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July 05, 2005 Current Operating Status

BOCYF Projects

Committee on Ethical Issues in Housing-Related Health Hazard Research Involving Children, Youth and Families

Connection to project scope, roster, and meetings (CPS system)

The Board on Children, Youth and Families (BCYF) of the National Research Council and the Institute of Medicine will convene a new committee to review the research challenges and ethical issues that occur during the design and conduct of research to control housing-related health hazards and protect the health of children and families, and compare and contrast them with those of traditional biomedical research conducted in children. The committee shall produce a consensus panel report based on this review that will provide ethics guidance to protect children, youth and families during the conduct of such research. This guidance shall consider and address the child, family and community context within which this research occurs, and pay special attention to the substantial housing constraints faced by the low-income families who are the most common human subjects in this field. In addition, these recommendations must be consistent with existing ethical and legal requirements for conducting therapeutic biomedical research on children.

The committee will do the following, during the course of this study:

1. Review and synthesize the approaches to conducting research to identify safe and effective methods for controlling environmental and structural hazards to children's health in housing, and compare and contrast them to approaches for conducting research to identify safe and effective biomedical therapies for children;

2. Identify the defining characteristics of "therapeutic" vs. "non-therapeutic" studies for controlling housing-related health hazards as compared to biomedical treatments;

3. Characterize the research challenges that come up during the planning and conduct of housing-related health hazard research and contrast them with those of biomedical research;

4. Review and synthesize the ethical issues that are intrinsic to the design and conduct of housing-related health hazard research on children and families and contrast them to those of biomedical research;

5. Discuss the ethical obligations of researchers to inform child study participants, their parents or guardians, and appropriate others of data collected during a study, including a consideration of how to balance issues such as timely provision of information vs. assuring relevance of the data, and making certain that information is provided in a way that is easily understood by recipients of the information; and

6. Identify approaches to deciding when and how researchers should intervene in a housing-related health hazard study to protect child participants from harm or treat conditions identified during the course of the study.

In addition to the issues raised above, the committee will consider the legal and ethical issues raised in the Grimes v Kennedy-Krieger case, and address the full range of issues of relevance to the ethical conduct of housing-related health hazard research with children, including: identifying whose responsibility it is to determine when a proposed project is considered ethical; whether there is a need for a specific institutional review process and how ongoing oversight of such studies should occur, and whether there is a need only for guidance or for the issuance of specific regulations governing this field of research.

The committee will produce a consensus report that summarizes its findings and will be widely disseminated to all interested stakeholders. The consensus report will include practical guidance for ensuring the ethical conduct of housing-related health hazard research in children and families.

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