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# Research Ethics for Mental Health Science Involving Ethnic Minority Children and Youths

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*In response to U.S. Public Health Service projects promoting attention to disparities in the outcomes of mental health treatments, in July 2001, the American Psychological Association, the National Institute of Mental Health, and the Fordham University Center for Ethics Education convened a group of national leaders in bioethics, multicultural research, and ethnic minority mental health to produce a living document to guide ethical decision making for mental health research involving ethnic minority children and youths. This report summarizes the key recommendations distilled from these discussions.*

**T**he new millennium has witnessed increased attention to the need for mental health research aimed at describing, understanding, and remedying the disproportionate access to mental health care for racial and ethnic minority groups (U.S. Department of Health and Human Services, 2001). Along with the scientific, social, and personal benefits that can be obtained from these laudable initiatives come the risks of group stigmatization, exploitation, and harm that have occurred throughout the history of medical and mental health research involving ethnic minority communities in the United States (Caplan, Edgar, & King, 1992; Darou, Hum, & Kurtness, 1993; Foulks, 1989; Harris, Gorelick, Samuels, & Bempong, 1996; Jones, 1993; Norton & Manson, 1996; Trimble, 1989). The stakes are especially high for ethnic minority children and youths, who require culturally validated mental health services but who are also most vulnerable to harms that can arise when ethical procedures do not adequately protect their rights and welfare.

The National Research Act (1974) mandates the establishment of institutional review boards (IRBs) by any institution receiving federal funding for biomedical or behavioral research. The purpose of the IRB is to protect the

rights and safety of human research participants. In fulfilling its task, the IRB must carefully examine research

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The Research Ethics in Mental Health Science Involving Ethnic Minority Children and Youth Conference cochairs were Celia B. Fisher and Kimberly Hoagwood. Cheryl Boyce served as National Institute of Mental Health liaison and Troy Duster, Deborah A. Frank, Thomas Grisso, Robert J. Levine, Ruth Macklin, Margaret Beale Spencer, Ruby Takanishi, Joseph E. Trimble, and Luis H. Zayas served as conference advisory board members; each contributed equally to this article. Conference participants are listed in the Appendix. Portions of this conference were supported by the Science and Public Interest Directorates of the American Psychological Association (APA), the Fordham University Center for Ethics Education, National Institute of Mental Health Contract 263-MD-109137 awarded to Celia B. Fisher, and National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID) Grant 5-T15-AI07551-03 awarded to Celia B. Fisher. The statements contained in this article are the views of the authors and do not necessarily reflect the views or perspectives of individual participants, the APA, the U.S. Department of Health and Human Services, the National Institutes of Health, NIAID, or the National Institute of Mental Health.

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proposals to arrive at an independent determination that (a) risks to participants are minimized and reasonable in relation to anticipated benefits, and, when appropriate, participant safety is adequately monitored; (b) selection of participants is equitable, and vulnerable populations are not subject to coercion or undue influence; (c) informed consent is sought from each prospective participant or from the participant's legally authorized representative, and this consent is documented; and (d) adequate provisions for the protection of participants' privacy and the confidentiality of the data have been made. The American Psychological Association's (APA's) "Ethical Principles of Psychologists and Code of Conduct" (APA, 2002, this issue, Section 8) requires psychologists to obtain appropriate IRB approval before conducting research and sets forth specific standards that must be followed to protect participants' rights and ensure participants' safety.

The general rules of scientific conduct embodied in federal regulations ("Protection of Human Subjects," 2001) and professional codes of conduct (APA, 2002) provide critical, yet incomplete, guidance for investigators and for IRBs identifying and resolving the dynamic and complex ethical challenges inherent in mental health research involving ethnic minority group members. Investigators engaged in the critical task of generating the information on which mental health services, public opinion, and policies for ethnic minority children will be based are thus faced with the formidable responsibility of ensuring that their procedures are scientifically sound, culturally valid, and morally just.

On July 16–17, 2001, the Science and Public Policy Directorates of the APA, the Child and Adolescent Consortium of the National Institute of Mental Health, and the Fordham University Center for Ethics Education sponsored

a working conference at Fordham University entitled "Research Ethics for Mental Health Science Involving Ethnic Minority Children and Youth." Invited participants (listed in the Appendix) were nationally recognized experts in bioethics, multicultural research, mental health science, ethnic minority child and family development, community advocacy, and federal regulations for research with human participants. A primary goal of the conference was to raise for consideration points related to encouraging ethical decision making in mental health research that reflects the unique historical and sociocultural realities of ethnic minority children and youths. This report summarizes the key issues distilled from these discussions. These issues are organized around four critical dimensions of mental health research that facilitate ethical behavior: (a) applying a cultural perspective to the evaluation of research risks and benefits, (b) developing and implementing respectful informed consent procedures, (c) constructing confidentiality and disclosure policies sensitive to cultural values, and (d) engaging in community and participant consultation. Each section incorporates as background a summary of leading research and scholarship on these issues and provides specific points (numbered below) for consideration.

Ethical planning for mental health science involving diverse populations requires flexibility and sensitivity to the contextual challenges and concerns of each ethnic group and research problem (U.S. Department of Health and Human Services, 2001). The points for consideration that are raised in this report are thus not intended to serve as regulation, policy, or absolute prescriptions for research ethics practices. Rather, the goal is to assist investigators, federal and private funding agencies, and IRBs in identifying key ethical crossroads and in developing culturally sensitive decision-making strategies that reflect the values and merit the trust of ethnic minority children, their families, and their communities.

## **Applying a Cultural Perspective to the Evaluation of Research Risks and Benefits**

As codified in federal regulations ("Protection of Human Subjects," 2001), ethical justification for mental health research requires investigators to maximize the probability of research benefits, minimize research risks, and demonstrate a favorable balance of benefits over harms (Section 46.111). Mental health scientists working with ethnic minority children and youths can enhance the prospect of benefits and reduce risks through thoughtful consideration of the design's scientific merit, the impact of historical and contemporary discrimination on mental health outcomes, and cultural and contextual factors that may interfere with or facilitate responsiveness to treatment.

### **Scientific Merit and the Assessment of Research Risks and Benefits**

Scientific merit is a minimal requirement for determining whether possible research risks to persons or groups are ethically justified by proposed research benefits (Freedman,

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1987). A poorly designed study holds no possibility of benefits. The valid application of research methodologies to mental health science involving ethnic minority children and youths requires that researchers have the following: (a) an awareness of the importance of scientific, social, and political factors governing definitions of race, ethnicity, and culture; (b) an understanding of within-group differences; (c) familiarity with and skills in constructing and implementing culturally valid and language-appropriate assessment instruments; and (d) knowledge of the cultural and political circumstances of participants' lives.

**Defining race, ethnicity, and culture.** The scientific value and validity of research findings aimed at examining children's mental health across various ethnic groups is threatened by the problem of definition (Jensen & Hoagwood, 1997). In the scientific literature, participant populations are often identified by *race*, *ethnicity*, or *culture* in the absence of clear definitions of what these terms mean and how they are continuously shaped and redefined by social and political forces. These terms are used with a disregard for their historical coupling with political beliefs about the inherent superiority of a particular group (Chan & Hune, 1995; Helms, 1996; Oboler, 1995; Phinney, 1996; Ponterotto & Casas, 1991; Yee, Fairchild, Weizmann, & Wyatt, 1993; Zuckerman, 1990).

1. Investigators need to carefully consider and explicitly describe the theoretical, empirical, and social frameworks driving the definitions of *race*, *ethnicity*, or *culture* that are used to select participant populations. This will ensure the scientific validity of the research question and will allow research findings to be evaluated within the context of continuously changing scientific and societal conceptions of these definitions.

**Sensitivity to within-group differences and individual factors.**

Investigators face significant challenges in their efforts to select and define the ethnic group membership of research participants. Experimental designs and research reports too frequently categorize participants into broad pan-ethnic labels (such as *Black*, *Hispanic*, *Asian*, or *American Indian*) that dilute and obscure the moderating effects of national origin, immigration history, religion, and tradition on normative and maladaptive development (Fisher, Jackson, & Villarruel, 1997; LaFromboise, Hardin, Coleman, & Gerton, 1993; Lin & Kelsey, 2000; Rumbaut, 1991; Spencer, Swanson, & Cunningham, 1991). Such an approach, termed *ethnic gloss* by Trimble (1990), produces overgeneralizations about the nature of development among ethnic minority youths and neglects the unique differences among individuals within various racial, ethnic, and cultural groups (Mio, Trimble, Arredondo, Cheatham, & Sue, 1999). The use of broad ethnic labels to categorize participants can also mask the influence on mental health of racial, ethnic, mixed-race, or bicultural self-identification (Oboler, 1995; Ogbu, 1994; Root, 1992).

2. In designing their research, investigators need to consider within-group variability and individual differences among ethnic groups that may influence children's mental health and responsiveness to treatment. Such factors include ethnic identification, acculturation, language, education, socioeconomic status, regional variation, and personal and familial immigration history. Although a single study may not examine all of these factors, the selection of variables and the discussion of findings should reflect an awareness of their possible influence on development and on the disorder or symptoms under investigation.

**Cultural equivalence of assessment measures.**

Ethnic minority youths may not derive equal benefits from or may be subject to harm in research that is based on assessment norms derived from samples that have too few racial and ethnic minority members to ensure cultural validity and measurement equivalence or when test items fail to consider the indigenous perspective (Council of National Psychological Associations for the Advancement of Ethnic Minority Interests [CNPAEMI], 2000; Knight & Hill, 1998; Parron, 1997; Shenkman, Vogel, Brooks, Wegner, & Naff, 2001; Trimble & Medicine, 1993). The use of such measures risks the over- or under-identification of mental health problems among children or adolescents. This type of error can compromise the scientific benefits of the research and lead to harmful social labeling or maladaptive self-conceptions of members of the racial or ethnic group studied (Canino & Guarnaccia, 1997; Manson, Bechtold, Novins, & Beals, 1997; Seráfica, 1997).

3. Whenever possible, investigators should select instruments that have been standardized on members of the research participants' racial or ethnic group. When culturally appropriate tests have not yet been developed or sufficiently evaluated, investigators should take steps to ensure that their instruments are assessing conceptually and operationally the mental health characteristics under study. One way to accomplish this is to examine the cultural,



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developmental, and item equivalence of instruments for each population studied. In the case of non-English-speaking or multilingual participants, investigators should use translated versions of standardized instruments that have been subjected to rigorous standards of measurement equivalence to ensure that the desired psychological constructs are properly measured.

**Ethnic discrimination and group stigmatization.** Racism and discrimination in education, jobs, juvenile justice, and social services are real conditions in the lives of many ethnic minority children and youths (Federal Glass Ceiling Commission, 1995; National Research Council, 1993; U.S. Sentencing Commission, 1995; Wilson, 1996). Daily encounters with overt or subtle forms of ethnic prejudice can threaten mental health through the development of racial mistrust, culturally marginalized identities, stereotype threat, lowered self-esteem, and generalized anxiety (Biafora et al., 1993; Chun, 1995; Fishbein, 2002; Fisher, Wallace, & Fenton, 2000; Fordham & Ogbu, 1986; Klonoff, Landrine, & Ullman, 1999; Phinney & Chavira, 1995; Steele, 1997; Terrell, Terrell, & Miller, 1993; Thompson, Neville, Weathers, Poston, & Atkinson, 1990). The extent to which poverty, inadequate health care, and other social factors contributing to poor developmental outcomes are mediated by racial and ethnic discrimination has received little theoretical attention in developmental research. Ignoring racial and ethnic discrimination as a variable in mental health research risks promoting treatments that mask rather than address the social realities of children's lives (Burkard, Medler, & Boticki, 2001; Trimble, 1988).

4. Programmatic research is needed on questions that examine historical and contemporary forms of prejudice and discrimination as implicating factors in the develop-

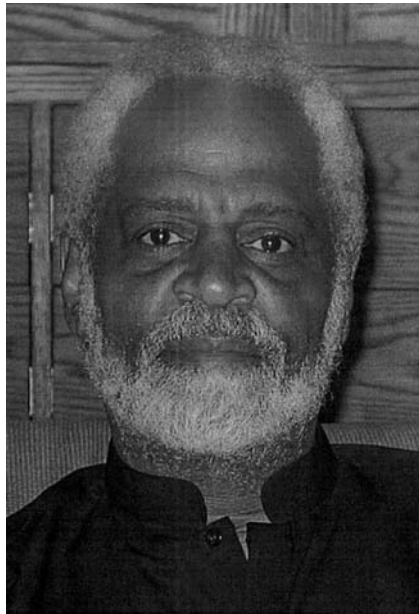
ment of well-being among ethnic minority children and adolescents. Racial and ethnic intolerance within peer groups, schools, employment settings, juvenile justice proceedings, and health care systems should be included in studies of person-context interactions contributing to positive and poor developmental outcomes if research is to fully inform mental health services for ethnic minority children and youths.

**Moving away from comparative and deficit approaches to research.** Another form of potential research risk for ethnic minority youths is the use of comparative research designs in which the developmental patterns of White or other ethnic majority groups serve as the standard of mental health (Heath, 1997; McAdoo, 1990; Padilla, 1995; Takanishi, 1994). When group differences emerge, they are typically interpreted as deficit outcomes for minorities, with little or no evidence of the meaning of these outcomes to ethnic minority mental health (Ponterotto & Casas, 1991). Health disparities between ethnic minority and majority groups may be inappropriately attributed to genetic, familial, or cultural factors or may be explained away by differences in socioeconomic status. Ignored is the destructive influence of discriminatory public policies on the quality of schools, access to drugs, exposure to violence, and inequities in juvenile justice proceedings in the neighborhoods in which many of these children live.

As important as it is to examine the problems facing ethnic minority youths, it is equally important to identify and examine the role of culture in the developmental pathways leading to mental health (Laosa, 1990). Many ethnic minority children in high-risk environments succeed, yet few studies have examined or constructed adequate measures of the assets, strengths, and resiliencies that support mental health development in ethnic minority children and youths (Connell, Spencer, & Aber, 1994; Scales, Benson, Leffert, & Blyth, 2000). In the absence of such data, studies designed to inform prevention and treatment approaches for developmental disorders may be of limited benefit to minority children and youths (Spencer, 1995).

5. Mental health research should examine participants' developmental capacities for coping and resilience in addition to factors that may influence vulnerability to mental disorders. Researchers examining the roles of race, ethnicity, and culture on the development of children and youths should consider how minority status may add a layer of mental health vulnerability imposed by social and institutional prejudices rather than by ethnic group characteristics, values, and traditions.

**The selection of treatment and control conditions in clinical trials.** Risk-benefit analysis of intervention research includes an assessment of the comparative harms and benefits produced by random assignment to experimental treatment or control conditions. Ethical justification for beginning a randomized controlled trial requires either (a) that there be no empirically validated reason to predict that the experimental treatment condition will be better or worse than the control condition or (b) that there is a current or likely dispute among experts in the



**Troy Duster**

mental health community about which condition is superior in all known respects (R. J. Levine, 1986; Roberts, Lauriello, Geppert, & Keith, 2001; Weijer, Shapiro, Glass, & Enkin, 2000). After this criterion is met, the best available treatment should serve as the control whenever possible. In some instances, the attention paid to treatment attendance and fidelity in a control condition of a randomized clinical trial may be more beneficial than if treatment as usual in the community is given to a comparison group (Spirito, Stanton, Donaldson, & Boergers, 2002).

Meeting these requirements is especially challenging for mental health research involving ethnic minority children and youths. The absence of culturally relevant diagnostic criteria for children from diverse ethnic backgrounds, combined with the paucity of information on how culture influences the effectiveness of mental health services, makes it difficult to ascertain whether a treatment with established efficacy in one ethnic group presents a lesser or greater probability of benefit when it is tested in or used as a control condition for members of a different ethnic group (Alvidrez & Areal, 2002). Furthermore, when research is conducted in politically underrepresented and economically underserved populations, the best treatment available in the local community may be inferior to treatments available in nonminority neighborhoods (Thomas, Pinto, Roach, & Vaughn, 1994).

6. Prior to testing an intervention developed for members of the majority culture or an ethnic minority population, researchers should have adequate theoretical, clinical, practical, or empirical bases for hypothesizing that it will be effective in the particular ethnic group recruited for the study. This includes knowledge of that group's cultural values, traditions, socioeconomic status, education, or other relevant variables that may facilitate or interfere with responsiveness or resistance to different treatment conditions under study.

7. Investigators testing a promising mental health treatment should consider ethnic disparities in access to quality mental health services when selecting as a control condition a treatment currently available to the community versus the best quality of treatment available nationwide.

### ***Culturally Knowledgeable Research Teams***

The design and conduct of research with ethnic minority children can benefit from the multiple perspectives that a culturally diverse research team provides (Sue et al., 1998). Investigators must be aware, however, that ethnic group membership of investigators, data collectors, or other front-line research staff does not, in and of itself, assure understanding of or competence to conduct research in ethnic minority communities.

8. Investigators must provide all members of the research team with training in the cultural competencies necessary to conduct research with the racial and ethnic populations involved in the study in order to ensure the highest quality of data collection. Principal investigators should also encourage staff to provide ongoing feedback about participants' responses to recruitment practices, experimental procedures, instruments, and all aspects of the research. This feedback will allow investigators to evaluate the effectiveness of the procedures and the need for culturally appropriate methodological adjustments.

9. Investigators and research team members from all ethnic backgrounds can benefit from examination of their own cultural biases. Through self-reflection and exchange of views, the research team can examine and address different cultural conceptions of the research, mental health goals, and scientific procedures aimed at understanding and promoting positive development of ethnic minority children and youths.

### **Developing and Implementing Respectful Informed Consent Procedures**

Informed consent protects participants' autonomy and welfare by providing a description of the study with its benefits and harms, thus enabling individuals to make an informed, rational, and voluntary decision about whether to participate. Consent procedures for studies involving children and adolescents require added protections because in most circumstances, minors do not have the legal right to consent, lack the cognitive maturity to understand research procedures, and do not have actual or perceived power to refuse participation (Abramovitch, Freedman, Henry, & Van Brunschot, 1995; Abramovitch, Freedman, Thoden, & Nikolich, 1991; Bruzzese & Fisher, 2003; Morton & Green, 1991; Nannis, 1991; Ruck, Abramovitch, & Keating, 1998; Ruck, Keating, Abramovitch, & Koegl, 1998). In light of these concerns, with few exceptions, federal regulations and professional codes of conduct require the informed permission of parents, legal guardians, or those who act in loco parentis before a child or adolescent can participate in research (APA, 2002; "Protection of Human Subjects," 2001). As a matter of respect for children's autonomy as

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developing persons, their assent is also required, unless the research holds out the prospect of direct benefit that is important to the child and only achievable through the experimental procedures (“Protection of Human Subjects,” 2001, Section 46.408a).

The development and implementation of culturally sensitive informed consent procedures for mental health research involving ethnic minority children and youths can be enhanced through consideration of participants’ and guardians’ familiarity with research, language preferences and proficiencies, cultural and institutional conceptions of adult authority and child autonomy, and economic and treatment concerns (Benatar, 2002; Macklin, 2001; Sanchez, Salazar, Tijero, & Diaz, 2001).

### **Familiarity With Research**

In ethnic minority communities, a lack of familiarity with the research process and scientific terminology can be a barrier to obtaining truly informed guardian permission and child or adolescent assent. For example, in some African American communities, where open and reciprocal discourse provides a valued means of constructing trusting relationships (Stevenson, De Moya, & Boruch, 1993), structured tests including repetitive items may be interpreted as a lack of sincere interest in and respect for the participant’s feelings and experiences. In some Asian cultures, high values are placed on deference to authority, the maintenance of harmonious relationships, efforts to meet the needs of a guest, and empathic interdependence (Tai & Lin, 2001). In some Hispanic or Latino/a communities, an individual’s ability to be simpatico to others is highly valued (Browner, Preloran, & Cox, 1999). If recruitment and consent procedures are insensitive to these values, members of ethnic groups may decline to participate, or

they may comply with research participation without adequate attention to informed consent information.

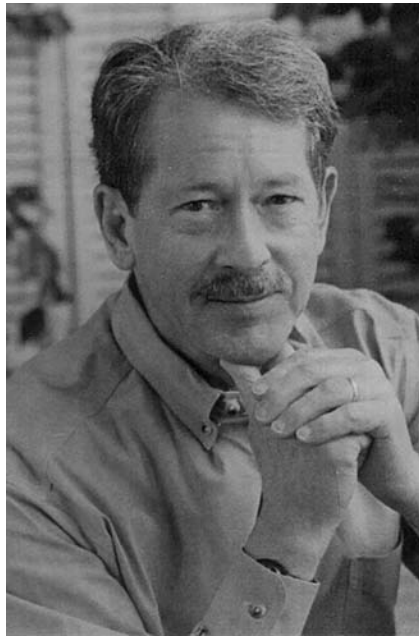
10. Investigators can enhance informed consent protections through individual and community awareness mechanisms aimed at educating prospective participants, their guardians, and their communities about the research process and participants’ rights. Such mechanisms include the use of recruitment handbooks and the dissemination of information through community-based speakers, bureaus, mass media, parent–school associations, health care centers, and religious organizations. Informed decisions to participate are also facilitated by providing prospective participants and their guardians with time to consider the information and to discuss it with family members or community elders.

### **Language**

U.S. Department of Health and Human Services (“Protection of Human Subjects,” 2001) regulations for the protection of human research participants require that informed consent information be presented “in language understandable to the subject or representative” (Section 46.116). The challenges of constructing appropriate informed consent procedures sensitive to developmental and generational requirements are more complex in research involving ethnic minority children and youths. Differences in language proficiency, language preference, and communication styles can result in misrepresentation or misunderstanding of consent information. For example, translation of research terminology may be inexact when there is no direct correspondence between the words and concepts of Western science and those of the culture of the prospective participant. Federal guidelines permit oral presentation of informed consent information in conjunction with a short written consent document in a language understandable to the participant. This consent procedure must be witnessed by an individual fluent in both English and the language of the participant (“Protection of Human Subjects,” 2001, Section 46.117b[2]). The IRB must receive all non-English translations of the short-form document as a condition of approval. When an interpreter assists the person obtaining consent, the interpreter may serve as the witness.

The unfortunate practice of selecting the most readily accessible and available interpreter, such as a family member or bystander unfamiliar with scientific or mental health terminology, can lead to interpreter distortion, breaches in confidentiality, exploitation, or harmful dual-role relationships between the prospective participant and the interpreter (Rogler, Malgady, Costantino, & Blumenthal, 1987; Trimble & Thurman, 2002). The APA ethics code requires that psychologists who use the services of interpreters see that such persons perform these services competently and that they take reasonable steps to avoid delegating such work to persons who have a multiple relationship with the participant that would likely lead to exploitation or loss of objectivity (APA, 2002, Standard 2.05).

11. Informed consent procedures must be conducted in a language understood and preferred by prospective participants and their guardian or guardians; researchers



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should recognize that children and adolescents may have different language competencies and preferences than adult members of their families. Investigators should also ensure that consent forms translated from English or other languages are adequate. These forms should be translated using procedures that ensure equivalency.

12. When necessary, investigators must use the services of interpreters who have the language and knowledge competencies necessary to ensure that consent is informed, rational, and voluntary. Having children serve as interpreters to obtain parent permission is not permissible because it may result in misinformation or may undermine respectful parent-child relationships. In small and cohesive ethnic communities, individuals qualified to serve as interpreters may have other role relationships with prospective participants and their families. Through careful and respectful questioning, investigators must determine whether these multiple relationships could be exploitative or otherwise harmful to participants, must select alternative interpreters when feasible, and must take steps to ensure that consent is voluntary and that participant confidentiality is protected.

### **Documentation of Consent**

For some members of ethnic minority groups, signing an informed consent document may be unfavorably viewed as an intrusion of bureaucracy into a social contract that should be based on relationships of trust, as a tool for tracking undocumented immigrants, or as a means of getting participants to sign away their right to withdraw or complain about investigators' conduct (Beauvais, 1999; Fisher, 2002). In most cases, federal guidelines require that informed consent be documented with the participant's and/or guardian's signature ("Protection of Human Subjects," 2001, Section 46.117a). However, this requirement

may be waived if signing could lead to a breach of confidentiality or when research presents no more than minimal risk of harm and involves no procedures for which written consent is normally required outside the research context ("Protection of Human Subjects," 2001, Section 46.117c).

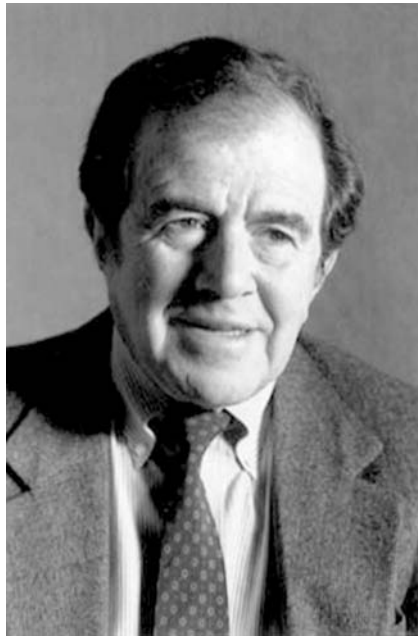
13. Informed consent procedures for research involving ethnic minority groups should reflect sensitivity to participants' concerns about signed forms. Investigators may seek a waiver for this requirement when appropriate, and, if granted, they should continue to provide prospective participants and their guardians with a detailed oral or written consent statement about the research and to document that oral consent has been obtained.

### **Guardian Permission**

**Cultural conceptions of adult authority and individual autonomy.** Variations in cultural conceptions of parental authority, individual autonomy, and collective responsibility may call for consideration of different levels of adult and community involvement in consent decisions (CNPAAEMI, 2000; R. J. Levine, 1991; Macklin, 1999). For example, prospective child or adolescent participants and their guardians from American Indian or Alaska Native tribes may recognize the political authority of a tribal leader to make decisions about whether and how investigators should approach tribal members (Beauvais & Trimble, 1992; Freeman, 1994; Norton & Manson, 1996). In some Asian cultures, the Confucian tradition of harmonious universe places family at the center of each person's life, thus rendering consent a family right rather than an individual privilege (Tai & Lin, 2001). In some African American families, grandparents, aunts and uncles, or older siblings who do not have legal guardianship serve as the primary decision makers in the everyday activities of children or adolescents. Investigators need to develop procedures that enable participants and their guardians to consent in accordance with federal guidelines, while respecting their cultural traditions.

14. When designing informed consent protocols, investigators should make an effort to understand expectations about guardian permission and child assent that reflect cultural attitudes, values, and histories related to the roles of family members and community structures in decisions regarding the welfare of children and adolescents. Investigators should respect these relationships while fulfilling legal obligations and should recognize that their primary obligation is participant protection.

**Waiving guardian permission.** The type of high-risk physical and social conditions that bring children and adolescents to the attention of mental health investigators can pose ethical questions about the extent to which guardian permission will be in the best interests of the child (Brooks-Gunn & Rotheram-Borus, 1994; Fisher, 2002; Holder, 1991; Koocher & Keith-Spiegel, 1990; R. J. Levine, 1995; Rogers, D'Angelo, & Futterman, 1994). Federal regulations ("Protection of Human Subjects," 2001, Section 46.408c) permit waiver of guardian permission when there is serious doubt about whether the guardian's interests adequately reflect the child or adolescent's inter-



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ests (e.g., research on child abuse or neglect) or when permission cannot be reasonably obtained (e.g., research on runaway youths), as long as such waivers are consistent with law. In such cases, an appropriate mechanism for protecting the child or adolescent must be substituted. This usually entails the appointment of an independent participant advocate who (a) verifies minors' understanding of assent procedures, (b) supports their preferences, (c) ensures that their participation is voluntary, (d) monitors their reactions to experimental procedures, and (e) ensures adequate debriefing (Fisher, Hoagwood, & Jensen, 1996).

Applying federal guidelines to decisions about the waiver of guardian permission for research involving ethnic minority youths can compromise the protections that such permission provides when institutional biases toward the competency of ethnic minority parents in social services or juvenile justice proceedings are not carefully considered (Mulvey & Phelps, 1988). For example, cultural differences in parental disciplinary practices (Dietz, 2000; Saadeh, Rizzo, & Roberts, 2002) or language obstacles to parent participation in the juvenile justice system may lead to inequities in judgments about whether guardians will make consent decisions in the best interests of their children.

15. When deciding whether to request a waiver of guardian consent, investigators should consider the meaning and consequences of the waiver to parent-child relationships within the norms and behavior of the ethnic group from which participants are recruited. Investigators should be sensitive to potential institutional biases regarding parental competence that may influence waiver decisions. A guardian's reluctance to return consent forms is not a justification for waiving guardian permission.

16. Assent procedures for children need to be tailored

to reflect the participants' developmental level, experience, and cultural expectations about adult authority. Assent procedures should provide sufficient opportunities for children or adolescents to express their wishes about agreement or refusal to participate in the research. When the requirement for guardian permission has been waived, investigators should identify participant advocates who have the language skills and cultural competencies necessary to protect the rights of the children or adolescents.

### ***The Voluntary Nature of Consent***

The voluntary nature of consent is essential to the ethical conduct of mental health research. According to federal regulations and professional codes of conduct, an investigator shall seek consent only under circumstances that minimize the possibility of coercion and undue influence (APA, 2002, Standards 8.02 and 8.06; "Protection of Human Subjects," 2001, Section 46.116).

**Economic concerns.** Different cultural perspectives and economic circumstances may lead to varying perceptions of different forms of research compensation as fair or coercive (R. J. Levine, 1986; Macklin, 1981; Saunders, Thompson, & Weijer, 1999). Financial concerns are often a barrier to research participation in economically distressed cultural minority communities. Taking time off from work to provide permission for or to participate in research may be an economic burden for guardians who earn an hourly wage or work double shifts to support their families. Research participation may pose a similar economic burden for adolescents with after-school jobs or sibling-care responsibilities.

Some suggest that compensation for research participation be restricted to reimbursement for travel and time lost at work to help ensure that children and adolescents from lower income families have equal opportunity to benefit without coercion from knowledge generated from mental health research. Others suggest that fair compensation at middle-class levels be offered to lower income families but that a neutral party should monitor the consent process for potential coercion (Arnold et al., 1996). How children and parents from different cultural groups view the legitimacy of cash payments for research participation also requires ethical attention. For example, some families may see financial compensation as undermining their desire to encourage their children to altruistically contribute to science, society, or the welfare of their community (Osher & Telesford, 1996; Sanchez et al., 2001).

17. Selection of fair and noncoercive compensation for research participation needs to reflect consideration of cultural, economic, and developmental factors influencing the value and meaning of monetary payments or other compensation alternatives as legitimate recompense for the time and effort contributed to a research project. Consultation with prospective participants and community leaders can assist in determining compensation that is perceived as fair and noncoercive by members of the cultural group recruited for research participation.



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**Research conducted in service delivery settings.** Informed consent procedures conducted within schools, emergency rooms, hospitals, or social service agencies pose challenges for ethnic minority children and their guardians. In these contexts, an invitation to participate in a research study may lead to confusion about the investigator's role and fear that failure to consent will result in denial or discontinuation of services. Parents and children may also transfer to the researcher their trust in the institution (e.g., school, clinic, hospital, agency) without understanding the difference between the investigator and practitioner roles. Language differences, lack of familiarity with research procedures, immigration status, and economic needs may compound this confusion for racial and ethnic minority families.

18. Informed consent procedures conducted in service settings must clarify the differential roles of investigators and professional staff, the relationship and obligations of the investigator to the service agency and to the participant, and the extent to which participation in the research is distinguishable from receipt of services. Investigators must also provide prospective participants and their guardians with clear explanations of the purpose of assessments and interventions conducted to gain scientific knowledge, those conducted exclusively for receipt of treatments or services, and those used in legal investigations or child welfare evaluations.

19. Investigators should work with institutions to develop safeguards to ensure that prospective participants understand that research refusal or withdrawal does not result in termination of services or other negative consequences. Reconsent procedures at appropriate intervals for longitudinal studies should be implemented to ensure that participation remains voluntary.

## Developing and Implementing Culturally Sensitive Confidentiality and Disclosure Policies

Research on the mental health of children and adolescents often uncovers evidence of mental health problems, family problems, illegal behavior, health-compromising behaviors, or health problems unknown to other adults concerned with a child's welfare. Such research may also elicit sensitive information that could place participants or their family members in social or legal jeopardy if disclosed beyond the research setting. Identifying conditions under which it is ethically appropriate to keep such information confidential or disclose it to parents or professionals is a daunting ethical challenge for investigators working with ethnic minority children and youths (Brooks-Gunn & Rotheram-Borus, 1994; Fisher, 1994, 1999; Scott-Jones, 1994).

### Protecting Participant Privacy

Federal regulations and professional codes of conduct require adequate provisions to protect participants' privacy ("Protection of Human Subjects," 2001, Section 46.111a[7]). Such procedures include the use of participant codes rather than identifiers, secure storage and limited access to data, disposal of unnecessary information, and anonymous data collection when possible. In addition, when the release of data could lead to stigmatization, discrimination, or legal action for participants, investigators can apply under Section 3.01d of the Public Health Service Act (2001) for a Certificate of Confidentiality, which would give them immunity from a government or civil order to disclose identifying information (Hoagwood, 1994; Melton, 1990).

Such procedures may not be sufficient to protect the confidentiality of individuals in small, rural, or closely knit ethnic neighborhoods. For example, in such settings, recruitment efforts can alert community members to the nature of a child's disorder. Similarly, media reports of research describing the unique characteristics of unnamed but small or unique ethnic communities or tribes may lead to public identification and stigma (Norton & Manson, 1996). Finally, procedures for protecting confidentiality may be seriously challenged in community-based ethnographic studies or research conducted in schools, health care facilities, juvenile detention facilities, or social service agencies when the research design uses informants to understand the child's mental health or evaluate services.

20. When working with rural or small and unique ethnic populations, investigators need to be aware of the added difficulties of protecting the confidentiality of individuals and their communities. During the recruitment, implementation, and dissemination stages of research, investigators should take extra precautions to protect the privacy and identity of research participants, their families, and their communities.

21. When research involves multiple informants, investigators must take precautions not to reveal confidential information about the participants to the informants. When research is conducted in institutional settings, investigators



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must take steps to protect participant privacy and recognize that institutional staff may have different disclosure and reporting obligations or that they may use the knowledge in ways that participants and their guardians may find undesirable.

### **Disclosing Confidential Information**

In clinical settings, conditions under which disclosure of personal information is appropriate are determined by researchers' legal and ethical obligations to protect participants from suspected child abuse and self-harming behaviors or to protect others from harm. However, the reporting obligations of mental health researchers not offering clinical services are less clear. Such investigators are often reluctant to disclose information derived from surveys or interviews out of concern that data collected may not be appropriate for judgments of imminent risk or that treatment or referrals precipitated by disclosures will threaten the internal validity of longitudinal designs, cause participants to feel betrayed, or jeopardize recruitment. Researchers may also be reluctant to disclose information about risky behaviors, mental health problems, or undocumented suspicions of abuse or neglect to school counselors or child protection agencies out of concern that such disclosure may harm participants or their families if those informed react punitively or incompetently or entangle the family in criminal proceedings (Fisher, 1994, 2002).

Decisions about disclosing confidential information to protect ethnic minority children and adolescents participating in research require special consideration for several reasons. First, use of the deficit approach to ethnic-minority research means that investigations involving minority youths are more likely to focus on and acquire sensitive information about maladaptive rather than normative de-

velopmental processes (Scott-Jones, 1994). Second, institutional biases and culturally invalid assessment techniques may result in under- or overidentification of problem behaviors that require reporting. Third, the use of public medical, social, and legal services by poorer ethnic minority families may make these groups more accessible to researchers studying psychological and social problems (Scott-Jones, 1994). Confidentiality and disclosure decisions are further complicated by emerging evidence that teenagers self-identified as African American, Asian, Hispanic or Latino/a, and non-Hispanic White often expect researchers to actively assist them in obtaining help for problems revealed during the course of an investigation (Fisher, 2002; Fisher, Higgins-D'Alessandro, Rau, Kuther, & Belanger, 1996; O'Sullivan & Fisher, 1997).

22. Criteria for disclosing information about an ethnic minority child's mental health status or risk behaviors need to include careful consideration of mandated reporting laws. Criteria should also be culturally valid and should include culturally appropriate means of assessing the following: (a) clinical levels of risk, (b) the truthfulness of reports, (c) whether a problem needs immediate attention, (d) whether a child or adolescent is already receiving services for the problem, and (e) sensitivity to the child or adolescent's expectations about the investigator's protective role.

### **Cultural Attitudes Toward Shared Information**

Confidentiality decisions are also complicated by ethnic variation in attitudes about information sharing between parents and children. For example, in some cultural groups, failure to provide information about a child to parents is considered disrespectful of the parental role, whereas in other groups, providing this information is considered an intrusion on parent-child communication (Casas & Thompson, 1991; Fisher, 2002; Oetting & Beauvais, 1990). Cultural values and traditions also influence the extent to which children and their guardians believe it is appropriate to disclose information to family members, school counselors, or mental health practitioners. Finally, ethnic minority families may be unfamiliar with local, state, and federal reporting laws. Therefore, blanket statements included in consent forms stating that confidentiality will be protected except where reporting of such information is required by law may be uninformative at best and deceptive at worst.

23. Members of different ethnic groups may differ in their expectations for and valuing of confidentiality when it relates to information indicating that a child or an adolescent has a mental health problem or is engaged in high-risk or health-compromising behaviors. Confidentiality and disclosure policies should reflect consideration of and respect for these differences to the extent that is possible given that such policies may be determined by state, local, or federal law or by IRB standards for that community.

24. Once culturally valid criteria for disclosing confidential information have been established, investigators should, whenever possible, identify culturally appropriate

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persons and agencies that can best serve the interests of participants in need of referral or immediate intervention. Working with community members, schools, child welfare agencies, courts, law enforcement agencies, and mental health facilities, investigators can build culturally sensitive systems of protection that define when, how, and to whom a problem will be reported in a manner consistent with laws governing reporting.

25. The specific confidentiality and disclosure policies selected for a study must be explained to prospective participants and their guardians during informed consent procedures. Such information includes an explanation of reporting requirements, such as those related to mandated child abuse reporting or duty-to-protect laws. When possible, participants and guardians should be allowed to choose among available disclosure and service referral procedures.

## **Community and Participant Consultation**

### ***The Importance of Community and Participant Perspectives***

Investigators studying the mental health of ethnic minority children and youths are repeatedly challenged to find the best ways to construct and conduct research that satisfies the requirements of good scientific design and ethical practice. In striving to meet these dual obligations, investigators have traditionally drawn on federal regulations, IRBs, organizational policies, and their own moral compass to plan ethical procedures that will have immediate and long-term impact on research participants and their families. However, ethical practices may be viewed differently by members of the science establishment and prospective participants with the unique life situations of ethnic minority

children and youths with mental health problems (Heath, 1997; Trimble, Manson, Dinges, & Medicine, 1984). Thus, an important resource for guiding culturally appropriate ethical decision making is the opinions of individuals with knowledge of and experience with the culture and problems that are the target of investigation (Fisher, 1997, 1999, 2002; Fisher & Wallace, 2000; Fullilove & Fullilove, 1993; Jensen, Hoagwood, & Trickett, 1999; C. Levine, Dubler, & Levine, 1991; R. J. Levine, 1986; Melton, Levine, Koocher, Rosenthal, & Thompson, 1988; Stevenson, De Moya, & Boruch, 1993).

Consultation with participants and community stakeholders involves reciprocity of information exchange and respect for the unique expertise offered by investigators, prospective participants, and community representatives so that the interests of the individual and the community and the standards of good science are met. The investigator brings to the consultation expertise in scientific methods and available empirical knowledge relevant to the mental health question to be examined. Prospective participants and community stakeholders bring traditional wisdom, their mental health and research priorities, their confidence in and concerns about human experimentation, and the extent to which specific scientific and ethical procedures can reflect their values and merit their trust (Fisher, 1999, 2002).

In recent years, increasing numbers of ethnic minority communities have denied researchers access to residents. Some American Indian and Alaska Native communities now have ordinances or community covenants prohibiting any research without the direct approval of the tribal or village council (Darou et al., 1993; Foulks, 1989; Trimble, 1989). In some communities, the use of independent support staff drawn from the community itself may help investigators respond to research issues and receive communications about prospective participant concerns. In other communities, the presence of the principal investigator may best promote a sense of trust that the consultation process will be taken seriously in the design of experimental and ethical procedures.

26. Community and participant consultations involve an ongoing reciprocal and respectful dialogue among scientists, prospective participants, their families, and other community stakeholders. This dialogue is aimed at strengthening scientific merit and responsibility during research design, implementation, and dissemination. In some communities, this may require that researchers establish a relationship with the community long before the study is commenced. This relationship can inform the study's goals and aims and engage community members as true collaborators.

27. Consultation is not a means of obtaining blind acceptance of an already worked-out protocol. Respectful and successful community and participant consultation often depends on relationships of trust that are established early in the research design phase and are continued through the data interpretation, implementation, and dissemination phases. When a substantial number of participants and community representatives indicate concern



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about the balance of risks and benefits, recruitment or informed consent procedures, confidentiality policies, research compensation, or dissemination plans for a proposed project, investigators should work to modify these procedures to best meet the standards of scientific rigor and participant protection.

28. Multicultural research teams, especially those in which the ethnicity of frontline workers differs from that of the principal investigators, need to carefully consider the community outreach role of each team member to ensure that principal investigators maintain awareness of and are responsive to community and participant concerns.

### **Defining Community**

Identifying persons who can best represent research-relevant concerns of prospective participants requires an understanding of the social structures and relationships that define a community (Weijer & Emanuel, 2000). The particular protections a community advisory board provides will vary with the extent of community cohesion and with whether the community includes individuals with legitimate authority and understanding who can reflect the views and interests of prospective participants.

**Member identification and recognized authority.** A community can refer to individuals from a common ethnic group who share culture, traditions, language, and religion or to persons from different ethnic groups who share similar barriers to employment, education, housing, or quality health care, barriers rooted in exposure to historical discrimination and contemporary racial and ethnic biases. Definitions of community for research consultation also depend on prospective participants' sense of community membership and on the extent to which there is a recognized political authority or com-

munity leader who can shed light on the cultural values that shape concerns about the benefits and costs of a study for the individual participants and for group members not directly involved in the research (Weijer & Emanuel, 2000). For example, members of American Indian and Alaska Native tribes empower their tribal councils with authority to make binding decisions to permit investigators to conduct research that will involve tribal members, thus facilitating the identification of community representatives for research ethics consultation (Norton & Manson, 1996). In contrast, prospective participants drawn from diverse Spanish-speaking or Asian American groups may have different countries of family origin, immigration histories, ethnic identifications, and levels of acculturation, thus making it more difficult for investigators to identify appropriate cultural representatives.

### **Vulnerable groups within communities.**

The challenge of identifying cultural representatives is compounded when research involves ethnic minority children and youths with mental health problems. Differences in the immigration and socialization histories of children or adolescents and their adult guardians may contribute to differences in the way each generation perceives and values the risks and benefits of the proposed research. In addition, the interests of the larger community may not always be congruent with the best interests or research goals of vulnerable groups within the community (Macklin, 1999). For example, children with mental health problems and their families may favor a clinical trial in the hopes that it will result in immediate or future remedies for the children's disorder, whereas nonaffected members of the community may reject the trial out of concern about group stigma.

29. When seeking community consultation and collaboration, investigators should draw on a definition of community that includes representatives who have a knowledge base about the cultural and mental health concerns of the individuals who will participate in the research. When the mental health problems of children and adolescents are the focus of investigation, this may require drawing community representatives from multiple ethnic groups.

30. When conflicts over ethical procedures emerge among prospective participants, their family members, and community stakeholders during the design phase of the research, investigators should strive to modify experimental procedures in a manner that continues to ensure scientific validity while adequately addressing the needs of all parties. Researchers should recognize that their primary responsibility is to ensure the protection of the rights and welfare of those who participate in the research.

### **Community Consultation and the Conduct of Responsible Science**

The views of children or adolescents acting as participants, their guardians, and members of their cultural communities can help investigators identify factors that might cause participants distress, threaten participants' autonomy, or produce group stigma. Consultation and collaboration can help community members avoid erroneous assump-



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tions that scientifically worthwhile research designs might present unacceptable risks to a community. These assumptions can be avoided when prospective participants see the research as posing little, if any, harm and see the direct or social benefits as clearly outweighing the risks. Engaging community stakeholders in dialogue about the ethical challenges of mental health research involving ethnic minority children and youths can enhance community support and participation in research, thus increasing both the population validity and the social sensitivity of this critical aspect of mental health science.

31. Research proposals describing plans for community consultation should emphasize the strategies that will be used to identify and ensure sufficient community input and the role that community and participant consultation will play at different stages of the research.

32. A description of the ways in which the consultation process contributed to the evaluation and enhancement of ethical procedures should be included in research reports to contribute to the ethical development of the field of mental health science involving ethnic minority children and youths.

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## **Appendix**

### **Research Ethics in Mental Health Science Involving Ethnic Minority Children and Youth Conference Participants**

Plenary Speaker  
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