

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)

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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.

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\* 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
- 49 • What is this child’s likely developmental course without (immediate) intervention? How  
50 strong is the evidence to support this prognosis?
  - 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.

3  
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.

14  
15 For health care decisions involving minor patients, physicians should:

- 16  
17 (a) Provide compassionate, humane care to all pediatric patients.  
18  
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.  
39  
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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