

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

---

\* 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 interests. With increasing numbers of HIV-infected children reaching cognitive, physical, and  
2 emotional maturity, the question of when and how to tell a child that he or she has HIV has become  
3 more challenging.

#### 4 5 History of Disclosure to Children with Terminal Illness

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

#### 20 21 *Factors Associated With Disclosure and Nondisclosure*

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

#### 37 38 *Effects of Disclosure*

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

1 Talking to children about their terminal diagnosis may be beneficial to their mental health and to  
 2 their families' psychological adjustment.<sup>3,10,11</sup> While some children experience anxiety, depression,  
 3 and withdrawal after having been told of their health status,<sup>9,12</sup> positive outcomes of disclosure  
 4 include improved physical, emotional, and psychological well-being; better adherence to treatment;  
 5 greater family communication and support; and for HIV, fewer risk behaviors and better adherence  
 6 to demanding antiretroviral treatment.<sup>1,3-5,13-16</sup> Because disclosing to a child that he or she has a  
 7 terminal illness often does not have the negative effects parents or caregivers fear, and can have  
 8 great benefits, "an incomplete ability to understand does not justify a lack of discussion" with a  
 9 minor about his or her illness.<sup>2,3</sup>

### 10 *Legal Environment*

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

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.<sup>4</sup> 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 virus<sup>4</sup> (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.<sup>4</sup> 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 Decisions regarding disclosure require careful consideration of the potential harm resulting from  
 38 disclosure or the failure to disclose the child's health status in light of concerns to respect and  
 39 promote patient autonomy. In making decisions regarding disclosure physicians must balance their  
 40 dual and sometimes conflicting loyalties to the minor patient and his or her parents or caregivers.  
 41

### 42 *Autonomy, Beneficence, & Nonmaleficence*

43 Beneficence and nonmaleficence may suggest that children should be protected from harsh and  
 44 painful information that is otherwise not necessary to know.<sup>4</sup> Disclosure has the potential to cause  
 45 psychological harm if the child lacks the cognitive capacity to understand the diagnosis of HIV and  
 46

47 © 2010 American Medical Association. All Rights Reserved

1 its implications.<sup>4</sup> That said, allowing an HIV-infected child to age into older childhood and  
 2 adolescence without knowledge of his or her condition risks physical and emotional harm to the  
 3 patient and physical harm to others.

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

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

#### 20 21 *Dual Loyalties*

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

33  
 34 However, the decision of parent(s) or guardian should not go without question in every case, such  
 35 as when a parent has been adjudicated not to be acting in their child's best interest.<sup>17</sup> The  
 36 Committee on Pediatric AIDS of the American Academy of Pediatrics holds that:

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

43  
 44 That said, in practice disclosing a child's HIV status without parental support can be  
 45 problematic.<sup>7,17-20</sup> Physicians may risk harm to parent(s) or guardian by telling the child that he or  
 46 she has HIV—for example, telling a child that he or she was perinatally infected with HIV  
 47 effectively violates the HIV-positive parent's right to medical confidentiality.<sup>7</sup>

48  
 49 When disagreements occur about when or how to disclose, physicians should follow institutional  
 50 policies for timely conflict resolution, including consultation with an ethics committee, pastoral

© 2010 American Medical Association. All Rights Reserved

1 service, or other counseling resource. If a health care facility does not have policies for resolving  
2 conflicts in a timely manner, physicians should encourage that policy be developed. Resolution of  
3 disagreements in the courts should be pursued only as a last resort.

4  
5 RECOMMENDATIONS

6  
7 The Council on Ethical and Judicial Affairs recommends that the following be adopted, and that  
8 the remainder of this report be filed. That Opinion E-10.016, "Pediatric Decision-Making," be  
9 amended as follows:

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

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

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

47  
48 (Modify HOD/CEJA Policy)

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

© 2010 American Medical Association. All Rights Reserved

REFERENCES

1. Wiener LS, Mellins MA, Marhefka S, Battles HB. Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions. J Dev Behav Pediatr. 2007;28(2):155-166.
2. Mitchell CD, Armstrong FD, Goodman KW, Cava A. Disclosure of HIV Status to an Infected Child: Medical, Psychological, Ethical, and Legal Perspectives in an Era of “Super-Vertical Transmission. J Clin Ethics. 2008;19(1):43-52.2.
3. Mellins CA, Brackis-Cott E, Dolezal C, et al. Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. Clin Child Psych and Psychiatry. 2002;7(1):101-114.
4. Klitzman R, Marhefka S, Mellins C, Wiener L. Ethical Issues Concerning Disclosures of HIV Diagnoses to Perinatally Infected Children and Adolescents. J Clin Ethics. 2008;19(1):31-42.
5. American Academy of Pediatrics, Committee on Pediatric AIDS. Disclosure of Illness Status to Children and Adolescents with HIV Infection. Pediatrics. 1999;103(1):164-166.
6. Kreicbergs U, Valdimarsdottir U, Onelov E, Henter JI, Steineck G. Talking About Death with Children Who Have Severe Malignant Disease. N Engl J Med. 2004;351(12):1175-1186.
7. Lipson M. What Do You Say to a Child with AIDS? Hastings Cent Rep. 1993;32(2):6-12.
8. Bluebond-Langer M. *The Private Worlds of Dying Children*. Princeton, NJ: Princeton University Press; 1978.
9. Dunlop S. The Dying Child: Should We Tell the Truth? Paediatric Nurs. 2008;20(6):28-31.
10. Slavin LA, O'Malley JE, Koocher GP, Foster DJ. Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-Term Adjustment. Am J Psych. 1982;139(2):179-183.
11. Spinetta JJ, Maloney ML. The Child With Cancer: Patterns of Communication and Denial. J Counseling & Clin Psych. 1978;46(6):1540-1541.
12. New M, Lee S, Pao M. Prevalence of Mental Health in Pediatric HIV: A Family Perspective. Paper presented at: The NIMH Conference on the Role of Families in Preventing and Adapting to HIV/AIDS; 2003; Washington, DC.
13. Levetown M, Committee on Bioethics of the American Academy of Pediatrics. Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. Pediatrics. 2008;121:e1441-e1460.
14. Blasini I, Chantry C, Cruz C, et al. Disclosure Model for Pediatric Patients Living with HIV in Puerto Rico: Design, Implementation, and Function. J Dev & Behav Pediatr. 2004;25(3):181-189.
15. Bachi T, Smith LC, Pomeroy EC. Exploration of Knowledge of Diagnosis and Depression in Children Ages 9-12 With HIV Infection. XII International Conference on AIDS. 1998;12:14269.
16. Funck-Brentano, Costagliola D, Seibel N, et al. Patterns of Disclosure and Perceptions of the Human Immunodeficiency Virus in Infected Elementary School-age Children. Arch Pediatr Adolesc Med. 1997;151:978-985.
17. Zawistowski CA, Frader JE. Ethical Problems in Pediatric Care: Consent. Crit Care Med. 2003;31:S407-S410.
18. Childress JF. Protecting handicapped newborns. In: *Genetics and the Law: III*. Milunsky A, Annas GJ (Eds). New York, NY: Plenum Press; 1985.
19. American Academy of Pediatrics, Committee on Bioethics. Responding to parental refusals of immunization of children. Pediatrics. 2005;115(5):1428-1431.
20. Frankel LR, Goldworth A, Rorty MV, Silverman WA. *Ethical Dilemmas in Pediatrics: Cases and Commentaries*. Cambridge, England: Cambridge University Press; 2005:1-11.