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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 1

Mark R. Mercurio, Mary B. Adam, Edwin N. Forman, Rosalind Ekman Ladd, Lainie Friedman Ross and Tomas J. Silber

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American Academy of Pediatrics Policy Statements on Bioethics: Summaries and Commentaries: Part 1

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Author Disclosure
Drs Mercurio, Adam, Forman, Ekman Ladd, Friedman Ross, and Silber did not disclose any financial relationships relevant to this article.

Introduction

The American Academy of Pediatrics (AAP) has a strong and longstanding interest in the field of bioethics and periodically publishes policy statements pertaining to specific ethical questions relevant to pediatrics. The subjects addressed cover a wide range of topics, from parental refusal of immunization to the care of critically ill children. These policies are authored initially by the AAP's Committee on Bioethics and undergo extensive internal review by other committees prior to publication.

This article is the first in a series of three intended to familiarize readers with many of the AAP policies currently in place that address issues in bioethics. In this series, 16 policies published by the AAP are summarized, each followed by a brief commentary. The commentaries are intended to address, at least on a cursory level, some of the ethical principles underlying the policies. Some briefly point out possible alternative viewpoints.

The policies referenced in this article represent the efforts of various committees and committee members over the years. Each of the summaries presented here, as well as the commentaries that follow, represents the work of individuals serving on the Executive Committee of the Section on Bioethics, as indicated at the beginning of each summary. Understandably, some of the wording of these summaries is taken directly from the published policies. When quotations are used within a summary and not referenced, it can be assumed that the quote is taken directly from the policy being summarized. For ease of use, the references for each policy are provided with each individual summary and commentary.

Policies Reviewed

Part 1 of this series reviews:

1. Informed Consent, Parental Permission, and Assent in Pediatric Practice
2. Religious Objections to Medical Care
3. Responding to Parental Refusals of Immunization of Children
4. Sterilization of Minors With Developmental Disabilities
5. Human Embryo Research

Part 2 of this series reviews:

6. Guidelines on Foregoing Life-sustaining Medical Treatment
7. Foregoing Life-sustaining Medical Treatment in Abused Children
8. Do-Not-Resuscitate Orders for Pediatric Patients Who Require Anesthesia and Surgery
9. Do-Not-Resuscitate Orders in Schools
10. Ethical Issues with Genetic Testing in Pediatrics
11. Ethics and Care of Critically Ill Infants and Children

Part 3 of this series reviews:

12. Female Genital Mutilation
13. Appropriate Boundaries in the Pediatrician-Family-Patient Relationship
14. Infants With Anencephaly as Organ Sources: Ethical Considerations
15. Palliative Care for Children
16. Institutional Ethics Committees

*On behalf of the American Academy of Pediatrics Section on Bioethics.

Informed Consent, Parental Permission, and Assent in Pediatric Practice

Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95:314–317. Available at: <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics%3b95/2/314>. Reaffirmed October 2006. Summary and comment by Edwin N. Forman, MD, and Rosalind Ekman Ladd, PhD.

Summary of Policy Statement

This statement comments on the concept of informed consent and its application and limitations in the practice of pediatrics, where a triad exists: physician, parent(s), and patient. The policy analyzes the problematic issue of who should make health-care decisions. It lays out the elements and moral and legal underpinnings of informed consent and consent by proxy (ie, by parents). The concepts of emancipated and mature minors are presented.

The policy defines and defends the concept of assent. Although children cannot be treated as rational, autonomous decision-makers, pediatricians should give serious consideration to the patient's developing capacities for participating in decision-making. Children should be involved in discussions about their health care, even in situations in which one should not and does not solicit their agreement to the proposed medical management. Four elements of assent are emphasized: 1) helping the child achieve a developmentally appropriate awareness of the condition, 2) telling the child what should be expected with tests and treatment, 3) assessing the child's understanding and factors that influence his or her response, and 4) soliciting an expression of the child's willingness to accept the proposed care. The policy notes that physicians and parents should not solicit children's views without intending to weigh them seriously. In situations in which the medical treatment is deemed essential and must be given despite the patient's objection, the child should be told of this fact.

The AAP argues for shared decision-making, points out limits on parental authority, and justifies the importance of involving the child in decision-making by noting that such actions foster trust, create better physician/patient relationships, and may improve long-term health outcomes. Specific steps are outlined in obtaining assent, depending on the patient's developmental stage and the medical situation, and in cases of conflict resolution. Rejected are outright medical paternalism and total parental authority.

Comment

This policy, which provides for a genuine form of child assent, is based clearly on Western values. Modeled after the informed consent requirement for competent adult patients, it takes seriously an ethical duty to keep the child informed in age-appropriate ways and to solicit an expression of the child's willingness (ie, assent), when appropriate, to undergo the proposed treatment.

The policy is somewhat unclear about when it is appropriate to solicit assent. Dissent may be ethically binding in the case of nontherapeutic research or non-essential treatment, but the policy notes that it is deceptive to ask for assent when treatment is necessary and the child's dissent will be overridden. On the other hand, it seems to recommend solicitation of the child's willingness to accept treatment, even when it is deemed essential and only parental permission is required, as one element of involving the child in discussions about his or her health care.

Asking the child for assent recognizes the dignity and moral status of the child. The model is to provide a gradually increasing involvement of the child in making choices as the child grows in competence and moves from complete dependency on parents to independence. However, in our pluralistic society, the ideal of an individual as independent and free-thinking is not accepted by all cultural groups. Some cultures expect decisions to be made exclusively by parents or elders, whatever the age of the younger generation. In addition, the idea of a school-age child expressing an opinion at variance with his or her parents may constitute an upheaval of traditional values when the parenting style is authoritarian.

In using the AAP policy, the pediatrician is following Western democratic values and should be sensitive to the fact that some families come from cultures that have different views of the role of the child.

Religious Objections to Medical Care

Committee on Bioethics. Religious objectives to medical care. *Pediatrics*. 1997;99:279–281. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;99/2/279>. Reaffirmed October 2006. Summary and comment by Mark R. Mercurio, MD, MA.

Summary of Policy Statement

In this statement, the Committee on Bioethics, speaking for the AAP, addresses parental decisions not to seek or accept medical care for their children based on religious objections. The major role that religion plays in the lives of many adults and children in the United States is recognized, and the need for the pediatrician to be

sensitive to and have respect for religious tradition is acknowledged. However, the AAP “believes that all children deserve effective medical treatment that is likely to prevent substantial harm or suffering or death,” despite religious objections that the parents may hold. If efforts at collaborative decision-making with parents are not successful in getting their approval for appropriate medical treatment in such cases, a court order ultimately should be sought. If the child’s life is in imminent danger, the physician should intervene over parental objections.

The AAP’s position is consistent with that of the United States Supreme Court. As the AAP notes: “Constitutional guarantees of freedom of religion do not permit children to be harmed through religious practices, nor do they allow religion to be a valid legal defense when an individual harms or neglects a child.” (1) The AAP opposes exemption, based on religion, from child abuse and neglect laws when children are not provided necessary medical care. Failure to seek medical care when a child is seriously ill should be considered child neglect, regardless of the motivation. Laws that would allow an exemption on religious grounds should be opposed or repealed.

In the area of preventive care, a somewhat less forceful stance is taken. Although the AAP strongly endorses universal immunization, for example, it “does not support the stringent application of medical neglect laws” when children do not receive those immunizations due to parental refusal.

Comment

An ethical justification for the AAP position on this matter could be presented as a rights-based argument. Every child, it could be argued, has a right to medical care that is “likely to prevent substantial harm or suffering or death.” The child’s right creates obligations for the parents, the physician, and society. The parents are obligated to bring the child for the needed treatment, which, in the opinion of the AAP, cannot be limited to prayer or other spiritual practices alone but should include appropriate medical care.

The physician’s responsibility is either to provide the necessary treatment if able or to attempt to procure appropriate medical treatment for the child. The policy states that the physician may withdraw from these cases if continuing would violate his or her own moral precepts, “after securing acceptable alternative care.” However, a practitioner willing to withhold medical treatment likely to prevent substantial harm would not seem to qualify as a provider of “acceptable alternative medical care.”

Society is obligated to facilitate the provision of the needed treatment to the child, including passing and enforcing laws that support necessary treatment of children despite parental religious objections. However, it could be argued, and rightly so, that society also is obligated to protect religious freedom. The courts often are asked to evaluate this tension between the parental right to religious freedom (for themselves and their children) and the child’s right to necessary medical care. In general, the courts have taken the position proffered by the AAP: If the treatment in question is “likely to prevent substantial harm or suffering or death,” the child’s right to treatment outweighs the parental right to religious freedom. This viewpoint is not intended to ignore the parents’ right to religious freedom, but rather to recognize another right that should be given priority. The choice of words within the AAP policy suggests, however, that if prevention of substantial harm is possible but perhaps not *likely*, the imperative to overrule parental objection to treatment may be less certain. Again, the courts often have held this position.

The policy alludes briefly to the concept of the mature minor, including a recognition that as children grow into adolescence, many have an increasing ability to contribute to or make their own medical decisions. In a previous statement, the Committee on Bioethics opined that “as children develop, they should gradually become the primary guardians of personal health . . . assuming responsibility from their parents.” (2) Based on that understanding, the policy at issue here states, “in selected cases, disputes may be avoided when a minor has the capacity to make an independent decision in light of religious values and recommended medical therapy.” The pediatrician, indeed, may perceive less dispute, and the right path may seem clearer, when a mature minor requests a recommended treatment that his or her parents seek to refuse on his or her behalf. However, what if the mature minor refuses a lifesaving treatment, in accord with his or her parents, based on religious objections? It is not clear what the AAP would recommend in such a case.

A competent adult’s right to refuse treatment on religious grounds is recognized widely. It is somewhat unclear exactly when that right obtains, particularly if we believe that the development of decision-making capacity is a gradual process. It seems reasonable to suggest, nevertheless, that an individual’s right to refuse medical treatment on religious grounds should be recognized at the same time as his or her right to refuse on any other basis.

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Responding to Parental Refusals of Immunizations

Diekema DS and the Committee on Bioethics. Responding to parental refusals of immunizations. *Pediatrics*. 2005;115:1428–1431. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;115/5/1428>. Summary and comment by Lainie Friedman Ross, MD, PhD.

Summary of Policy Statement

This statement begins with the AAP's strong endorsement of universal immunization, but acknowledges that despite their safety and efficacy profiles, some vaccines are refused by some parents. Some parents refuse because of erroneous information; others refuse because of religious or philosophical beliefs. (1)(2) Data from a periodic survey of AAP members found that 7 of 10 pediatricians reported that they had a parent refuse an immunization on behalf of a child in the 12 months preceding the survey, (3) similar to other recent data. (4) This statement recommends that when faced with a refusal, physicians should try to: 1) understand the parents' perspective, 2) correct any misinformation, and 3) encourage the parents to reconsider. It also asks the physicians to consider whether the refusal exposes the child to serious risk such that it constitutes medical neglect and puts others at serious risk of harm, justifying public health intervention. Because refusals rarely cause imminent threats to a child's or a community's health, the AAP recommends that physicians respect the refusals. The statement encourages physicians not to dismiss these families but to continue to work with them to ensure that their children have access to medical care and to maximize opportunities to encourage vaccinations.

Comment

This statement takes an ethical and pragmatic position: Encourage universal immunization because that practice serves the child's best interest and because it promotes herd immunity (community benefit), but respect refusals. The authors acknowledge that immunizations are neither 100% safe nor 100% effective but argue that the benefit-to-harm calculation is extremely high and justifies universal immunization policies and practices. The

policy is clear that pediatricians generally should respect families who refuse vaccines. The practice of respecting parental refusals of vaccinations also is addressed in another AAP statement, "Religious Objections to Medical Care." This latter statement notes that some religious groups deny children the benefits of routine preventive care such as immunizations and states, "[t]he AAP does not support the stringent application of medical neglect laws when children do not receive recommended immunizations." (5) This stance is consistent with an attitude that intervention by the state should be invoked only when it offers the "least detrimental alternative." (6) When most of the community is immunized, the risk to the child is low, and state intervention cannot be justified, even though outbreaks do occur with attendant serious consequences. (5)

With the development of new vaccines such as the human papillomavirus vaccine and continued work on human immunodeficiency virus vaccines, future policies will need to consider whether these vaccines fit into our current model of public health interventions and state-mandated vaccination policies and how pediatric practices will be able to deliver vaccines that should be provided to adolescents.

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Sterilization of Minors With Developmental Disabilities

Committee on Bioethics. Sterilization of minors with developmental disabilities. *Pediatrics*. 1999;104:337–340. Available at: <http://pediatrics.aappublications.org/cgi/content/full/104/2/337>. Reaffirmed Octo-

ber 2006. Summary and comment by Tomas J. Silber, MD, MAAS.

Summary of Policy Statement

This statement, reviewing the history of and considerations leading to the parental request of sterilization for a son or daughter who has developmental disabilities, develops five recommendations, summarized as follows:

1. The AAP encourages pediatricians to use the development of secondary sexual characteristics in persons who have developmental disabilities as an opportunity to explore the patients' and caregivers' understandings of the facts and implications of sexual maturation.

2. Consideration of sterilization should focus on whether a need for permanent prevention of reproduction exists. Concern about other consequences of sexual maturity or aspects of sexuality among persons who have cognitive disabilities should focus on interventions substantially less radical than sterilization. The AAP encourages pediatricians to familiarize themselves with the resources in their community to which they might refer families for additional information or for specialized education and counseling on such matters as appropriate expressions of affection and sexual drives, effective menstrual hygiene, sexual abuse avoidance training, and contraception.

3. Whenever possible, pediatricians should involve their patients who have developmental disabilities in decisions about reproduction and should advocate for the least permanent and intrusive method of contraception consistent with the lowest risk for the patient.

4. When a minor who has developmental disabilities requests sterilization and an assessment determines that the minor has adequate decision-making capacity to consent to the procedure, the minor's views on the matter should be respected. Such decisions generally benefit from the involvement of the adolescent's family, other adults close to the adolescent, or both.

5. Pediatricians should become familiar with the applicable law about sterilization of persons who have developmental disabilities. Pediatricians should establish relations with local agencies and attorneys knowledgeable about the legal complexities of sterilization of persons who have developmental disabilities in their jurisdiction. If sterilization is legally permissible on the authority of parents or legal guardians and is chosen as the best course of action, substantial effort should be made to communicate to the patient the facts and implications of the sterilization. To the extent possible, the patient should participate in planning for the procedure.

Comment

This policy statement updates a previous AAP statement entitled, "Women Who Are Mentally Handicapped," published in 1990. That statement was published as a companion to a policy of the American College of Obstetricians & Gynecologists. The revised policy is based on concepts developed in the earlier statements, but now applies them to both males and females. This is the policy to consult whenever parents or legal guardians approach pediatricians or other health-care professionals about the possibility of surgical sterilization of children, adolescents, and young adults who have developmental disabilities.

Sterilization has a long history of abuse in the United States. However, by the middle of the 20th century, the United States Supreme Court prompted a major change in the legal landscape by declaring human procreation a fundamental right. Since then, requests for authorization to sterilize those who have developmental disabilities have been the object of scrutiny, limitations, and even prohibition in many jurisdictions. In the 1970s, for example, regulations were enacted to prevent the use of federal funds to perform sterilization procedures on those deemed mentally incompetent. It should come as no surprise that, at present, we face so many federal rules, state laws, and judicial rulings that pediatricians whose advice is requested find themselves facing "a confusing and contradictory array of restrictions on surgical sterilization of persons with development disabilities." Indeed, this confusion may not be a coincidence because an ethical tension exists between the obligation to honor the least restrictive alternatives for those who have cognitive disabilities and the concern about abuse and coercion leading to unwanted pregnancy or, worse, a pregnancy that the child may not comprehend or may be terrified by. Moreover, those who love and care for developmentally delayed children certainly may have their best interest at heart when they know that those individuals are not capable of caring for offspring.

Although this statement gives guidance on how to proceed when sterilization becomes the choice, its major strength is that it develops the fundamental criteria required to make that decision ethically permissible, namely, that the person lacks adequate mental capacity to make decisions about his or her health care and is unable to interpret his or her own interests. Thus, there is a moral mandate before sterilization can be considered: Assessment of an individual's capacity to decide matters specifically concerning reproduction and an obligation to obtain help from professionals experienced with evaluat-

ing the capabilities of persons with disabilities. Once the decision has been reached, the advocacy work starts.

Human Embryo Research

Committee on Bioethics and Committee on Pediatric Research. Human embryo research. *Pediatrics*. 2001; 108:813–816. Available at: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics%3b108/3/813>. Reaffirmed January 2005. Summary and comment by Mary B. Adam, MD, MA.

Summary of Policy Statement

On behalf of the AAP, the AAP Committee on Bioethics, and the AAP Committee on Pediatric Research wrote a policy statement asserting, “under certain conditions, research involving human embryos and pluripotent stem cells is of sufficient scientific importance that the National Institutes of Health should fund it and that federal oversight is morally preferable to the current unregulated private sector.” According to the statement, embryos are defined as “human organisms derived by fertilization from one or more gametes or diploid cells.” (Embryos formed using a diploid cell is a reference to cloning human embryos.) Justification for use of human embryos includes the possible identification of potential benefits to children as a class as well as the more global potential for medical benefits.

The statement acknowledges that its position is controversial because some believe that research using human embryos is morally problematic. Opponents to the AAP’s position object to the destruction of human embryos for research purposes because they view humans at all stages of development as deserving full human value. Those who object to the use of human embryos in research concede that even if that research may have great therapeutic potential, the “ends do not justify the means.”

Ethical concerns also arise regarding how the embryos are acquired for research and the possible moral complicity of researchers. The statement claims that using discarded embryos that are no longer needed by parents for assisted reproduction (clinical need) is less problematic than the creation of embryos for the specific purpose of research. However, the use of embryos that are no longer clinically needed as children for the couple using in vitro fertilization techniques still can cause “ethical problems related to obtaining adequate informed consent from donors, ensuring privacy of donors, and decreasing potential or perceived conflicts of interest by those who may request the donation and concerns about undue financial inducement to acquire embryos.” These concerns are

addressed by recommending limiting human embryo research to a set of eight conditions and suggesting a group of considerations for obtaining informed consent from donor parents. The eight recommended conditions are:

1. The embryos are already frozen and no longer are clinically needed.

2. A clear separation exists in the donor decision process between the decision by the donors to create embryos for infertility treatment and the decision to donate frozen embryos for research purposes after they are no longer clinically needed.

3. The decision to donate is strictly voluntary and without monetary inducements.

4. The physician responsible for fertility treatments is not to be the person performing the research on the same frozen embryos, and there should be no monetary relationship, that is, transfer of funds in the research project to the physician responsible for the fertility treatments.

5. There are to be no personal identifiers associated with the embryos used for research.

6. No restrictions can be placed by the donor on the type of research performed.

7. The research performed on the frozen embryos can be of no direct benefit to the original donors.

8. The embryo research does not involve research in reproductive cloning, transferring an altered embryo to a woman’s uterus, or using a human embryo in combination with other human or animal embryos.

A unique status of the individual human embryo is acknowledged, and the following limitations are proposed as safeguards: 1) research is to be limited to embryos in the first 14 days after fertilization, and 2) funding and additional oversight at the federal level are appropriate, including the creation of a new Department of Health and Human Services committee to oversee human embryo research specifically and develop ethical guidelines for its use.

Comment

The moral standing of the embryo has generated significant debate in the public sector, and this statement, not surprisingly, created some controversy. Drs Chesney, Botkin, and Nelson responded for the Committees on Pediatric Research and Bioethics to a letter to the editor of *Pediatrics*, stating, “Given the fundamental disagreements over the moral status of embryos, it probably is impossible to develop a position on this subject that all would consider acceptable.” (1) These fundamental disagreements are not scientific in origin because all parties would agree that the human embryo is a being of human

origin. The disagreement, rather, is the result of different perspectives on the meaning and ramifications of protecting human value and dignity. Those who hold to a view that the human embryo is deserving of full moral respect point out that various criteria have been used wrongly during different periods of human history to identify beings of human origin not believed to be worthy of full human value, dignity, and respect. These criteria have included: location, ethnicity, mental capacity, stage of development, and sex (especially female sex). It is argued that a similar injustice is done when human embryos are denied full protection because they are members of the human community. To do so would provide a toehold for other potential abuses of human beings, a “slippery slope” argument. Those who hold this view might agree that research has therapeutic potential but would say that the ends do not justify the means.

On the other hand, the argument that the potential for scientific progress outweighs morally problematic concerns is a utilitarian perspective. Research on nonconsenting human embryos, for whom there is no prospect of direct benefit and who would be destroyed in the process, could be acceptable from a utilitarian view if the potential gain for others might outweigh the concern. A developmental perspective is another perspective that may be consistent with permitting research on human embryos. In this view, one would assign different levels of moral status to human beings at different stages of development or capacity, with those individuals at the earliest stages of development being accorded less moral status (and, thus, more limited rights) than those later in development.

The AAP recognizes the human embryo as unique, a special tissue deserving of respect, but by allowing their use in research up to 14 days after fertilization, places embryos before 14 days of existence as having less moral worth than individuals at later developmental stages. This combining of a utilitarian and developmental perspective permits the AAP to encourage lifting restrictions on federal funding for research on human embryos in some limited circumstances when the embryo is early enough in development, where potential benefit is seen, and where additional oversight is included. The statement does not specifically address protections or oversight for embryos when the research is privately funded.

Other ethical issues in the statement flow out of a value for the “unique” moral standing of the human embryo. For example, the issue of the commodification of human embryos is addressed. The Committee expresses concern about the potential sale of human embryos and

recommends that no embryo be offered for research with monetary inducements on the part of the physician responsible for fertility treatments, donor parents, or researchers. This point of view is prudent because the sale of human gametes for financial profit (via Internet and newspaper advertisements) is widespread. This issue also highlights the needs and challenges of oversight because creating embryos is not illegal, and human gametes are easily procured for cash.

The AAP statement identifies parents as the “donors” who are entitled to represent the interests of the embryo. Parents are required to give their consent to donate their embryos for research. However, no statement is included discussing if one or both parents must agree with the “for research” designation. Concerns about the potential for coercion of parents by researchers are part of the impetus to recommend that the donation be strictly voluntary and without monetary inducements.

The limitations on the use of human embryos in research provided by the AAP’s statement include a prohibition on the use of embryos for reproductive cloning. There is no specific mention of the related research issue of human “therapeutic” cloning. However, donor consent in cases of therapeutic cloning would be problematic because there is no separation of the decision process to create the embryo and to use the embryo for research/therapeutic purposes (see recommendation 2).

The AAP’s position was challenged in a letter to the editor. (2) The response included the following statement: “We feel that an ongoing debate on these topics is meaningful, pertinent, appropriate, and a right of all American citizens.” (1) Given the call for meaningful debate, this statement can be a launch point for discussions on what it means to be human. Do all beings of human origin deserve full moral status, worth, and human dignity? If not, why not? If so, how does one justify drawing a line on the continuum of human development? Where do we draw the line? How do we safeguard against turning beings of human origin into commodities or parts for sale? Are humans worth more than the sum of and sale of their parts? (3)(4)(5)

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Conclusion

The AAP periodically publishes policy statements and guidelines addressing difficult ethical issues that physicians caring for children will continue to face. This review is intended to provide readers an overview of some of those guidelines and possibly stimulate additional thought and dialogue within the profession. It is presented by the AAP Section on Bioethics as part of its mission to foster education in this area among pediatricians. As the commentaries suggest, there may not be unanimity about the positions taken, which is important to recognize. The full text of each policy, as well as other relevant references and information, can be found on the web site for the Section on Bioethics at <http://www.aap.org/sections/bioethics>.

The Section on Bioethics serves primarily an educational role within the AAP and beyond. They organize educational forums in bioethics at the annual AAP Na-

tional Conference and Exhibition, publish a newsletter that includes original articles in the area of bioethics, and carry out other educational efforts intended primarily for pediatricians. In addition, they provide input to the Board of Directors and other committees regarding proposed policy statements and guidelines. Membership in the Section is open to all AAP Fellows who have an interest in bioethics. Affiliate membership also is available to physicians and other health professionals not eligible for AAP membership.

This is the first in a series of three articles on AAP policies that address ethical issues in pediatrics. The next two articles will appear in subsequent issues of *Pediatrics in Review*.

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