

2.2.1 Pediatric Decision Making

As the persons best positioned to understand their child's unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children's capacity to become independent decision makers. In giving or withholding permission for medical treatment for their children, parents/guardians are expected to safeguard their children's physical health and well-being and to nurture their children's developing personhood and autonomy.

But parents' authority as decision makers does not mean children should have no role in the decision-making process. Respect and shared decision making remain important in the context of decisions for minors. Thus, physicians should evaluate minor patients to determine if they can understand the risks and benefits of proposed treatment and tailor disclosure accordingly. The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to seek minor patients' assent to treatment. Except when immediate intervention is essential to preserve life or avert serious, irreversible harm, physicians and parents/guardians should respect a child's refusal to assent, and when circumstances permit should explore the child's reason for dissent.

For health care decisions involving minor patients, physicians should:

- (a) Provide compassionate, humane care to all pediatric patients.
- (b) Negotiate with parents/guardians a shared understanding of the patient's medical and psychosocial needs and interests in the context of family relationships and resources.
- (c) Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult the patient will become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.
- (d) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.
- (e) Provide a supportive environment and encourage parents/guardians to discuss the child's health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents/guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.
- (f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.

- (g) When it is not clear whether a specific intervention promotes the patient's interests, respect the decision of the patient (if the patient has capacity and is able to express a preference) and parents/guardians.
- (h) When there is ongoing disagreement about patient's best interest or treatment recommendations, seek consultation with an ethics committee or other institutional resource.

AMA Principles of Medical Ethics: IV, VIII

Background report(s):

CEJA Report 3-I-18 Amendment to 2.2.1, Pediatric Decision Making

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 1-I-10 Amendment to 10.16, Pediatric Decision Making

CEJA Report 8-I-07 Pediatric Decision Making

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 3-I-18

Subject: Amendment to E-2.2.1, “Pediatric Decision Making”
(Resolution 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development [DSD]”)
(Resolution 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex Development”)

Presented by: James E. Sabin, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Todd M. Hertzberg, MD, Chair)

1 At the 2016 Interim Meeting, the American Medical Association (AMA) House of Delegates
2 referred Board of Trustees Report 7-I-16, “Supporting Autonomy for Patients with Differences of
3 Sex Development (DSD),” responding to Resolution 3-A-16 of the same title introduced by the
4 Medical Student Section, which asked:

5
6 That our AMA affirm that medically unnecessary surgeries in individuals born
7 with differences of sex development are unethical and should be avoided until the
8 patient can actively participate in decision-making.
9

10 Testimony regarding BOT 7-I-16 expressed concern about lack of expert insight into the medical
11 complexities in treating differences of sex development in pediatric patients in its analysis and
12 possible unintended consequences of its recommendations.
13

14 Resolution 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex
15 Development,” brought by the Michigan Delegation, asked
16

17 That our American Medical Association oppose the assignment of gender binary sex to infants
18 with differences in sex development through surgical intervention outside of the
19 necessity of physical functioning for an infant and believes children should have meaningful
20 input into any gender assignment surgery.
21

22 Noting that the issue was under study by the Council on Ethical and Judicial Affairs (CEJA), the
23 House of Delegates referred this resolution so that the council could address it during its ongoing
24 deliberations in this area.
25

26 This CEJA report provides ethics guidance for physicians in relation to the concerns expressed in
27 Resolutions 3-A-16 and 13-A-18. The council is grateful for participants’ contributions during
28 reference committee hearings and for additional written communications received from multiple
29 stakeholders, which have greatly enhanced its deliberations.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 CLARIFYING THE QUESTION

2
3 Resolutions 3-A-16 and 13-A-18 speak to clinical decisions that have enormous significance for
4 individual patients and families, decisions that also implicate socially and culturally sensitive issues
5 of embodiment, gender, and sexuality. Each asks AMA to endorse specific broadly framed
6 statements intentionally limiting the range of decisions physicians, patients, and families should
7 reach. Yet as multiple stakeholders have pointed out, the label “differences [or disorders] of sex
8 development” is problematic in that it encompasses a very broad range of conditions that carry
9 quite variable implications for patients’ immediate and longer-term health, making for an
10 extremely complex clinical picture overall [e.g., 1,2,3].

11
12 It is, moreover, a clinical picture in which the body of evidence available to inform decisions
13 remains both limited and contested in important ways. In part, this reflects the difficulty in
14 collecting data, given the relative rarity of these conditions and the sheer range of conditions
15 currently labeled “differences of sex development” [e.g., 4]. Importantly, it reflects divergence
16 among understandings of children’s physical and psychosocial development on which
17 stakeholders’ perspectives rest [e.g., 4,5,6,7,8,9].

18
19 Literature reviews that stakeholders have provided to help inform CEJA’s deliberations indicate
20 ongoing, significant differences in how the published evidence is interpreted [e.g., 1,10]. Concerns
21 have been expressed about not just the quantity, but also the quality of the data available to inform
22 clinical decisions, with questions raised about whether studies have asked the “right” question and
23 about how well the framing of key research questions and the methodology, sample size, and data
24 analysis support the conclusions drawn in a given study [e.g., 11]. Stakeholders concur on the need
25 for systematic, well-designed research to provide robust evidence on the long-term outcomes that
26 are meaningful to patients of different clinical approaches.

27
28 CEJA appreciates the challenge this state of affairs poses for families and physicians who strive to
29 make clinically well-informed decisions for individual children. Thoughtful stakeholders differ in
30 good faith, at times profoundly, about whether and at what developmental stage in the child’s life
31 intervention should be considered medically essential, preferred, or acceptable for children born
32 with differences of sex development. Despite these differences, stakeholders clearly share a deep
33 professional commitment to serving the best interest of pediatric patients.

34
35 However, to the extent that Resolutions 3-A-16 and 13-A-18 call on the council to address the lack
36 of clinical consensus, they seek guidance that is not within CEJA’s purview to offer. It is not the
37 council’s role to adjudicate clinical disagreement or to prescribe what manner of decision is
38 “correct” or “best,” but rather to clarify the values at issue and identify what factors must be
39 considered to arrive at an *ethically sound* decision in any given patient’s unique situation.

40 41 MAKING DECISIONS FOR PEDIATRIC PATIENTS

42
43 Health care decisions for pediatric patients necessarily have a different character than decisions for
44 adult patients. Decisions for children are made in the context of a three-way relationship among
45 patient, parents (or guardians), and physician rather than the patient-physician dyad typical of
46 decision making for most adult patients. Further, except for emancipated minors, who are
47 authorized to make their own health care decisions, or certain decisions that other minor patients
48 are permitted to make independently (e.g., [E-2.3.3](#), Confidential Care for Minors), decisions for
49 pediatric patients are made, not by the patient, but by parents/guardians acting on the patient’s
50 behalf. Finally, the substituted judgment standard for surrogate decision making on behalf of adult
51 patients is for the most part unavailable to those who make decisions for minors, insofar as

1 children, especially very young children, are unlikely to have formed settled views and preferences
2 upon which substituted judgment could be based.

3
4 *The Patient's "Best Interests"*

5
6 Ethically, and legally, then, parents are expected to make health care decisions in their children's
7 best interests. As the persons best positioned to understand their child's unique needs and interests,
8 parents/guardians are asked to fulfill the dual responsibility of both protecting their children and, at
9 the same time, empowering them and promoting development of the child's capacity to become an
10 independent decision maker. Parents/guardians are expected to safeguard their children's physical
11 health and well-being *and* to nurture their children's developing personhood and autonomy.

12
13 Best interests, and thus goals for care, then, should be understood broadly, as encompassing more
14 than simply medical considerations. Parents/guardians are indeed expected to weigh the clinical
15 benefits and risks of treatment alternatives, including the option of no treatment or the timing of
16 interventions, but to do so against the broader background of likely impact on the child's
17 psychosocial well-being, relationships within the family, and family resources and values. As
18 CEJA noted in its original report on decisions for pediatric patients (2007), because families
19 provide a child's usual, often only, source of support and care, the family's needs and interests can
20 also be relevant to treatment decisions. The council further observed that, "If none of the
21 reasonable alternatives the health care team recommends can be reconciled with the family's
22 circumstances, deciding on the best course of treatment may be 'an exercise in psychosocial, as
23 well as technical medical, expertise'" [12].

24
25 The Committee on Bioethics of the American Academy of Pediatrics similarly holds that best
26 interest should be understood broadly, to encompass more than purely clinical considerations. The
27 committee urges decision makers to "acknowledge the pediatric patient's emotional, social, and
28 medical concerns along with the interests of the child's family in the process of medical decision
29 making" [13]. However, the committee argues, the concept of "harm" may be a "more realistic
30 standard" for decisions on behalf of pediatric patients, noting that,

31
32 The intent of the harm principle is not to identify a single course of action that is in the minor's
33 interest or is the physician's preferred approach, but to identify a harm threshold below which
34 parental decisions will not be tolerated ... [13].

35
36 Using the harm principle to inform choices for individual patients, including pediatric patients,
37 requires that decision makers take into account the kind, degree and duration of foreseeable harms,
38 as well as the likelihood of their occurrence.

39
40 *Engaging Children in Care Decisions*

41
42 Absent reason to believe otherwise, parents/guardians are understood to be best able to take a
43 child's long-term interests to heart in reaching a decision about care and in general their decisions
44 should be respected. But that does not mean children should have no role in the decision-making
45 process. In its original report CEJA noted that "the ethical principle of respect for persons also
46 applies to children" and urged physicians to seek pediatric patients' assent to decisions made on
47 their behalf [12,13]. Assent, the council observed, "weighs a child's ability to understand options
48 and potential outcomes and to communicate preferences" [12].

49
50 CEJA recognized that "the notion of assent can be applied most readily to adolescent patients," but
51 instructed physicians to evaluate younger patients' "cognitive capacities and judgment to determine

1 if they can understand the risks and benefits of treatment” and to engage them accordingly in the
2 decision-making process. Not all information is cognitively and emotionally appropriate for every
3 pediatric patient, nor is it necessary to communicate all information about a diagnosis and proposed
4 care all at once. As for any patient, physicians should assess the amount of information the
5 individual is capable of receiving at a given time and tailor disclosure to meet patients’ needs,
6 preferences, and ability to understand ([E-2.1.3](#), Withholding Information from Patients).

7
8 Respecting children as (developing) persons also entails seeking to understand their reasons for
9 disagreeing with treatment decisions. When an intervention is not immediately necessary to
10 safeguard the child’s welfare, CEJA has argued, physicians (and parents/guardians) should respect
11 a child’s refusal to assent to proposed treatment. Even when immediate treatment is essential to
12 preserve well-being, physicians should explore the child’s reason for dissent, when circumstances
13 permit. The more mature a minor patient is, the better able to understand what a decision will
14 mean, and the more clearly the child can communicate preferences, the stronger the ethical
15 obligation to engage young patients in decisions about their own care. As CEJA noted in refining
16 its guidance on decisions for pediatric patients in 2010, communicating even sensitive and
17 potentially frightening information—about HIV status or a terminal diagnosis, for example—can
18 improve a child’s well-being [14].

19 20 *Preserving Future Choices*

21
22 In fulfilling their responsibility to nurture their children’s developing capacity to make autonomous
23 decisions, parents/guardians are expected to make health care decisions that will least impinge on
24 children’s opportunity to make important life choices themselves in the future. In general, decisions
25 taken now on a child’s behalf should be made with an eye not to foreclose decisions the child can
26 reasonably be expected, in time, to want and be able to make independently, realizing that choosing
27 *not* to have a treatment or procedure performed also forecloses a future choice. This “right to an
28 open future” is not absolute, of course. Parents/guardians must balance their responsibility to
29 preserve the child’s opportunity for future exercise of self-determination with the need to protect
30 the child’s immediate well-being. Physicians should be prepared to support them in that process,
31 providing the best available data to inform their decision and directing them to appropriate
32 psychosocial and other resources.

33
34 Finally, the opportunity to meet with and learn from others who have faced similar decisions can
35 provide valuable firsthand insight and support that clinicians themselves may not be able to offer.
36 Physicians should familiarize themselves with local peer support groups as resources to help
37 inform decision making by parents and their minor children.

38 39 A CONTINUUM OF DECISIONS

40
41 The degree of difficulty faced by parents/guardians in making well-considered, ethically justifiable
42 decisions for young patients who are not able to make their own health care choices varies across a
43 continuum. At one end of that continuum are decisions that involve interventions about which there
44 is consensus in the professional community, whose benefits are significant, supported by robust
45 evidence, and significantly outweigh the risks they pose (the likelihood and magnitude of which are
46 themselves well understood). In those situations, physicians have a responsibility to persuade
47 reluctant parents/guardians to accept the intervention on their child’s behalf. Where the
48 intervention would preserve life or avert serious harm and disagreement persists despite efforts to
49 resolve the tension, physicians have legal and ethical obligations to seek court interventions against
50 parental refusal of treatment.

1 At the other end are decisions that involve interventions that carry significant risk of harm or that
 2 currently available evidence would suggest offer little prospect of clinical benefit or cannot
 3 reasonably be expected to achieve the intended goal. In these cases, physicians have a
 4 responsibility to dissuade parents/guardians from pursuing the intervention, especially when it is
 5 irreversible, and should decline to provide the requested care when a patient’s parents/guardian
 6 persist, in keeping with ethics guidance (e.g., [E-5.5](#), Medically Ineffective Interventions).
 7

8 Between are decisions that involve interventions about which physicians may in good faith reach
 9 diverging professional judgments, and for which evidence as to short- and long-term benefit and
 10 risk is limited, equivocal, or contested. In such situations, how physicians interpret available
 11 evidence and its implications for an individual patient is shaped in significant part by their
 12 understanding of how to balance the competing values of beneficence and respect in upholding
 13 medicine’s foundational commitment to serve the patient’s (best) interests. In this “grey zone”
 14 physicians are challenged to negotiate with decision makers a shared agreement about how to
 15 understand this patient’s medical and psychosocial interests and what plan of care will best serve
 16 those interests in the individual’s unique circumstances and in most cases should give great
 17 deference to parental preferences.
 18

19 SHOULD DECISIONS ABOUT DSD BE DIFFERENT FROM OTHER DECISIONS?
 20

21 Helping parents/guardians make decisions for young patients with differences of sex development
 22 is inescapably challenging given the range of conditions at issue and the physiological/clinical
 23 complexity of many of those conditions. The fact that DSDs are entangled with socially and
 24 culturally sensitive issues of bodies, genders, and sex compounds that challenge—the more so in an
 25 environment in which a binary understanding of sex and gender is increasingly contested.
 26

27 Yet whether these decisions are more challenging than decisions for pediatric patients with other
 28 diagnoses—say, decisions about cochlear implants for congenitally deaf newborns—is far from
 29 clear. The specific interventions about which decisions must be made and the timing of those
 30 decisions will be sensitive to the child’s clinical situation, of course, but the fundamental task
 31 facing parents/guardians and physicians will still be to agree on a path forward that balances
 32 safeguarding the child’s well-being, short and longer term, and nurturing the child’s development
 33 as an individual with capacity to make decisions autonomously.
 34

35 Regardless of the specific decision at issue, it is important that parents/guardians and physicians
 36 appreciate the fact that a pediatric patient will of necessity live out the consequences of a choice
 37 made by others—one with which the individual may ultimately come to disagree. Moreover, when
 38 decisions implicate issues that are socially and culturally divisive, such as sex assignment and
 39 “normalizing” surgery for DSD patients, patients and their families can be thrust into the role of
 40 agent of social change or preserver of the status quo, knowingly, willingly, or otherwise [4].
 41 Ensuring that parents/guardians have the information and—absent immediate, life-threatening
 42 emergency—the time to make well-considered decisions is essential.
 43

44 For physicians, supporting thoughtful, ethically sound decision making for all pediatric patients,
 45 especially very young patients, requires that they consider several fundamental questions and tailor
 46 recommendations to the individual’s specific circumstances:
 47

- 48 • What is this child’s likely developmental course without (immediate) intervention? How
- 49 strong is the evidence to support this prognosis?
- 50 • What are these parents/guardians’ (and this patient’s) overall goals for care?

- 1 • To what extent is the clinical anomaly a significant threat to health, immediately and in the
2 long term?
- 3 • Is providing the proposed intervention at this stage in the child’s development supported by
4 clear, high quality evidence?
- 5 • Could other interventions reasonably be staged developmentally to allow the patient and
6 family time to gain experience living with the condition and to reflect on and perhaps
7 adjust goals for care?
- 8 • To what extent would the proposed intervention (or lack of intervention) foreclose
9 important life choices for the adolescent and adult the child will become? Are there
10 reasonable alternatives that would address immediate clinical needs while preserving
11 opportunity to make important future choices?
- 12 • What resources will the child and family need to support the child’s healthy physical and
13 psychosocial development? How can the physician assist in making those resources
14 available to the patient and family?

15
16 COMING TO COMMON GROUND

17
18 Parents/guardians are expected to make health care decisions in children’s “best interest.” In doing
19 so, they are expected both to protect children and, at the same time, to empower children and
20 promote children’s developing capacity to become independent decision makers. To nurture this
21 developing capacity, health care decisions are preferable that will least impinge on children’s
22 opportunity to make important life choices themselves in the future.

23
24 Making decisions for children that involve socially or culturally sensitive issues—for example,
25 whether or how to discuss a terminal diagnosis with a child, or whether, when, or how to intervene
26 medically for conditions that involve differences of sex development—is always challenging. The
27 greater the uncertainty or lack of robust evidence supporting alternative courses of action, the more
28 difficult the task becomes.

29
30 In such circumstances, despite a common commitment to serving the best interest of pediatric
31 patients, thoughtful stakeholders may, in good faith, differ about whether a particular intervention,
32 at a particular time is medically essential, preferred, or acceptable. When no single approach can be
33 said a priori to be “best.” Ethically sound practice requires that decisions be carefully tailored for
34 each patient in a process of shared decision making among parents/guardians, physician and the
35 patient (in keeping with the child’s capacity to participate). Decision makers should seek a shared
36 understanding of goals for care in creating a treatment plan that respects the unique needs, values,
37 and preferences of the individual patient and family.

38
39 RECOMMENDATION

40
41 In light of the foregoing analysis, the Council on Ethical and Judicial Affairs recommends that
42 Opinion E-2.2.1, “Pediatric Decision Making,” be amended by substitution as follows in lieu of
43 Resolutions 3-A-16, “Supporting Autonomy for Patients with Differences of Sex Development
44 (DSD),” and 13-A-18, “Opposing Surgical Sex Assignment of Infants with Differences of Sex
45 Development,” and the remainder of this report be filed:

46
47 As the persons best positioned to understand their child’s unique needs and interests, parents
48 (or guardians) are asked to fill the dual responsibility of protecting their children and, at the
49 same time, empowering them and promoting development of children’s capacity to become
50 independent decision makers. In giving or withholding permission for medical treatment for

1 their children, parents/guardians are expected to safeguard their children's physical health and
2 well-being and to nurture their children's developing personhood and autonomy.

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4 But parents' authority as decision makers does not mean children should have no role in the
5 decision-making process. Respect and shared decision making remain important in the context
6 of decisions for minors. Thus, physicians should evaluate minor patients to determine if they
7 can understand the risks and benefits of proposed treatment and tailor disclosure accordingly.
8 The more mature a minor patient is, the better able to understand what a decision will mean,
9 and the more clearly the child can communicate preferences, the stronger the ethical obligation
10 to seek minor patients' assent to treatment. Except when immediate intervention is essential to
11 preserve life or avert serious, irreversible harm, physicians and parents/guardians should
12 respect a child's refusal to assent, and when circumstances permit should explore the child's
13 reason for dissent.

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15 For health care decisions involving minor patients, physicians should:

- 16
17 (a) Provide compassionate, humane care to all pediatric patients.
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19 (b) Negotiate with parents/guardians a shared understanding of the patient's medical and
20 psychosocial needs and interests in the context of family relationships and resources.
21
22 (c) Develop an individualized plan of care that will best serve the patient, basing treatment
23 recommendations on the best available evidence and in general preferring alternatives that
24 will not foreclose important future choices by the adolescent and adult the patient will
25 become. Where there are questions about the efficacy or long-term impact of treatment
26 alternatives, physicians should encourage ongoing collection of data to help clarify value to
27 patients of different approaches to care.
28
29 (d) Work with parents/guardians to simplify complex treatment regimens whenever possible
30 and educate parents/guardians in ways to avoid behaviors that will put the child or others at
31 risk.
32
33 (e) Provide a supportive environment and encourage parents/guardians to discuss the child's
34 health status with the patient, offering to facilitate the parent-child conversation for
35 reluctant parents. Physicians should offer education and support to minimize the
36 psychosocial impact of socially or culturally sensitive care, including putting the patient
37 and parents/guardians in contact with others who have dealt with similar decisions and
38 have volunteered their support as peers.
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40 (f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that
41 patients have an opportunity to be involved in decision making in keeping with their ability
42 to understand decisions and their desire to participate. Physicians should ensure that the
43 patient and parents/guardians understand the prognosis (with and without treatment). They
44 should discuss the option of initiating therapy with the intention of evaluating its clinical
45 effectiveness for the patient after a specified time to determine whether it has led to
46 improvement and confirm that if the intervention has not achieved agreed-on goals it may
47 be discontinued.
48
49 (g) When it is not clear whether a specific intervention promotes the patient's interests, respect
50 the decision of the patient (if the patient has capacity and is able to express a preference)
51 and parents/guardians.

- 1 (h) When there is ongoing disagreement about patient's best interest or treatment
- 2 recommendations, seek consultation with an ethics committee or other institutional
- 3 resource.

(Modify Current HOD/CEJA Policy)

Fiscal Note: Less than \$500

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2.2.1 Pediatric Decision Making

Unlike health care decisions for most adult patients, decisions for pediatric patients usually involve a three-way relationship among the minor patient, the patient's parents (or guardian), and the physician. Although children who are emancipated may consent to care on their own behalf, in general, children below the age of majority are not considered to have the capacity to make health care decisions on their own. Rather, parents or guardians are expected, and authorized, to provide or decline permission for treatment for minor patients. Nonetheless, respect and shared decision making remain important in the context of decisions for minors, and physicians have a responsibility to engage minor patients in making decisions about their own care to the greatest extent possible, including decisions about life-sustaining treatment. [New content sets out key ethical values and concerns explicitly, drawing in part on CEJA background report 8-I-07]

Decisions for pediatric patients should be based on the child's best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies and the needs and interests of the patient and the family as the source of support and care for the patient. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents/guardian should generally receive preference.

For health care decisions involving minor patients, physicians should:

- (a) Involve all patients in decision making at a developmentally appropriate level.
- (b) Base recommendations for treatment on the likely benefit to the patient, taking into the effectiveness of treatment, risks of additional suffering with and without treatment, available alternatives, and overall prognosis. [new guidance addresses gap in current opinion]
- (c) For patients capable of assent, truthfully explain the medical condition, its clinical implications, and the treatment plan in a manner that takes into account the child's cognitive and emotional maturity and social circumstances for patients capable of assent.
- (d) Provide a supportive environment and encourage parents to discuss their child's health status with the patient. Offer to facilitate the parent-child conversation for reluctant parents. [new content incorporated to be consistent with 2.2.2]
- (e) Recognize that for certain medical conditions, such as those involving HIV/AIDS or inherited conditions, disclosing the child's health status may also reveal health information about biological relatives or disrupt existing presumptions about the child's relationships within the family.
- (f) Work with parents/guardians to simplify complex treatment regimens whenever possible and educate parents in ways to avoid behaviors that put the child or others at risk.
- (g) Ensure that when decisions involve life-sustaining interventions, patients have opportunity to be involved in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardian understand the patient's diagnosis, both with and without treatment. Physicians should discuss with the patient and parents/guardian the option of initiating an intervention with the intention of evaluating its clinical effectiveness after a specified amount of time to determine if it has led to improvement. Confirm that if the intervention has not achieved agreed-on goals it may be withdrawn. [New content addresses gap in current guidance, consistent with 5.3.]
- (h) Respect the decisions of the patient and parents/guardian when it is not clear whether a specific intervention promotes the patient's best interests.
- (i) Seek consultation with an ethics committee or other institutional resource when:

- (i) there is a reversible life-threatening condition and the patient (if capable) or parents/guardian refuse treatment the physician believes is clearly in the patient's best interest; or
- (ii) there is disagreement about what the patient's best interests are. Physicians should turn to the courts to resolve disagreements only as a last resort.
- (i) Provide compassionate and humane care to all pediatric patients, including patients who forgo or discontinue life-sustaining interventions. [New content addresses gap in current guidance.]

AMA Principles of Medical Ethics: IV, VIII

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 1-I-10

Subject: Amendment to E-10.016, “Pediatric Decision-Making”

Presented by: John W. McMahon, Sr., MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Daniel B Kimball, Jr, MD, Chair)

1 INTRODUCTION

2
3 This report is submitted in response to adopted Resolution 2-I-09 (Policy D-60.970, AMA Policy
4 Database), “Disclosure of Health Status to Children and Adolescents”, which was introduced by
5 the Medical Student Section. Resolution 2-I-09 asked that the American Medical Association
6 (AMA) encourage relevant members of the Federation of Medicine and nonphysician organizations
7 to provide ongoing communication, support, and training to health care providers to assist parents
8 with disclosing their children’s health status to them in a timely and prudent manner. The
9 resolution asked the AMA to specifically address the case of a child with human
10 immunodeficiency virus (HIV). Because informed consent and pediatric decision making are
11 ethical issues discussed in the AMA’s *Code of Medical Ethics*, the Council on Ethical and Judicial
12 Affairs (CEJA) was asked to review the proposed policy.

13
14 Based on its review of the data available, relevant policy of members of the Federation of
15 Medicine, and the ethical analysis that informs current AMA policies, CEJA concludes that there
16 are currently no compelling reasons to issue new policy specifically related to disclosure of health
17 status to children and adolescents. Rather, CEJA recommends that editorial changes as noted
18 below be made to clarify CEJA Opinion E-10.016, “Pediatric Decision making.” This report
19 examines issues of disclosure with the goal of amending current policy to clarify ethical guidance.

20
21 BACKGROUND

22
23 Some of the questions faced by the parent(s) or guardian of a seriously or terminally ill child are
24 how much to tell the child about his or her health status, when and how to do so, and who should
25 lead the discussion. AMA ethics policy recommends that minor patients be involved in decisions
26 about their health care in developmentally appropriate ways (E-10.016, E-5.055). Meaningful
27 involvement requires that minor patients be informed about their health status in ways that are
28 sensitive to their level of cognitive and emotional maturity (E-10.016). However, these situations
29 can be ethically complex, particularly when the child has acquired a condition such as human
30 immunodeficiency virus (HIV). An ethical conundrum may arise in the case of disclosure of an
31 HIV diagnosis, which is one case where parent(s) or guardian and child may have disparate
32 interests. With increasing numbers of HIV-infected children reaching cognitive, physical, and

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1 emotional maturity, the question of when and how to tell a child that he or she has HIV has become
2 more challenging.

3 4 History of Disclosure to Children with Terminal Illness

5
6 Historically, children with terminal illness were given limited information about their diagnosis and
7 prognosis, due to a desire to protect them from emotional burdens associated with illness and a
8 belief that children would not understand their situation.¹ Communication with minors about their
9 illness improved as a result of better survival rates, the children's rights advocacy movement, and
10 the results of studies that showed that open communication about terminal diagnoses improved
11 children's psychological development.¹ Changes in disclosure practices to HIV-infected minor
12 patients began to take place in the mid-1990s with the advancement of highly active anti-retroviral
13 therapy and improvements in the morbidity and mortality of HIV-infected children.¹⁻³ HIV-
14 infected minors are presently reaching a level of cognitive development that allows them to
15 understand their diagnosis and participate in treatment decisions, and a level of physical and
16 emotional development that can lead to sexual activity and risk for sexual transmission of HIV.^{1,4}
17 While disclosure is an increasingly common issue, a variety of factors influence the decision of a
18 parent(s) or guardian decision to disclose to a child his or her health status.⁷

19 20 *Factors Associated With Disclosure and Nondisclosure*

21
22 Parents and guardians provide a variety of reasons for disclosure or nondisclosure of their child's
23 HIV status. There is no consistent link between timing of disclosure and the child's health status or
24 specific clinical factors.¹ Stated reasons for nondisclosure, include concern that the child cannot
25 handle the emotional burdens associated with the diagnosis and that a breach of confidentiality will
26 have negative psychosocial consequences for child and/or parent.¹⁻³ Parent(s) or guardians who
27 choose to tell their child his or her health status often do so in support of the child's autonomy or
28 with hope that their child will better understand and adhere to a sometimes unpleasant medication
29 regimen and refrain from engaging in risk behavior, including unprotected sexual activity¹ or
30 activities that could result in open wounds and the exchange of bodily fluids (for example, fighting
31 or high contact sports). Other considerations influencing disclosure include fear of accidental
32 disclosure and opposition to or weariness of secret-keeping.¹ Notably, parents who disclose to their
33 child his or her HIV status are more likely to be HIV-negative themselves.¹ The decision to tell a
34 child that he or she has HIV clearly involves consideration of not only the minor patient's best
35 interest, but also familial and social circumstances.

36 37 *Effects of Disclosure*

38
39 Though a parent(s) or guardian may wish to keep their child's diagnosis secret, children often
40 understand more than that has been assumed, having become aware of their illness through direct
41 information or by reasoning about their health care experiences.⁶ Health professionals may be
42 privy to children's explicit references to their disease, even if the child's parent(s) or guardian think
43 that their child is ignorant of his or her condition.⁷ As Myra Bluebond-Langner's landmark study
44 of terminally ill children indicated, patients as young as three years of age are often aware of their
45 diagnosis and prognosis without ever having been told by an adult.⁹⁻¹¹ The developmental
46 literature similarly indicates that children older than four years of age understand the concepts of
47 illness and death in keeping with their stage of emotional and cognitive development.⁷

48
49 Talking to children about their terminal diagnosis may be beneficial to their mental health and to
50 their families' psychological adjustment.^{3,10,11} While some children experience anxiety, depression,
51 and withdrawal after having been told of their health status,^{9,12} positive outcomes of disclosure

1 include improved physical, emotional, and psychological well-being; better adherence to treatment;
 2 greater family communication and support; and for HIV, fewer risk behaviors and better adherence
 3 to demanding antiretroviral treatment.^{1,3-5,13-16} Because disclosing to a child that he or she has a
 4 terminal illness often does not have the negative effects parents or caregivers fear, and can have
 5 great benefits, “an incomplete ability to understand does not justify a lack of discussion” with a
 6 minor about his or her illness.^{2,3}

7 *Legal Environment*

9
 10 While parents or guardians generally have the authority to make decisions related to their child’s
 11 welfare and health care, there is no clear legal mandate concerning disclosure of diagnosis to
 12 children.⁴ Under state informed consent laws, minors cannot make decisions about their health
 13 without the permission of their parent(s) or guardian, with some exceptions. In some
 14 circumstances, a pediatric patient can be deemed a mature decision-maker, legally authorized to
 15 make medical decisions. Also, emancipated or mature minors may be legally permitted to make
 16 their own health care decisions. Adolescents who are neither emancipated nor mature are allowed
 17 by some states to consent to treatment in specific circumstances—testing and treatment for sexually
 18 transmitted infections, reproductive care, drug or alcohol abuse, and mental health care—without
 19 parental notification.¹³

20
 21 Many state privacy laws may prevent a physician from informing a child over the objection of
 22 parent(s) or guardian that the child is perinatally infected with HIV, since such a disclosure would
 23 violate confidentiality of the mother’s diagnosis.⁴ In at least one state (Georgia), physicians may
 24 tell a child that his or her mother has HIV, given the reasonable belief that the child is at risk of
 25 being infected with the virus⁴ (OCGA § 24-9-47). Nonetheless, state statutes that impose a “duty
 26 to warn” third parties of possible exposure to HIV generally fail to address the patient’s child.

27
 28 State laws also govern parental rights. While the law generally assumes that a parent(s) or
 29 guardian is acting in the child’s best interest, according to the principle of *parens patriae*, protection
 30 of a child’s welfare sometimes outweighs the right of parent(s) or guardian to refuse medical
 31 treatment for the child. However, this principle has limited application since it most often applies
 32 to medical treatment, not disclosure of health status.⁴ As there is no legal mandate that governs
 33 when and how to tell a child his or her health status, physicians should turn to their ethical and
 34 professional values for guidance.

35 36 ETHICAL CONSIDERATIONS

37
 38 Decisions regarding disclosure require careful consideration of the potential harm resulting from
 39 disclosure or the failure to disclose the child’s health status in light of concerns to respect and
 40 promote patient autonomy. In making decisions regarding disclosure physicians must balance their
 41 dual and sometimes conflicting loyalties to the minor patient and his or her parents or caregivers.

42 43 *Autonomy, Beneficence, & Nonmaleficence*

44
 45 Beneficence and nonmaleficence may suggest that children should be protected from harsh and
 46 painful information that is otherwise not necessary to know.⁴ Disclosure has the potential to cause
 47 psychological harm if the child lacks the cognitive capacity to understand the diagnosis of HIV and
 48 its implications.⁴ That said, allowing an HIV-infected child to age into older childhood and
 49 adolescence without knowledge of his or her condition risks physical and emotional harm to the
 50 patient and physical harm to others.

1 Respect for patient autonomy applies to children as well as adults. Since a child's autonomy
 2 develops along with cognitive and emotional capacities, increased age or maturity may equate to an
 3 increased right to know his or her health status.⁷ Involving children in communication about their
 4 health and decisions regarding their medical care shows respect for their capacities and will
 5 enhance their decision making capacity.^{4,13} In this sense, promoting autonomy through disclosure
 6 does not conflict with the principle of beneficence, but coincides with it.⁷

7
 8 AMA ethics policy calls on physicians to promote the autonomy of minor patients by involving
 9 them in the medical decision making process to a degree commensurate with their abilities. (E-
 10 10.016, E-5.055). The physician should seek the patient's assent, or agreement, by explaining the
 11 medical condition, its clinical implications, and the treatment plan. (E-10.016). If the patient does
 12 not or cannot assent, the physician should still explain the plan of care and tell him or her what to
 13 expect, without deception. (E-10.016). In the case of an adolescent patient who has decision
 14 making capacity, the physician should encourage the patient's active participation in decision
 15 making. (E-10.016).

16 17 *Dual Loyalties*

18
 19 Decision making in the pediatric setting is complicated by the direct involvement of more than two
 20 parties in the patient's management: patient, parent(s) or guardian, and physician. At times,
 21 parent(s) or guardian and physicians may disagree about whether disclosure is the course of action
 22 that best serves the minor patient's interests. Yet given the fundamental professional obligation to
 23 deal honestly and openly with patients (E-8.12, E-5.055, E-3.22), physicians may become
 24 increasingly uncomfortable with secrecy as children age into older childhood and adolescence.¹ It
 25 is also possible to imagine instances when parents (especially if separated or divorced) or guardian
 26 are not in accord with when, how, and how much to tell the child about his or her health status. As
 27 with other decisions involving minor patients, when consensus cannot be reached on whether
 28 disclosure is in the "best interest" of the child, the wishes of the parents should generally prevail.

29
 30 However, the decision of parent(s) or guardian should not go without question in every case, such
 31 as when a parent has been adjudicated not to be acting in their child's best interest.¹⁷ The
 32 Committee on Pediatric AIDS of the American Academy of Pediatrics holds that:

33
 34 [A]lthough physicians can listen to and discuss with parents potential reluctance to
 35 disclose, pediatricians should not accept parental or guardian requests to withhold the
 36 diagnosis under all circumstances. Pediatricians need to inform parents that if older
 37 children question them about their HIV infection status they will answer direct
 38 questions truthfully.⁵

39
 40 That said, in practice disclosing a child's HIV status without parental support can be
 41 problematic.^{7,17-20} Physicians may risk harm to parent(s) or guardian by telling the child that he or
 42 she has HIV—for example, telling a child that he or she was perinatally infected with HIV
 43 effectively violates the HIV-positive parent's right to medical confidentiality.⁷

44
 45 When disagreements occur about when or how to disclose, physicians should follow institutional
 46 policies for timely conflict resolution, including consultation with an ethics committee, pastoral
 47 service, or other counseling resource. If a health care facility does not have policies for resolving
 48 conflicts in a timely manner, physicians should encourage that policy be developed. Resolution of
 49 disagreements in the courts should be pursued only as a last resort.

1 RECOMMENDATIONS

2
3 The Council on Ethical and Judicial Affairs recommends that the following be adopted, and that
4 the remainder of this report be filed. That Opinion E-10.016, "Pediatric Decision-Making," be
5 amended as follows:

6
7 Medical decision making for pediatric patients should be based on the child's best interest,
8 which is determined by weighing many factors, including effectiveness of appropriate medical
9 therapies, the patient's psychological and emotional welfare, and the family situation. When
10 there is legitimate inability to reach consensus about what is in the best interest of the child, the
11 wishes of the parents should generally receive preference.

12
13 Physicians treating pediatric patients generally must obtain informed consent from a parent or a
14 legal guardian. Certain classes of children, such as emancipated or mature minors, may
15 provide consent to their own medical care. Physicians should give pediatric patients the
16 opportunity to participate in decision making at a developmentally appropriate level. The
17 physician should seek the patient's assent, or agreement, by explaining the medical condition,
18 its clinical implications, and the treatment plan in ways that take into account the child's
19 cognitive and emotional maturity and social circumstances. The physician should provide a
20 supportive environment and encourage reluctant parents to discuss their child's health status
21 with the patient, in private themselves or with the physician. For HIV-infected children in
22 particular, the physician should be sensitive to the fact that disclosure of health status can have
23 implications for the child's relationships with biological relatives, household members, and
24 peers; adherence to a complex medical regimen; and participation in behaviors that put the
25 child or others at risk. Physicians should also be sensitive that disclosure of HIV and other
26 conditions (e.g., some inherited conditions) can also have implications for family members
27 other than the child. If the patient does not or cannot assent, physicians should still explain the
28 plan of care and tell him or her what to expect, without deception. In the case of an adolescent
29 patient who has decision making capacity, the physician should encourage the patient's active
30 participation in decision making. The use of force such as with using physical restraints to
31 carry out a medical intervention in adolescent patients who do not assent should be a last
32 resort.

33
34 Parents and physicians may disagree about the course of action that best serves the pediatric
35 patient's interests, including how much to tell the child about his or her health status, when and
36 how to do so, and who should lead the discussion. When disagreements occur, institutional
37 policies for timely conflict resolution should be followed, including consultation with an ethics
38 committee, pastoral service, or other counseling resource. If a health care facility does not
39 have policies for resolving conflicts in a timely manner, physicians should encourage their
40 development. Physicians should treat reversible life-threatening conditions regardless of any
41 persistent disagreement. Resolution of disagreements in the courts should be pursued only as a
42 last resort. (IV, VIII)

43
44 (Modify HOD/CEJA Policy)

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

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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)

1 INTRODUCTION

2
3 Recent events challenging parents' authority to make health care decisions for their children have
4 received considerable national media attention.^{1,3} 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.⁴ Likewise, the Code of Ethics of the
28 American Academy of Child and Adolescent Psychiatry (AACAP) states that a parent or legal
29 guardian is responsible for a minor's health care decision-making and that a psychiatrist may not
30 need to obtain agreement of a child or adolescent patient to pursue "evaluation, treatment, or
31 prevention efforts."⁵ The guidelines from both the AAP and the AACAP further suggest that
32 young patients be informed of a medical treatment plan and that assent be obtained directly from
33 the patient when developmentally appropriate.^{4,5}

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

7
8 Parties other than parents may make health care decisions. If a parent is not available to approve a
9 medical intervention in an emergency situation, it is legally and ethically permissible to provide
10 emergent care with presumed parental consent as the duty to preserve the health and life of the
11 pediatric patient is paramount.⁶

12
13 In some circumstances, a pediatric patient can be deemed a mature decision-maker, legally
14 authorized to make medical decisions. A court may make a decision to this effect based on the age
15 of the patient, the patient's understanding of the relevant medical procedure and potential
16 outcomes, as well as the degree of risk of the intended treatment. Also, emancipated minors—
17 minors who are living on their own and self-supporting, are married, or are parents themselves, or,
18 in at least one state, pregnant—may be legally permitted to make their own health care decisions.⁶
19 The AACAP's Code of Ethics acknowledges that there are circumstances when minors have been
20 given the legal authority to make decisions on their own and emphasizes that it is the ethical
21 responsibility of a physician to attempt to resolve conflicts that may arise within families.⁵

22
23 There are specific areas of health care—notably reproductive care—where laws specify the
24 circumstances in which decisions can be made by parties other than a parent, including minors
25 themselves. Many state laws similarly permit minors seeking treatment for substance use or mental
26 health care to provide their own consent.⁶

27
28 Although the AMA's *Code of Medical Ethics* does not currently include comprehensive guidance
29 regarding pediatric care, several Opinions are worthy of consideration. Opinion 8.081, "Surrogate
30 Decision-Making," which outlines the factors to be considered when a surrogate or proxy is
31 making health care decisions for a patient, is particularly relevant. It is pertinent to decision-
32 making for pediatric patients who are either too young to have a health care value system or, due to
33 cognitive disabilities, lack the decision-making capacity typical for children their age.⁷ It states
34 that a surrogate decision:

35
36 . . . should be based on the best interest of the patient or the outcome that would best
37 promote the patient's well being. Factors that should be considered when weighing
38 the harms and benefits of various treatment options include the pain and suffering
39 associated with treatment, the degree of and potential for benefit, and any
40 impairments that may result from treatment.⁷

41
42 Opinion E-2.015 provides further guidance on parental involvement in reproductive care for
43 minors. It states:

44
45 Physicians should strongly encourage minors to discuss their pregnancy with their
46 parents. Physicians should explain how parental involvement can be helpful and
47 that parents are generally very understanding and supportive. If a minor expresses
48 concerns about parental involvement, the physician should ensure that the minor's

1 reluctance is not based on any misperceptions about the likely consequences of
2 parental involvement.⁸

3
4 ETHICAL CONSIDERATIONS

5
6 Determining the decision-maker

7
8 Whereas decision-making for adult patients is guided both in law and in medical ethics by the
9 principle of autonomy, there is little ethical concordance when it comes to pediatric patients.
10 While the law generally grants a patient the right to make health care decisions only upon reaching
11 the age of majority, it is well recognized by health care professionals that minor children are often
12 capable of understanding their circumstances and of expressing their preferences in ways similar to
13 adult patients. In such circumstances, physicians can find themselves torn between the decision of
14 parents, the legally authorized decision-makers, and the differing preferences of the child who is
15 actually being treated. It is also possible to imagine instances when two parents, especially if
16 separated or divorced, or guardians are not in accord. If every effort has been made to fully inform
17 equally authorized decision-makers of all options and related risks and benefits and all available
18 means of conflict resolution have been exhausted, persisting conflicts may have to be resolved in
19 courts of law.

20
21 When consensus about what is in the “best interest” of the child cannot be reached despite
22 reasonable efforts to do so, the wishes of the parents should prevail. Though parents ordinarily
23 make all health care decisions for their children, the decision of a parent should not go without
24 question in every case.⁹ It may be necessary to challenge their decision-making authority. The law
25 recognizes that parental decision-making authority can be removed when it is abusive, negligent, or
26 otherwise places their children at risk. Parents should not make health care decisions for their
27 children if they clearly are not committed to serving the child’s interests, are emotionally unstable,
28 or lack capacity to make informed decisions.⁹⁻¹²

29
30 When the health care team finds it necessary to challenge a parental decision, attempts should be
31 made within the institution to resolve the conflict; for example, through the involvement of an
32 ethics committee, ethics consultant, pastoral service, or other counselor. Legal or regulatory
33 intervention should be used as a last resort, because it can diminish the collaborative nature of
34 medical care, it is a trying process for all parties, and it can place considerable strain on a family.

35
36 The ethical principle of respect for persons also applies to children, so treating physicians should
37 make efforts to seek the pediatric patient’s assent, which is similar to consent, but is not binding. It
38 weighs a child’s ability to understand options and potential outcomes and to communicate
39 preferences. Though the notion of assent can be applied most readily to adolescent patients, it is
40 important that the cognitive capacities and judgment of younger patients be evaluated in order to
41 determine if they can understand and evaluate risks and benefits of treatment.⁹ Pediatric patients
42 with a history of a chronic condition often acquire knowledge about their condition and treatment
43 that gives them a greater ability to give assent than other children of the same age.

44
45 The AAP lists factors that should be considered when asking for a child’s assent: explaining, at a
46 developmentally appropriate level, the medical condition and its clinical implications, and
47 assessing how well the patient can understand the situation and how willing the patient is to
48 proceed with the proposed care.⁵ The assent process may be compromised if parents do not want
49 their child informed of their diagnosis, prognosis, or other aspects of medical care. Yet, the

1 opportunity for children to be informed and to provide assent is analogous to the right of adults to
2 make informed decisions and consent to medical care.¹³ The cooperation of parents in the assent
3 process should be sought through assurance that knowledge and participation in decision-making
4 has great value for the child.

5
6 This being said, not all information is cognitively and emotionally appropriate for all pediatric
7 patients; thus, the information provided should be individualized as developmentally appropriate.
8 Opinion E-8.082, “Withholding Information from Patients,” states: “All information need not be
9 communicated to the patient immediately or all at once; physicians should assess the amount of
10 information a patient is capable of receiving at a given time, delaying the remainder to a later, more
11 suitable time, and should tailor disclosure to meet patients' needs....”¹⁴ This standard applies to
12 pediatric as well as to adult patients. In the case of an adolescent patient who has decision-making
13 capacity, the physician should encourage the patient’s active participation in decision-making. If it
14 seems likely that a pediatric patient will not assent to the course the parents and physician have
15 chosen, the pediatric patient should still be provided with sufficient information to understand the
16 proposed treatment. A pediatric patient’s refusal to assent should be respected in instances when a
17 medical intervention is not immediately necessary to safeguard the welfare of the patient. In
18 situations where the treatment is essential to preserve wellbeing, reasons for dissent should be
19 explored to achieve a more complete understanding of the patient’s circumstances. It may be
20 necessary to use force (e.g. physical restraints) in situations when the parents and physician agree
21 that a particular medical intervention is necessary to preserve the welfare of child patient lacking
22 decision-making capacity. However, the use of force should be a last resort in situations when
23 adolescent patients with decision-making capacity refuse life-saving interventions.

24
25 Decision-making criteria

26
27 In determining treatment options for a child, it is important for physicians to rely on the principles
28 of beneficence and non-maleficence and discuss with parents and, to the extent appropriate, their
29 child, the severity of the condition, the risks and benefits of the treatment, and therapeutic
30 alternatives. The best interest standard guides decision-making for young patients and is the basis
31 for laws that empower parents to make decisions for their children. The substituted judgment
32 standard is often employed for incapacitated adult patients. This standard is not applicable to
33 pediatric patients who do not and never did possess the maturity and capacity to make informed
34 health care decisions, such as very young patients and older children whose cognitive disabilities
35 prevent them from making informed decisions. Under the best interest standard, a surrogate aims
36 to determine the course of action that offers the greatest net benefit to the patient by weighing the
37 risks and benefits of possible courses of action.¹⁵ For the large group of pediatric patients who
38 have some ability to understand their condition, the best interest standard should be augmented by
39 discussing the situation with the patient, whose priorities should influence the decision-making
40 process.

41
42 When assessing the risks and benefits of a course of action, it is appropriate for parents to consider
43 the psychosocial welfare of the child, as well as the medical impact of the possible treatments. The
44 needs and interests of the patient in relation to those of the family may also be relevant
45 considerations, because the family usually represents the child’s only means of support and care. If
46 none of the reasonable alternatives the health care team recommends can be reconciled with the
47 family’s circumstances, deciding on the best course of treatment may be “an exercise in
48 psychosocial, as well as technical medical, expertise.”¹¹ Under those circumstances, the treatment

1 team should seek help from an ethics committee, ethics consultant, pastoral service, or other
2 counselor to help in reaching a decision.

3

4 Special health care decisions

5

6 *Childhood immunization*

7

8 Over the past half century, a universal childhood immunization program has evolved whereby all
9 50 states have laws that require children to receive specified vaccines before entering school.¹⁶⁻¹⁷
10 At the same time, all state laws exempt children whose medical history provides a contraindication,
11 and at the time of publication 48 states have exceptions for religious beliefs. Furthermore, an
12 increasing number of states (19 in 2004) allow children to enter school without vaccinations if their
13 parents present a philosophical reason why they do not want their children immunized.¹⁷ However,
14 this can present a problem for physicians, who have an ethical obligation to protect the health of
15 their patients as well as the health of the community.

16

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

20

21 Therefore, physicians should educate parents on the preventive benefits of vaccines for their child
22 and the community at large.¹⁷ A parent's refusal to have a child vaccinated, however, generally
23 should be respected.

24

25 *Reproductive health*

26

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

39

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

1 *Terminal illnesses*

2

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

7

8 Physicians must provide parents clear and timely information about the clinical situation and the
9 possible outcomes if a recommended treatment is continued or is not carried out. In addition,
10 physicians should provide parents with information about alternative treatments and their probable
11 outcomes. Reciprocally, physicians should gain as much understanding as possible about the
12 parents' concerns. At times, this may require seeking information from a religious source or the
13 intervention of a religious advisor, an ethics committee or consultant, or other counselor. Such
14 consultations often reveal parental misunderstanding of the risks and benefits of the medical
15 interventions, point to a fundamental parental distrust of medical care, or uncover a
16 misunderstanding on the part of the health care team.

17

18 In assessing the reasonableness of parents' decisions that are contrary to medical recommendations,
19 physicians should consider the strength of evidence of the treatments' effectiveness, the risks of
20 additional suffering, and the availability of alternative options.¹⁹ If a physician determines that an
21 intervention other than the course chosen by the parents would medically serve the patient best, and
22 the parents' reasons for rejecting the recommendations are inadequate, they should seek
23 reconciliation using available resources. If attempts to resolve the conflict fail, the physician may
24 appropriately seek regulatory intervention or court authorization to provide the recommended
25 treatment.¹⁹ Overriding parental decision-making authority is a very serious step and will almost
26 certainly result in added stress for the medical team, the patient, and the family, and could result in
27 separation of a seriously ill child from his or her parents.²⁰ Therefore, physicians should seek
28 regulatory or legal intervention only after every other avenue for resolution has been exhaustively
29 pursued.

30

31 CONCLUSION

32

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

1 RECOMMENDATION

2

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

5

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

11

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

15

16 Physicians should give pediatric patients the opportunity to participate in decision-making
17 at a developmentally appropriate level. The physician should seek the patient's assent, or
18 agreement, by explaining the medical condition, its clinical implications, and the treatment
19 plan. If the patient does not or cannot assent, physicians should still explain the plan of care
20 and tell him or her what to expect, without deception. In the case of an adolescent patient
21 who has decision-making capacity, the physician should encourage the patient's active
22 participation in decision-making. The use of force such as with using physical restraints to
23 carry out a medical intervention in adolescent patients who do not assent should be a last
24 resort.

25

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

34

35 (New CEJA/AMA Policy)

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

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