their own and self-supporting, are married, or are parents themselves, or,  
23 in at least one state, pregnant—may be legally permitted to make their own health care decisions.<sup>6</sup>  
24 The AACAP’s Code of Ethics acknowledges that there are circumstances when minors have been  
25 given the legal authority to make decisions on their own and emphasizes that it is the ethical  
26 responsibility of a physician to attempt to resolve conflicts that may arise within families.<sup>5</sup>

27  
28 There are specific areas of health care—notably reproductive care—where laws specify the  
29 circumstances in which decisions can be made by parties other than a parent, including minors  
30 themselves. Many state laws similarly permit minors seeking treatment for substance use or mental  
31 health care to provide their own consent.<sup>6</sup>

32  
33 Although the AMA’s *Code of Medical Ethics* does not currently include comprehensive guidance  
34 regarding pediatric care, several Opinions are worthy of consideration. Opinion 8.081, “Surrogate  
35 Decision-Making,” which outlines the factors to be considered when a surrogate or proxy is  
36 making health care decisions for a patient, is particularly relevant. It is pertinent to decision-  
37 making for pediatric patients who are either too young to have a health care value system or, due to  
38 cognitive disabilities, lack the decision-making capacity typical for children their age.<sup>7</sup> It states  
39 that a surrogate decision:

40  
41 . . . should be based on the best interest of the patient or the outcome that would best  
42 promote the patient’s well being. Factors that should be considered when weighing  
43 the harms and benefits of various treatment options include the pain and suffering  
44 associated with treatment, the degree of and potential for benefit, and any  
45 impairments that may result from treatment.<sup>7</sup>

1 Opinion E-2.015 provides further guidance on parental involvement in reproductive care for  
2 minors. It states:

3  
4 Physicians should strongly encourage minors to discuss their pregnancy with their  
5 parents. Physicians should explain how parental involvement can be helpful and  
6 that parents are generally very understanding and supportive. If a minor expresses  
7 concerns about parental involvement, the physician should ensure that the minor's  
8 reluctance is not based on any misperceptions about the likely consequences of  
9 parental involvement.<sup>8</sup>

10  
11 **ETHICAL CONSIDERATIONS**

12  
13 Determining the decision-maker

14  
15 Whereas decision-making for adult patients is guided both in law and in medical ethics by the  
16 principle of autonomy, there is little ethical concordance when it comes to pediatric patients.  
17 While the law generally grants a patient the right to make health care decisions only upon reaching  
18 the age of majority, it is well recognized by health care professionals that minor children are often  
19 capable of understanding their circumstances and of expressing their preferences in ways similar to  
20 adult patients. In such circumstances, physicians can find themselves torn between the decision of  
21 parents, the legally authorized decision-makers, and the differing preferences of the child who is  
22 actually being treated. It is also possible to imagine instances when two parents, especially if  
23 separated or divorced, or guardians are not in accord. If every effort has been made to fully inform  
24 equally authorized decision-makers of all options and related risks and benefits and all available  
25 means of conflict resolution have been exhausted, persisting conflicts may have to be resolved in  
26 courts of law.

27  
28 When consensus about what is in the "best interest" of the child cannot be reached despite  
29 reasonable efforts to do so, the wishes of the parents should prevail. Though parents ordinarily  
30 make all health care decisions for their children, the decision of a parent should not go without  
31 question in every case.<sup>9</sup> It may be necessary to challenge their decision-making authority. The law  
32 recognizes that parental decision-making authority can be removed when it is abusive, negligent, or  
33 otherwise places their children at risk. Parents should not make health care decisions for their  
34 children if they clearly are not committed to serving the child's interests, are emotionally unstable,  
35 or lack capacity to make informed decisions.<sup>9-12</sup>

36  
37 When the health care team finds it necessary to challenge a parental decision, attempts should be  
38 made within the institution to resolve the conflict; for example, through the involvement of an  
39 ethics committee, ethics consultant, pastoral service, or other counselor. Legal or regulatory  
40 intervention should be used as a last resort, because it can diminish the collaborative nature of  
41 medical care, it is a trying process for all parties, and it can place considerable strain on a family.  
42 The ethical principle of respect for persons also applies to children, so treating physicians should  
43 make efforts to seek the pediatric patient's assent, which is similar to consent, but is not binding. It  
44 weighs a child's ability to understand options and potential outcomes and to communicate  
45 preferences. Though the notion of assent can be applied most readily to adolescent patients, it is

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1 important that the cognitive capacities and judgment of younger patients be evaluated in order to  
2 determine if they can understand and evaluate risks and benefits of treatment.<sup>9</sup> Pediatric patients  
3 with a history of a chronic condition often acquire knowledge about their condition and treatment  
4 that gives them a greater ability to give assent than other children of the same age.

5  
6 The AAP lists factors that should be considered when asking for a child's assent: explaining, at a  
7 developmentally appropriate level, the medical condition and its clinical implications, and  
8 assessing how well the patient can understand the situation and how willing the patient is to  
9 proceed with the proposed care.<sup>5</sup> The assent process may be compromised if parents do not want  
10 their child informed of their diagnosis, prognosis, or other aspects of medical care. Yet, the  
11 opportunity for children to be informed and to provide assent is analogous to the right of adults to  
12 make informed decisions and consent to medical care.<sup>13</sup> The cooperation of parents in the assent  
13 process should be sought through assurance that knowledge and participation in decision-making  
14 has great value for the child.

15  
16 This being said, not all information is cognitively and emotionally appropriate for all pediatric  
17 patients; thus, the information provided should be individualized as developmentally appropriate.  
18 Opinion E-8.082, "Withholding Information from Patients," states: "All information need not be  
19 communicated to the patient immediately or all at once; physicians should assess the amount of  
20 information a patient is capable of receiving at a given time, delaying the remainder to a later, more  
21 suitable time, and should tailor disclosure to meet patients' needs..."<sup>14</sup> This standard applies to  
22 pediatric as well as to adult patients. In the case of an adolescent patient who has decision-making  
23 capacity, the physician should encourage the patient's active participation in decision-making. If it  
24 seems likely that a pediatric patient will not assent to the course the parents and physician have  
25 chosen, the pediatric patient should still be provided with sufficient information to understand the  
26 proposed treatment. A pediatric patient's refusal to assent should be respected in instances when a  
27 medical intervention is not immediately necessary to safeguard the welfare of the patient. In  
28 situations where the treatment is essential to preserve wellbeing, reasons for dissent should be  
29 explored to achieve a more complete understanding of the patient's circumstances. It may be  
30 necessary to use force (e.g. physical restraints) in situations when the parents and physician agree  
31 that a particular medical intervention is necessary to preserve the welfare of child patient lacking  
32 decision-making capacity. However, the use of force should be a last resort in situations when  
33 adolescent patients with decision-making capacity refuse life-saving interventions.

34  
35 Decision-making criteria

36  
37 In determining treatment options for a child, it is important for physicians to rely on the principles  
38 of beneficence and non-maleficence and discuss with parents and, to the extent appropriate, their  
39 child, the severity of the condition, the risks and benefits of the treatment, and therapeutic  
40 alternatives. The best interest standard guides decision-making for young patients and is the basis  
41 for laws that empower parents to make decisions for their children. The substituted judgment  
42 standard is often employed for incapacitated adult patients. This standard is not applicable to  
43 pediatric patients who do not and never did possess the maturity and capacity to make informed  
44 health care decisions, such as very young patients and older children whose cognitive disabilities  
45 prevent them from making informed decisions. Under the best interest standard, a surrogate aims

1 to determine the course of action that offers the greatest net benefit to the patient by weighing the  
2 risks and benefits of possible courses of action.<sup>15</sup> For the large group of pediatric patients who  
3 have some ability to understand their condition, the best interest standard should be augmented by  
4 discussing the situation with the patient, whose priorities should influence the decision-making  
5 process.

6  
7 When assessing the risks and benefits of a course of action, it is appropriate for parents to consider  
8 the psychosocial welfare of the child, as well as the medical impact of the possible treatments. The  
9 needs and interests of the patient in relation to those of the family may also be relevant  
10 considerations, because the family usually represents the child's only means of support and care. If  
11 none of the reasonable alternatives the health care team recommends can be reconciled with the  
12 family's circumstances, deciding on the best course of treatment may be "an exercise in  
13 psychosocial, as well as technical medical, expertise."<sup>11</sup> Under those circumstances, the treatment  
14 team should seek help from an ethics committee, ethics consultant, pastoral service, or other  
15 counselor to help in reaching a decision.

16  
17 Special health care decisions

18  
19 *Childhood immunization*

20  
21 Over the past half century, a universal childhood immunization program has evolved whereby all  
22 50 states have laws that require children to receive specified vaccines before entering school.<sup>16-17</sup>  
23 At the same time, all state laws exempt children whose medical history provides a contraindication,  
24 and at the time of publication 48 states have exceptions for religious beliefs. Furthermore, an  
25 increasing number of states (19 in 2004) allow children to enter school without vaccinations if their  
26 parents present a philosophical reason why they do not want their children immunized.<sup>17</sup> However,  
27 this can present a problem for physicians, who have an ethical obligation to protect the health of  
28 their patients as well as the health of the community.

29  
30 When parents refuse to have a child vaccinated, not only the child is at risk, but also the health or  
31 life of others who were not vaccinated and those for whom the vaccination did not result in  
32 adequate immunization.

33  
34 Therefore, physicians should educate parents on the preventive benefits of vaccines for their child  
35 and the community at large.<sup>17</sup> A parent's refusal to have a child vaccinated, however, generally  
36 should be respected.

1 *Reproductive health*

2

3 Issues related to reproductive choices remain highly contentious socially and politically,  
4 particularly when adolescents are involved, due in part to religious and moral beliefs. The medical  
5 profession as a whole, however, has reached a significant degree of ethical consensus on many  
6 aspects of reproductive health care. The American Academy of Family Physicians, the American  
7 Academy of Pediatrics, the American College of Obstetricians and Gynecologists, and the Society  
8 for Adolescent Medicine jointly released a position paper on access to confidential health care for  
9 sexually active minors, which the AMA has endorsed (See Policy H-60.938, “Adolescent Sexual  
10 Activity”).<sup>18</sup> Studies have shown that almost half of adolescent females would discontinue seeking  
11 prescription birth control, and ten percent would stop treatment of a sexually transmitted disease if  
12 informing their parents were required.<sup>18</sup> The confidentiality of reproductive care may be  
13 compromised, however, by legal requirements to report sexual abuse, which some states define  
14 broadly to include consensual sexual activity among same-age minors.<sup>18</sup>

15

16 In assessing disclosure requirements, physicians must weigh the minor patient’s capacity to make  
17 decisions, the physical and psychosocial risks the patient faces, and the benefits of maintaining a  
18 confidential, trusting relationship. In some instances, it may be justifiable for physicians to  
19 disclose patient information to a third party, but when more harm than good would likely result  
20 from reporting sexual activities, physicians should opt to protect their adolescent patients’  
21 confidential information unless disclosure is required by law.

22

23 *Terminal illnesses*

24

25 The selection of one treatment over another or the choice either to continue or cease treatment can  
26 lead to fundamental disagreements between the health care team and the parents of terminally ill  
27 children. Additional difficulties may arise when parents claim to be making decisions on the basis  
28 of religious beliefs.

29

30 Physicians must provide parents clear and timely information about the clinical situation and the  
31 possible outcomes if a recommended treatment is continued or is not carried out. In addition,  
32 physicians should provide parents with information about alternative treatments and their probable  
33 outcomes. Reciprocally, physicians should gain as much understanding as possible about the  
34 parents’ concerns. At times, this may require seeking information from a religious source or the  
35 intervention of a religious advisor, an ethics committee or consultant, or other counselor. Such  
36 consultations often reveal parental misunderstanding of the risks and benefits of the medical  
37 interventions, point to a fundamental parental distrust of medical care, or uncover a  
38 misunderstanding on the part of the health care team.

39

40 In assessing the reasonableness of parents’ decisions that are contrary to medical recommendations,  
41 physicians should consider the strength of evidence of the treatments’ effectiveness, the risks of  
42 additional suffering, and the availability of alternative options.<sup>19</sup> If a physician determines that an  
43 intervention other than the course chosen by the parents would medically serve the patient best, and  
44 the parents’ reasons for rejecting the recommendations are inadequate, they should seek  
45 reconciliation using available resources. If attempts to resolve the conflict fail, the physician may

1 appropriately seek regulatory intervention or court authorization to provide the recommended  
2 treatment.<sup>19</sup> Overriding parental decision-making authority is a very serious step and will almost  
3 certainly result in added stress for the medical team, the patient, and the family, and could result in  
4 separation of a seriously ill child from his or her parents.<sup>20</sup> Therefore, physicians should seek  
5 regulatory or legal intervention only after every other avenue for resolution has been exhaustively  
6 pursued.

7

## 8 CONCLUSION

9

10 In pediatric practice, medical decisions are usually made by the parent or guardian of the patient.  
11 In most circumstances, physicians are legally required to obtain consent from a parent before  
12 treating a child. Medical emergencies and the autonomy of emancipated minors represent two  
13 exceptions to this rule. The best interest of the patient should be the paramount consideration when  
14 weighing the medical and psychosocial risks of any course of treatment. Though pediatric patients  
15 cannot legally consent to medical care, physicians should provide them with developmentally  
16 appropriate explanations of their conditions, intended courses of action, and likely consequences of  
17 proposed treatments. Physicians should, when appropriate, elicit assent from the patient; however,  
18 dissent should be respected. If a physician believes the best interest of the patient is not being  
19 considered, or suspects child abuse, the physician should challenge the decision through  
20 institutional conflict resolution resources. Involvement of the regulatory or legal system should be  
21 a last resort but legal requirements must be respected.

22

## 23 RECOMMENDATION

24

25 The Council on Ethical and Judicial Affairs recommends that the following be adopted and that the  
26 remainder of this report be filed.

27

28 Medical decision-making for pediatric patients should be based on the child's best interest, which  
29 is determined by weighing many factors, including effectiveness of appropriate medical therapies,  
30 the patient's psychological and emotional welfare, and the family situation. When there is  
31 legitimate inability to reach consensus about what is in the best interest of the child, the wishes of  
32 the parents should generally receive preference.

33

34 Physicians treating pediatric patients generally must obtain informed consent from a parent  
35 or a legal guardian. Certain classes of children, such as emancipated or mature minors, may  
36 provide consent to their own medical care.

37

38 Physicians should give pediatric patients the opportunity to participate in decision-making  
39 at a developmentally appropriate level. The physician should seek the patient's assent, or  
40 agreement, by explaining the medical condition, its clinical implications, and the treatment  
41 plan. If the patient does not or cannot assent, physicians should still explain the plan of care  
42 and tell him or her what to expect, without deception. In the case of an adolescent patient  
43 who has decision-making capacity, the physician should encourage the patient's active  
44 participation in decision-making. The use of force such as with using physical restraints to

1 carry out a medical intervention in adolescent patients who do not assent should be a last  
2 resort.

3  
4 Parents and physicians may disagree about the course of action that best serves the pediatric  
5 patient's interests. When disagreements occur, institutional policies for timely conflict  
6 resolution should be followed, including consultation with an ethics committee, pastoral  
7 service, or other counseling resource. If a health care facility does not have policies for  
8 resolving conflicts in a timely manner, physicians should encourage their development.  
9 Physicians should treat reversible life-threatening conditions regardless of any persistent  
10 disagreement. Resolution of disagreements in the courts should be pursued only as a last  
11 resort.

12  
13 (New CEJA/AMA Policy)

Fiscal Note: Staff cost estimated at less than \$500 to implement.



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