

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Bioethics

## Institutional Ethics Committees

**ABSTRACT.** In hospitals throughout the United States, institutional ethics committees (IECs) have become a standard vehicle for the education of health professionals about biomedical ethics, for the drafting and review of hospital policy, and for clinical ethics case consultation. In addition, there is increasing interest in a role for the IEC in organizational ethics. Recommendations are made about the membership and structure of an IEC, and guidelines are provided for those serving on an ethics committee.

ABBREVIATIONS. IEC, institutional ethics committee; JCAHO, Joint Commission on Accreditation of Healthcare Organizations.

Institutional ethics committees (IECs) initially were proposed to review decisions to limit or withdraw life-sustaining treatment for neurologically devastated or dying adult patients<sup>1,2</sup> and were viewed as a reasonable approach to the complex issues raised by decisions not to treat seriously ill or disabled newborns.<sup>3</sup> IECs have evolved considerably since the 1984 American Academy of Pediatrics statement concerning infant bioethics committees.<sup>4</sup> Rather than being simply a mechanism for implementing federal regulations about treatment of disabled infants and children,<sup>5</sup> IECs help resolve conflicts about treatment decisions through case consultation, provide a forum for discussion of policies relating to institutional ethics, and educate their health care communities about ethical concepts. The Academy supports the availability of an IEC as an important mechanism for the discussion and resolution of ethical issues raised in the individual and institutional provision of patient care.

IECs traditionally have been involved in clinical ethics and have an emerging role in organizational ethics. Recognizing that the development of an IEC is a process, this statement discusses 3 typical roles for an IEC: 1) case consultation; 2) the drafting and review of institutional policy; and 3) the education of health care professionals, patients, and other health care employees. The statement also describes the membership and structure of an IEC. Finally, the statement advises physicians and other health care professionals about their participation as IEC members or as members of an ethics consultation team.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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### THE ROLES OF AN IEC IN CLINICAL ETHICS

#### Case Consultation

For the majority of physician-patient encounters in pediatrics, the necessary scope, value, and desirability of the anticipated medical intervention is shared among physician, patient, and family. Problems tend to arise when no one intervention is clearly preferable, when there are conflicts about the value of an intervention, or when communication breaks down. As a result, parents, children, physicians, and others may experience uncertainty or conflict over how to respond to the situation. An IEC may be asked to help when uncertainty or conflict exists, when questions of moral, legal, or economic justification are raised, when problems of communication seem to be impeding patient care, or when it is simply unclear whom to ask for advice. In this role, the IEC or a subset of members constituting a "consultation team" may be requested to review the clinical situation and offer suggestions for resolution of the problem.<sup>6-8</sup>

The potential importance of the IEC's consultative role has been recognized in numerous ways, including the following: 1) case law suggesting that IEC deliberations may serve as evidence in court<sup>9-11</sup>; 2) state proposals to establish an IEC as an alternative to judicial review<sup>12,13</sup>; and 3) the requirement of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) that every health care organization have an established mechanism to address conflicts—a requirement most often met by establishing an IEC.<sup>14</sup>

The Academy recognizes that there are a range of acceptable approaches to the many issues that need to be considered in providing an ethics consultation service. An IEC that is engaged in providing ethics consultations should have a policy and procedure statement that includes the following: who can request a consultation, how the IEC is contacted, who responds to the request, how the consultation is conducted, who is to be included in the consultation, proper notification of affected persons, protection of patient confidentiality, how the consultation is documented, whether in some circumstances an ethics consultation is required, and the advisory nature of the consultant's recommendations. Information about the availability and process of ethics consultation should be widely distributed to patients, parents, family members, physicians, nurses, and other individuals who may have reason to call on the consultative services of the IEC.

The 2 characteristic features of an ethics consultation that distinguish it from an informal request for

advice or a case-based educational session are the involvement of a patient, family, or both and the documentation in a patient's medical record. If an ethics consultation is deemed inappropriate in favor of a case-based educational session, it may be appropriate for the patient, family, or both to be informed of the session and invited to participate. If hospital staff who are not involved in the patient's care will attend the session, the prior consent of the patient, family, or both for the disclosure of confidential information should be obtained, or the case should be presented while maintaining confidentiality. Acceptable approaches may vary among institutions and even from case to case. However, the following guidelines should apply to providing ethics consultation to ensure fairness and accountability:

- 1) Any patient, parent or guardian, or family member should be able to initiate an ethics consultation.
- 2) The patient and parent or guardian should be able to refuse to participate in an ethics consultation.
- 3) The refusal of a patient or parent or guardian to permit an ethics consultation should not obstruct the ability of an ethics committee to provide consultation services to physicians, nurses, and other concerned staff.
- 4) Any physician, nurse, or other health care provider who is involved in the care of the patient should be able to request an ethics consultation without fear of reprisal.
- 5) The process of consultation should be open to all persons involved in the patient's care, yet conducted in a manner that respects patient and family confidentiality.
- 6) Anonymous requests for consultation should not be accepted in the absence of an identified person who is willing to speak to the issue being raised.
- 7) The primary care pediatrician should be invited to participate in the consultation to support existing physician-family relationships.

Three models of prospective case consultation generally have been used: 1) an individual consultant who reports on a periodic basis to the entire committee; 2) a small team of committee members; or 3) a meeting of the entire committee. Each model has advantages and disadvantages. In some circumstances, consultation provided by a single person from the IEC may suffice. Although an individual consultant may respond in a timely and flexible manner, such an approach risks losing the diversity and range of perspectives offered by a group. In most situations, small consultation teams made up of individuals of varying personal and professional backgrounds are recommended to balance a timely and flexible response with the value of diverse points of view. The skills and knowledge necessary to participate as a member or leader of such a consultation team varies with one's role in the process.

IECs and their members should attend to the following concerns in developing a reasonable policy and procedure for ethics consultation. First, IECs must concern themselves with questions of proce-

dural fairness and confidentiality. They must have a mechanism for involving or advising patients and others who are the subjects of consultation, and they must respect the privacy and confidentiality of all persons affected by all aspects of IEC consultation. Second, IECs must have means of keeping current with relevant basic bioethics and health law, including information relevant to infants, children, and adolescents, to avoid giving incorrect advice or supporting questionable actions; they must know when to seek further consultation or review (from "authorities" in ethics, medicine, or law) and when judicial involvement should be sought. Finally, a consultation service should report to the IEC, and there should be an IEC mechanism for quality review and improvement of ethics consultations. Failure to develop and then follow reasonable policies and procedures for ethics consultation violates JCAHO standards. Furthermore, these policies and procedures must be communicated to all patients, parents or guardians, and hospital personnel.

The quality of an ethics consultation rests on the IEC's ability to provide a forum for open discussion of the medical, moral, and legal issues surrounding a difficult situation. On occasion, a request for an ethics consultation is motivated by a desire to bring the perceived authority of an IEC to bear on a difference of opinion or conflict, usually with the hope that the IEC will support the position of the person requesting the consultation. The authority, whether institutional, moral, or legal, of an ethics consultant and an IEC is limited.<sup>15</sup> The Academy supports the view that the recommendations from an ethics consultation are advisory only, with all parties to a disagreement taking full responsibility for their own actions. Although the interpretation and application of case law and state regulations may be part of an ethics consultation, the mere fact that an IEC was involved in a case is of uncertain value in providing legal protection to the participants. Improved communication, clarification of differences and available options, and careful documentation of the decisional process may well reduce the potential for future legal action.<sup>16-18</sup> Finally, all ethics consultations should be documented in the committee records, and, in most cases, a summary of the consultation should be briefly, yet completely, included in the patient's medical record. The form and extent of chart documentation of ethics consultations may vary depending on local hospital regulations and requirements.

### Policy Development

In addition to involvement in case consultation and educating patients, families, and staff members about ethical issues, the functions of an IEC generally include the drafting and review of institutional policy and procedures. Policies for the limitation or withdrawal of various treatments, such as cardiopulmonary resuscitation or fluid and nutrition, often have been drafted with IEC involvement. The IEC also may be involved in drafting other policies with ethical import, such as the ability of hospital employees to object to taking care of certain patients, the resolution of conflict, and the statement on institu-

tional business ethics now required by JCAHO.<sup>19</sup> The IEC may not only respond to administrative requests, but may also proactively identify issues with ethical ramifications that warrant an institutional policy and procedure.

### Ethics Education

An IEC should have a major role in educating all health care professionals, employees, and administrative staff in the ethical foundations of patient care and institutional relationships. Such education can occur as traditional didactic presentations, as ad hoc discussions about common clinical situations, or as one aspect of clinical case consultation. Whenever possible, students and house officers should be included in these educational opportunities. Most important, an IEC should engage in continuing education and ongoing training to ensure the highest quality clinical ethics consultations.

### THE ROLE OF AN IEC IN ORGANIZATIONAL ETHICS

Recent trends in the financing and provision of health care have raised concerns about the impact of institutional commitments such as managed-care contracts, integrated systems, and performance incentives on the care of patients. IECs are being looked to in some institutions as a venue within which these concerns might be addressed. Including organizational ethics in the purview of the IEC raises specific questions about its structure, function, and member qualifications.<sup>20,21</sup> The IEC should establish standards of membership, process, and self-improvement specific to organizational ethics issues and to the organizational structure of its home institution. In addition, the IEC should establish procedures for the evaluation and quality improvement of committee functions, process, and success in meeting institutional expectations. One approach is to establish an organizational ethics subcommittee of the IEC that includes additional representatives from administration and finance, along with persons committed to developing the requisite knowledge and skills in business ethics. Processes that organizational ethics teams commonly use to carry out their mission mirror those of clinical ethics: education, policy development, and case consultation.

### MEMBERSHIP AND STRUCTURE OF AN IEC

The membership of an IEC should be multidisciplinary with sufficient knowledge and experience to address the range of ethical issues brought to the committee. The ability of a larger committee to encompass a diverse range of perspectives and expertise argues in favor of an IEC retaining overall responsibility for functions such as ethics consultation that are delegated to an individual or a smaller team. Also, the required knowledge and experience depend on the task at hand; that is, there are likely to be differences in the skills needed to draft a policy on organizational ethics, to develop a policy addressing the withdrawal of life-sustaining treatment, or to perform a clinical ethics consultation.

Diversity of IEC membership benefits from community representation, while recognizing the impossibility of including all points of view and the potential for inappropriate generalization in considering any individual "representative" of his or her class, race, gender, or professional group. As medical technology and information become more complex and ethical issues expand to encompass resource allocation and business practices, an IEC may need to seek and incorporate the advice of consultants. The IEC size necessary to include a sufficient diversity of personal, community, and professional views may hinder the IEC's efficiency. It thus may be appropriate for the larger IEC to delegate certain tasks to smaller subgroups (such as providing ethics consultation or drafting specific policies) while retaining the authority for coordination, oversight, and approval of activities of the subcommittees.

Two important issues concerning IEC structure are: 1) the participation of the hospital attorney or risk manager in the IEC; and 2) whether there are 1 or more IECs within a single institution. First, the hospital attorney or risk manager may experience a conflict of interest between a duty to protect the institution and a duty to protect the patient's interest. Such conflicts should be recognized prospectively, and, in some circumstances, the consultation team may choose to restrict the hospital attorney, risk manager, or other administrators to function as ex officio advisors on specific legal or administrative matters. Many IECs have found that the inclusion of nonhospital attorneys familiar with ethical issues is beneficial. In addressing organizational ethics issues, their membership may be essential.

Second, a single multidisciplinary IEC should have authority over all IEC subcommittees addressing consultative, educational, nursing, pediatric, or administrative concerns. The existence of special interest ethics committees, such as an infant care review committee or nursing ethics committee, undermines the diverse multidisciplinary context that is the strength of an IEC. The establishment of multiple IECs may indicate that the process and deliberations of one IEC are not inclusive. Although an institutional review board functions independently to ensure the protection of human subjects in research, it is advisable for an IEC and an institutional review board to establish a mechanism of communication. An IEC may fulfill its functions whether it reports to the medical staff, hospital administration, or board of directors; however, as some ethical issues may involve conflicts between the clinical, administrative, and financial commitments of an institution, reporting to the institutional board of directors may be advantageous in these cases.

At institutions with academic affiliations, the IEC may exist with an academic bioethics program engaged in teaching, research, and ethics consultation. Nevertheless, the IEC should retain oversight within an institution for ethics consultation, policy review, and education when these functions have been delegated to such programs.

## SERVING ON AN IEC

Ideally, the members of an IEC encompass a wide range of clinical experiences, personal backgrounds, and professional perspectives, combined with personal integrity and a willingness to discuss and debate the ethical issues raised in the provision of health care. Integrity, diversity, and shared interest, however, do not guarantee that the members of an IEC collectively will have sufficient knowledge and experience in such areas as clinical ethics, health policy, law, communication, and group process. Accordingly, IEC membership requires a commitment to acquire, and then maintain, the knowledge sufficient to address the complex issues faced by an IEC. Each IEC should establish a continuing education program designed to assist IEC members in fulfilling the stated mission of the IEC, especially as new issues emerge.<sup>22,23</sup> When asked to be a member of an IEC, a pediatrician, pediatric subspecialist, or pediatric surgeon should assess his or her commitment to acquiring and then maintaining a sufficient level of knowledge in bioethics appropriate to the tasks of the IEC. A prospective IEC member should be comfortable with the committee's general mission statement, policies, and operation and the required responsibilities with respect to these functions.

If a pediatrician, pediatric subspecialist, or pediatric surgeon is involved in ethics consultation, clinical experience alone is insufficient to engage competently in clinical ethics consultation. An experienced clinician may possess the necessary medical and technical knowledge that often needs clarification during a consultation. An experienced clinician may also possess considerable skill in talking with patients and families about the difficult practical and moral problems faced in complex and, at times, uncertain situations. In addition, however, clinical experience must be supplemented with a basic knowledge of ethical theory, health policy, law, and clinical ethics literature. Performing an ethics consultation requires advanced knowledge of the aforementioned issues along with additional knowledge and skill in communication, group leadership, individual and group dynamics, techniques of mediation, and self-awareness.<sup>24-27</sup> An IEC should permit different levels of member involvement, ranging from simply attending general committee meetings, discussing and drafting institutional policy, or participating in ethics consultation, to leading an ethics consultation team, depending on the skills and experience of each member.

If engaged in clinical ethics consultation, it is reasonable to ask what one's legal liability might be in offering this service. An IEC should clarify the extent to which IEC proceedings are discoverable and whether its members are covered by liability insurance. The question of legal liability is difficult to answer except in general terms. Responsibility increases with authority, so it is generally "riskier" for IECs to act on their own or to mandate or require actions by others than to give advice and make recommendations. However, even IECs whose function is strictly advisory or educational can wield great

apparent authority within an institution. IECs unquestionably have a responsibility to persons affected by their deliberations. Furthermore, the actual policies of an IEC are less important than the manner in which those policies are executed and the IEC's success in educating the hospital community, including patients and their families, about the availability and process for clinical ethics consultation. The likelihood that IEC members will be held legally liable for the actions arising from a consultation is, practically speaking, remote. Nevertheless, IECs and their members have an important opportunity to help set the standards for their own work by careful attention to continuing education, preparation, policy, procedure, and documentation.<sup>28</sup>

## RECOMMENDATIONS

1. Membership on an IEC should be diverse and reflect different perspectives within the hospital and general community.
2. An IEC should have responsibility within an institution for clinical ethics consultation, review of policies, and education of professional, administrative, and support staff about ethical issues, regardless of whether these functions are delegated to other subcommittees or programs.
3. An IEC that is engaged in clinical ethics consultations should have policies and procedures that conform to ethical principles of fairness and confidentiality.
4. An IEC should establish continuing education and training programs that assure that IEC members are qualified to perform their specific duties within the IEC.
5. Independent ethics committees, such as an infant care review committee, should be dissolved or restructured to report to the larger IEC.
6. IECs within a general hospital setting should ensure an adequate degree of multidisciplinary expertise for addressing ethical issues specific to pediatrics.

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