

Title: Ethical Issues in Longitudinal Research with At-Risk Children and Adolescents

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Description: A researcher wants to conduct surveys and interviews with grade school children to study resilience and exposure to maladaptive environments. The school principal insists that she does not need parental consent for the study, as the school supports the study.

Headings: Informed Consent: Disclosure and Deception; Passive consent; Minors (children, adolescents); Survey and qualitative research (behavioral, social science)

Case Type: Decision making

Ethical Issues in Longitudinal Research with At-Risk Children and Adolescents

Dr. Judy Brewster, long interested in the effects of exposure to maladaptive environments on development, plans to design a study to examine resilience. Why are some individuals able to fend off the deleterious consequences associated with stressful environments and adverse circumstances, while others are not? What characteristics are associated with adaptation to such environments? To learn more about the characteristics associated with resilience to environmental insult, Judy will study fourth, sixth and eighth graders who have been exposed to violence within their communities.

Youths will be assessed at six-month intervals for a period of four years. Assessments will be conducted in school through group-administered written surveys and individual interviews of approximately one to two hours in length. The amount and frequency of exposure to community violence will be measured, as well as short- and long-term psychological (anxiety, depression, perception of social support), behavioral (academic achievement, risk engagement) and adaptational (psychological and behavioral coping) responses. Aside from assessment interviews, participants will have no contact with the researcher.

Ms. Rosen, the principal of a private parochial school, has agreed to allow her school to participate in the study. She is eager to assist her students and suggests that Judy begin at once. When Judy asks for advice on how to approach parents for their permission, the principal says that it is not necessary, as the school supports the study. Judy is unsure of how to respond. She recalls that ethical guidelines do not require parental consent to conduct evaluations of educational curricula; however, she is not evaluating a curriculum.

Judy explains to Ms. Rosen that her funding agency and university institutional review board require that she obtain parental consent. Ms. Rosen notes the difficulty in obtaining responses from every parent in the fourth, sixth, and eighth grades; she suggests that a letter be sent to parents advising them that the study will be conducted and asking them to return the permission form if they do not want their child to participate.

Approximately two years into her study, Judy notices two distinct patterns of adaptation. Some of the children exhibit signs of distress, anxiety and depression, and report that they have begun to engage in

multiple risk behaviors such as substance use, delinquency, violence and sexual promiscuity. Other children show no signs of distress, or have outgrown and discontinued such behaviors. Judy is concerned about the acting-out youth, but she notes that many children have engaged in such behaviors and later discontinued engagement.

After extensive discussion with colleagues, Judy decides that she has four options available. She may: 1) do nothing and maintain confidentiality, as initially promised; 2) report excessive risk engagement to parents; 3) provide students with referral information so that they may obtain help; or 4) intervene. However, reporting, intervening or providing referral information may defeat the purpose of her study: to examine long-term effects of exposure to community violence in natural conditions.

Judy is not clinically trained; she is not competent to diagnose or treat distressed participants. She is, however, competent to teach students adaptive skills such as anger management and conflict resolution, which have been shown to have limited success in altering behavior. However, intervening may invalidate her results. After deliberation, Judy decides to do nothing to protect the validity of her study.

What consent processes should Judy use in this study?

Questions For Further Reflection

What are Judy's responsibilities to the students, parents and Ms. Rosen, if any?

What are the potential consequences of not obtaining consent for the students, parents, Ms. Rosen, and Judy, if any?

Given the potential consequences, should Judy obtain parental consent?

How well does this method of consent protect the autonomy rights of the students? What about the parents?

Are there alternative methods of obtaining consent? What are the advantages and disadvantages of each?

What are Judy's responsibilities to the participants in her study? How do they differ from her responsibilities to the parents? the university? the funding agency?

Does Judy have the same obligations and responsibilities to fourth graders as sixth graders? What about eighth graders?

What options of action are available to Judy?

How well do each of these options protect the rights of the students? the parents?

Does maintaining confidentiality fulfill Judy's ethical obligations and responsibilities to her participants, parents, university and funders? Why or why not?