

Ethical Standards for Research with Children

The principles listed below were published in the 1990-91 Directory, except for Principles 15 and 16, first published in the Fall 1991 Newsletter.

Principle 1. NON-HARMFUL PROCEDURES: The investigator should use no research procedure that may harm the child either physically or psychologically. The investigator is also obligated at all times to use the least stressful research procedure whenever possible. Psychological harm in particular instances may be difficult to define; nevertheless, its definition and means for reducing or eliminating it remain the responsibility of the investigator. When the investigator is in doubt about the possible harmful effects of the research procedures, consultation should be sought from others. When harm seems inevitable, the investigator is obligated to find other means of obtaining the information or to abandon the research. Instances may, nevertheless, arise in which exposing the child to stressful conditions may be necessary if diagnostic or therapeutic benefits to the child are associated with the research. In such instances careful deliberation by an Institutional Review Board should be sought.

Principle 2. INFORMED CONSENT: Before seeking consent or assent from the child, the investigator should inform the child of all features of the research that may affect his or her willingness to participate and should answer the child's questions in terms appropriate to the child's comprehension. The investigator should respect the child's freedom to choose to participate in the research or not by giving the child the opportunity to give or not give assent to participation as well as to choose to discontinue participation at any time. Assent means that the child shows some form of agreement to participate without necessarily comprehending the full significance of the research necessary to give informed consent. Investigators working with infants should take special effort to explain the research procedures to the parents and be especially sensitive to any indicators of discomfort in the infant. In spite of the paramount importance of obtaining consent, instances can arise in which consent or any kind of contact with the participant would make the research impossible to carry out. Non-intrusive field research is a common example. Conceivably, such research can be carried out ethically if it is conducted in public places, participants' anonymity is totally protected, and there are no foreseeable negative consequences to the participant. However, judgments on whether such research is ethical in particular circumstances should be made in consultation with an Institutional Review Board.

Principle 3. PARENTAL CONSENT: The informed consent of parents, legal guardians or those who act in loco parentis (e.g., teachers, superintendents of institutions) similarly should be obtained, preferably in writing. Informed consent requires that parents or other responsible adults be informed of all the features of the research that may affect their willingness to allow the child to participate. This information should include the profession and institution affiliation of the investigator. Not only should the right of the responsible adults to refuse consent be respected, but also they should be informed that they may refuse to participate without incurring any penalty to them or to the child.

Principle 4. ADDITIONAL CONSENT: The informed consent of any persons, such as schoolteachers for example, whose interaction with the child is the subject of the study should also be obtained. As with the child and parents or guardians informed consent requires that the persons interacting with the child during the study be informed of all features of the research which may affect their willingness to participate. All questions posed by such persons should be answered and the persons should be free to choose to participate or not, and to discontinue participation at any time.

Principle 5. INCENTIVES: Incentives to participate in a research project must be fair and must not unduly exceed the range of incentives that the child normally experiences. Whatever incentives are used, the investigator should always keep in mind that the greater the possible effects of the investigation on the child, the greater is the obligation to protect the child's welfare and freedom.

Principle 6. DECEPTION: Although full disclosure of information during the procedure of obtaining consent is the ethical ideal, a particular study may necessitate withholding certain information or deception. Whenever withholding information or deception is judged to be essential to the conduct of the study, the investigator should satisfy research colleagues that such judgment is correct. If withholding information or deception is practiced, and there is reason to believe that the research participants will be negatively affected by it,

adequate measures should be taken after the study to ensure the participant's understanding of the reasons for the deception. Investigators whose research is dependent upon deception should make an effort to employ deception methods that have no known negative effects on the child or the child's family.

Principle 7. ANONYMITY: To gain access to institutional records, the investigator should obtain permission from responsible authorities in charge of records. Anonymity of the information should be preserved and no information used other than that for which permission was obtained. It is the investigator's responsibility to ensure that responsible authorities do, in fact, have the confidence of the participant and that they bear some degree of responsibility in giving such permission.

Principle 8. MUTUAL RESPONSIBILITIES: From the beginning of each research investigation, there should be clear agreement between the investigator and the parents, guardians or those who act in loco parentis, and the child, when appropriate, that defines the responsibilities of each. The investigator has the obligation to honor all promises and commitments of the agreement.

Principle 9: JEOPARDY: When, in the course of research, information comes to the investigator's attention that may jeopardize the child's well-being, the investigator has a responsibility to discuss the information with the parents or guardians and with those expert in the field in order that they may arrange the necessary assistance for the child.

Principle 10. UNFORESEEN CONSEQUENCES: When research procedures result in undesirable consequences for the participant that were previously unforeseen, the investigator should immediately employ appropriate measures to correct these consequences, and should redesign the procedures if they are to be included in subsequent studies.

Principle 11. CONFIDENTIALITY: The investigator should keep in confidence all information obtained about research participants. The participants' identity should be concealed in written and verbal reports of the results, as well as in informal discussion with students and colleagues. When a possibility exists that others may gain access to such information, this possibility, together with the plans for protecting confidentiality, should be explained to the participants as part of the procedure of obtaining informed consent.

Principle 12. INFORMING PARTICIPANTS: Immediately after the data are collected, the investigator should clarify for the research participant any misconceptions that may have arisen. The investigator also recognizes a duty to report general findings to participants in terms appropriate to their understanding. Where scientific or humane values justify withholding information, every effort should be made so that withholding the information has no damaging consequences for the participant.

Principle 13. REPORTING RESULTS: Because the investigator's words may carry unintended weight with parents and children, caution should be exercised in reporting results, making evaluative statements, or giving advice.

Principle 14. IMPLICATIONS OF FINDINGS: Investigators should be mindful of the social, political and human implications of their research and should be especially careful in the presentation of findings from the research. This principle, however, in no way denies investigators the right to pursue any area of research or the right to observe proper standards of scientific reporting.

Principle 15. SCIENTIFIC MISCONDUCT: Misconduct is defined as the fabrication or falsification of data, plagiarism, misrepresentation, or other practices that seriously deviate from those that are commonly accepted within the scientific community for proposing, conducting, analyzing, or reporting research. It does not include unintentional errors or honest differences in interpretation of data. The Society shall provide vigorous leadership in the pursuit of scientific investigation that is based on the integrity of the investigator and the honesty of research and will not tolerate the presence of scientific misconduct among its members. It shall be the responsibility of the voting members of Governing Council to reach a decision about the possible expulsion of members found guilty of scientific misconduct.

Principle 16. PERSONAL MISCONDUCT: Personal misconduct that results in a criminal conviction of a felony may be sufficient grounds for a member's expulsion from the Society. The relevance of the crime to the purposes of the Society should be considered by the Governing Council in reaching a decision about the matter. It shall be the responsibility of the voting members of Governing Council to reach a decision about the possible expulsion of members found guilty of personal misconduct.

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