# Author's Commentary on "Ethical Issues in Longitudinal Research with At-Risk Children and Adolescents"

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



Although many considerations are involved in this case, four broad areas deserve comment: researcher obligations, the role of informed consent, developmental factors; and options of action available to researchers who discover that minors may be in jeopardy.

## 1. Researcher Obligations

### *Who are the interested parties? What are Judy's responsibilities to each? How might each conflict?*

The interested parties include the students, parents, Ms. Rosen and Judy's funders. She holds different responsibilities to each party, which, at times, conflict. For example, Judy promises the students that she will keep their responses secret and will not disclose their information to anyone. The students trust Judy not to violate that promise.

On the other hand, parents give permission for their children to participate in research with the understanding that Judy will act to maximize potential benefits and will not cause harm to the children, in accordance with the principles of

beneficence and nonmaleficence (National Commission, 1979). In designing her research protocol and consent procedures, it is imperative that Judy consider parental expectations. Parents of at-risk youth may view any contact with professionals as a means of gaining assistance for their children and may erroneously assume that benefit will come from participation; that assumption may influence parental consent (Fisher, 1993; Thompson, 1992). In addition, parents may believe that the researcher's responsibility to act in the interests of the youth requires the researcher to disclose information that suggests that a student is in jeopardy; however, research protocols do not always correspond to this belief. Although Judy is obligated to keep the participants in her study from foreseeable harm, the parents may also feel that she is obligated to inform them of potential dangers to the students (i.e., excessive engagement in risky behavior).

Ms. Rosen, as a principal or school administrator, seeks information that will help the school as a whole and assist her in making administrative decisions. She seeks some disclosure of information; however, unlike the parents, she does not require unique identifiers or student names.

Judy is obligated by her sense of scientific integrity to conduct sound research. However, Judy's proposal is supported by grants; she is obligated by more than scientific virtue to conduct the best study possible. Her grant sources require her to conduct a thorough, scientifically valid study that, ideally, finds significant results.

It is apparent that Judy's obligations to these parties conflict. In sum, Judy is obligated to protect confidentiality, as she promised the students, as well as to protect them from harm. Appropriately, parents trust her to act in the best interests of the youth and may expect good, or at least no harm, to come from the interaction. Parents may also assume that information pertinent to youths' welfare will be fully disclosed; here, Judy's responsibilities to parents may conflict with her promise to her participants. In addition, Judy's relationship with funders obligates her to obtain meaningful, valid results. Providing a referral or intervention for a child or teen in jeopardy may damage the validity of Judy's study, compromising her obligation to her funders.

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# 2. The Role of Informed Consent

## *What is informed consent?*

The requirement of informed consent for participation in research was first iterated in the Nuremberg Code (1949), following the Nazi atrocities in World War II. Informed consent is a means of protecting participant autonomy and providing protection for those with diminished autonomy, an extension of the ethical principle of respect for persons (National Commission, 1979). The provision of consent to participate in research implies that an individual has made a voluntary and informed decision to participate. That is, the decision to participate must be made by a person with the rational as well legal capacity to decide; the person must be adequately informed; and the decision must not be coerced.

The following information must be disclosed to the participant: an explanation of the purpose of the research, anticipated duration of involvement; the procedures involved; potential risks, discomforts, benefits, alternatives; assurances of confidentiality; and identification of whom to contact with questions (ß46.116; Department of Health and Human Services [DHHS], 1991). In addition, participants must understand that participation is voluntary and that refusal will not penalize them in any way and will not result in a loss of benefits (ß46.116). In research on minors, parents' or guardians' permission is required, as well as the child's assent. In other words, both parent and child must be informed of the voluntariness, risks and benefits of participation in a way that is appropriate to the individual's developmental and educational level (ß46.408). Although parents must provide permission, minors have absolute veto power (Tymchuk, 1992).

## *When is informed consent required, and how may it be sought?*

Federal guidelines (ß46.101; DHHS, 1991) stipulate that all research involving human subjects requires informed consent from participants. The exception is research examining normal educational practices such as a comparison of the effectiveness of instructional methods or curriculum techniques. As Judy's research does not fall under the umbrella of educational research, she is not exempt from consent requirements.

Parental consent for minors' participation in research may be sought either actively,

whereby parents and guardians are informed of the proposed research procedures and must respond in order for their child to participate, or passively, whereby parents are sent letters describing the research and are to respond only if they do not want their child to participate. It has been argued that passive consent does not respect parental autonomy in that the researcher can never be certain that the parent received the information or that failure to respond reflects an informed agreement to allow the child to participate (Fisher, 1993). Parental permission may be differentiated from child assent, which refers to the child's agreement to participate and protects his or her developing autonomy (Tymchuk, 1992); both permission and assent are necessary in research with minors.

### *How may the rights of parents and minors conflict?*

As the principle of respect for persons requires autonomous decisions about whether to engage in treatment (National Commission, 1979), the requirement of parental permission until age 18 presumes that youth need parental protection because they are not autonomous, or able to make rational decisions on their own. Youths' lack of autonomy may be challenged on two grounds: 1) parents do not always act in the best interests of their children, as is evident in cases of child abuse; and 2) many adolescents are cognitively able to make reasoned decisions (Brooks-Gunn and Rotheram-Borus, 1994). The developmental literature provides a wealth of information about the cognitive capacities of adolescents to consent. Minors below the age of 11 generally do not have the intellectual ability and volition to give informed, voluntary and rational consent; by mid-adolescence, however, teens are able to consider treatment alternatives, risks and benefits, and provide rational and voluntary consent comparable to that of adults (Grisso and Vierling, 1978; Weithorn, 1983; Weithorn and Campbell, 1982).

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# 4. Developmental Factors

### *How important are developmental factors in decision making? Does Judy's responsibility vary with the age of the participants?*

The developmental status of the participants must be carefully considered at least twice in the research plan: first, when planning research and weighing minor

vulnerabilities with proposed research protocols; and second, when making decisions about reporting and referring minors who may be in need of assistance. When planning research with children and youth, an investigator's assumptions about development and vulnerability are crucial to the decision-making process. Children do not become less vulnerable in a linear fashion over the course of development; Thompson (1992) has argued that vulnerability differs by domain, and not merely developmental status. In other words, the risks and benefits associated with different domains of research risk must be evaluated according to the age of the child, as children of different ages may not be equally vulnerable to certain risks.

As the process of weighing protocol risks with developmental factors can be quite complex, Thompson (1992) has offered a few developmental guidelines. With increasing age, the self-concept becomes more coherent and integrated. Therefore, threats to self-concept become more stressful; however, the range of coping skills increases as well, permitting greater adaptive functioning in the face of adversity. These developments suggest that although participation in some types of psychological research may be more stressful for teens than children, they may also have developed coping resources to adapt. As children grow older, they are increasingly able to infer the attitudes and motives of others and develop a greater understanding of individual rights, which serves to balance their views of authority, thus making them less susceptible to coercion. With increasing age, youth are able to take a greater responsibility for their own participation in research, suggesting that perhaps they should be afforded a greater role in consent procedures and decisions regarding reporting and referring.

Second, developmental knowledge must be used to assist investigators in making decisions outside the original protocol, as when a researcher discovers that a participant is in jeopardy. Consider Judy's case: Her data are based on surveys and interviews, therefore she is not manipulating variables with the potential to harm children. However, she may learn that a child is in jeopardy. Should her reaction vary depending upon the age of the child? Some experimentation and risk is developmentally appropriate for teenagers, but what about fourth and sixth graders? It is imperative that Judy be aware of the developmental literature and use this literature to make decisions. For example, we know that by age 16, 50-60 percent of youth have engaged in sexual intercourse; the exact percentage varies by sex and ethnicity (Hofferth and Hayes, 1987). If a participant substantially

younger (e.g., aged 11-13) reports sexual activity, that may signal special needs and difficulties, which Judy must attend to. If Judy believes that the child may need treatment or intervention, how should she decide what to do?

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# 5. Options for Action

At least four options are available to Judy and other researchers confronted with similar decisions about how to handle minor participants in danger: maintaining confidentiality, reporting, directly intervening and referring the participant to outside sources of assistance (Fisher, Higgins, Rau, Kuther and Belanger, in press).

### *Maintain confidentiality -- take no action.*

When scientists discover that participants are in potential jeopardy, a no-action stance is common. This response reflects a concern for confidentiality as well as a commitment to scientific validity, which may be threatened by humanitarian actions (Fisher et al., in press; Fisher 1993). Taking no action is supported by ethical guidelines that stress maintaining confidentiality of information derived from research in order to protect participants' right to privacy (APA, 1992; DHHS, 1991; National Commission, 1979). Sharing information about minor participants with parents may, at times, have adverse consequences, especially if the parents react to the disclosure with punitive measures. In addition, acting to assist the participant may threaten the internal validity of a study and jeopardize the trust and participation of other participants.

This tension between the investigator's commitment to scientifically valid designs and the humanitarian obligation to protect participant welfare has been referred to as the "scientist-citizen dilemma" (Veatch, 1987). It has been argued that the interests of researchers and participants diverge, as researchers seek to produce scientifically generalizable knowledge rather than participants' well-being (Scott-Jones, 1994). Many investigators do not acknowledge a humanitarian obligation to their participants outside the provision of informed consent.

### *Reporting*

Unlike the guidelines articulated by the federal government (DHHS, 1991) or

American Psychological Association (1992), the Society for Research in Child Development (SRCD)'s Ethical Standards for Research with Children support taking action when a researcher encounters information suggesting that a minor is in danger:

> 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 (SRCD, 1993, p. 339).

In applied research contexts such as Judy's case, where information suggests delinquent behavior, substance abuse or sexual promiscuity on the part of minors, SRCD's professional guidelines (1993) could be interpreted as encouraging Judy to report the problem to adults who could assist the youths. (Fisher et al., in press) In some cases, the investigator's obligation to protect the immediate welfare of participants may outweigh his or her obligation to produce scientifically valid results, thus supporting the reporting of information obtained in research. In addition, federal, state and local laws must be considered in weighing the decision to report information obtained in research, especially in the case of child abuse, where researchers may be mandated reporters. (See Liss, 1994.)

The decision to report information obtained in research must be carefully considered, especially if error is possible. Reporting may have a negative impact upon the youth and his or her family. For example, child abuse carries a negative social stigma and legal consequences (Scott-Jones, 1994). Investigators must recognize that reporting and referring practices may be affected by their own assumptions about participants, especially if participants are members of vulnerable populations, such as low-income minority youth. In fact, increased surveillance rather than a higher rate of occurrence may promote greater reporting in groups considered to be of low status (e.g., low income, minority and single parent families; Scott-Jones, 1994). Without carefully considering the evidence and potential consequences of reporting information, researchers are in danger of over-reporting suspected problems.

Investigator competence is at the forefront of issues to consider in decisions about whether to report research-derived information. In many cases, investigators are

trained in research methodology and may not be clinically trained or equipped to assess the extent of participant problems such as child abuse, substance abuse and depression, or to determine whether treatment is necessary. Although the scientists may recognize that their opinions must be taken with the proverbial grain of salt, as they are not clinicians, their reports are likely to be taken quite seriously (Scott-Jones, 1994). Therefore, they should exercise restraint in reporting suspected problems, and in fact, SRCD's ethical principles recognize this danger: "Because the investigator's words many carry unintended weight with parents and children, caution should be exercised on reporting results, making evaluative statements, or giving advice" (SCRD, 1993, p. 339).

In addition, reporting can violate confidentiality, which has long been regarded as the cornerstone of ethical research. If there is potential for reporting , consent and assent procedures must be modified to include this possibility; the obligation to report changes the nature of informed consent and voluntary participation (Scott-Jones, 1994). For example, if the investigator plans to report abuse, then informed consent and assent require a statement to that effect, so that parents and participants are forewarned. This requirement applies to high risk behavior with minor participants as well.

## *Intervention*

Intervention is an option that may be considered by researchers in Judy's position. In this case, Judy would teach the students coping skills relevant to their particular vulnerabilities. For example, students having difficulties with violence would learn skills such as anger management and conflict mediation. There are two problems with this option: 1) This intervention is not appropriate for every problem encountered (e.g., what skills would be taught in cases of sexual promiscuity?); and 2) intervention would create a dual relationship between Judy and the participants. The ethical guidelines of the American Psychological Association (1992) suggest that professionals refrain from entering into multiple relationships, which may impede objectivity and interfere with a professional's duty. If she intervened, Judy would be entering into a therapeutic relationship with her participants, perhaps creating conflicting roles.

## *Referral*

Referrals may be appropriate in cases where an investigator obtains information

suggesting that an adolescent research participant would benefit from medical, social or psychological services, but not from the reporting of the risk status to parents or guardians (Fisher et al., in press). The provision of referral information is an attempt to balance the teen's right to confidentiality with his or her need for treatment. In school-based research, students may be referred to sources within the school, such as the school psychologist or counselor, without violating promises to parents, as these sources of assistance are available to all who attend the school. Provision of a blanket referral could be standard procedure in school-based research; for example, all participants could be provided with a list of local sources of help for common problems such as anxiety, substance abuse and risk of pregnancy. Referral information could be provided for services that adolescents can obtain in normal circumstances without parental consent (i.e., contraception and family planning at a local clinic). However, the provision of referral information is sometimes not enough to protect the participant; the researcher's obligations may be extended depending upon the law, the situation at hand and what the he or she deems appropriate.

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# 6. What should Judy do?

Should Judy suspect that an adolescent research participant is having difficulties, she should first consider whether the difficulties are within the range of normative developmental phenomena for the participant's age. In addition, she should interview the youth to see whether concern is warranted. This step is especially important when the information is derived from survey techniques such as depression, anxiety or risk questionnaire inventories. Such indices usually offer a cut-off score to indicate risk. High scores are indicative of risk, but they are not proof, as identification is not perfect (Brooks-Gunn and Rotheram-Borus, 1994). Because the teen has provided assent and the parent consent, Judy should contact the teen directly to determine whether her suspicions have merit.

If Judy's suspicions are confirmed, the teen must be referred for clinical services. Depending upon the problem, that may or may not require disclosure to parents and their consent. Disclosure to parents violates confidentiality, but failure to provide clinical intervention may not be in the child's best interests (Brooks-Gunn and Rotheram-Borus, 1994). For example, a referral without parental disclosure

would be appropriate when services are available to teens without parental permission. For example, referral would be appropriate when a teen has a sexually transmitted disease and can obtain services from a local clinic, unless the teen is engaging in abnormally early sexual activity. However, if a teen has a serious or life-threatening problem such as HIV, the parents must be notified regardless of the participant's wishes. Here, the researcher must assist the youth in obtaining treatment because early treatment increases the length of life and must disclose the information to parents in order to facilitate the pursuit of treatment, which is expensive and often requires hospitalization (Brooks-Gunn and Rotheram-Borus, 1994).

Ideally, the researcher should anticipate the need for treatment or intervention and should make provisions for reporting and referring in the initial protocol. In the consent/assent forms, Judy could have included a statement explaining the possibility of discussing any medical or psychological condition with a parent. If such a statement was not included in the consent/assent form, as in Judy's case, then the researcher must discuss the problem and potential solutions with the teen, as well as the advisability of discussing the problem with parents. The investigator is responsible for working with the participant on a plan for seeking treatment. Depending upon the problem, if the teen refuses to tell his or her parents, the researcher must disclose out of her clinical responsibility to ensure participant welfare, unless there is reason to believe that the parent would not act in the teen's best interest.

Other strategies for protecting participants' privacy could be implemented at the assent or data collection stages. For example, the consent form could include a statement that if problems are identified the researcher would contact the teen and discuss it further (Brooks-Gunn and Rotheram-Borus, 1994). At this time, blanket referrals could be made, providing the participant with information about a variety of available services, as indicated earlier. Another possibility is to ask participants directly, during data collection, if they want to talk with someone about a particular problem or current issue (Brooks-Gunn and Rotheram-Borus, 1994). Participants can be informed that parents will not be told of this desire, and then can be referred to resources within the school such as the school counselor or psychologist, who is better equipped to make decisions about the students' welfare. Finally, should a researcher make a decision that is not in the initial protocol, he or she must seek approval from the institutional review board before taking action.

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# References


- American Psychological Association. "Ethical Principles of Psychologists and Code of Conduct." *American Psychologist* 47 (1992): 1597-1611.
- Brooks-Gunn, J., and Rotheram-Borus, M. J. "Rights to Privacy in Research: Adolescents versus Parents." *Ethics and Behavior* 4 (2; 1994): 109-121.
- Department of Health and Human Services (1991). "Protection of Human Subjects." Code of Federal Regulations, Title 45, Part 46, revised 1991.
- Fisher, C. B. "Integrating Science and Ethics in Research with High-risk Children and Youth." Society for Research in Child Development: Social Policy Report 7 (4, Winter 1993): 1-26.
- Fisher, C. B.; Higgins, A.; Rau, J. M. B.; Kuther, T. L.; and Belanger, S. "Reporting and Referring Research Participants at Risk: Views from Urban Adolescents." *Child Development* (in press).
- Gisso, T. and Vierling, L. "Minors' Consent to Treatment: A Developmental Perspective." *Professional Psychology* 9 (1978): 412-427.
- Hufferth, S. L., and Hayes, C. D. *Risking the Future: Adolescent Sexuality, Pregnancy and Child-bearing*. Washington, D. C.: National Academy Press, 1987.
- Liss, M. B. (1994). "Child Abuse: Is There a Mandate for Researchers to

Report?" Ethics and Behavior 4 (2, 1994): 133-146.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects Research." Washington, D. C.: Government Printing Office., 1979.
- Nuremberg Code. *Journal of the American Medical Association* 132 (1949): 1090.
- Scott-Jones, D. "Ethical Issues in Reporting and Referring in Research with Low-income Minority Children." *Ethics and Behavior* 4 (2, 1994): 97-108.
- Society for Research in Child Development. "Ethical Standards for Research with Children." In *Directory of Members*. Ann Arbor: Society for Research in Child Development, 1993, pp. 337-339.
- Thompson, R. A. "Developmental Changes in Research Risk and Benefit: A Changing Calculus of Concerns." In B. Stanley and J. E. Sieber , eds. *Social Research on Children and Adolescents: Ethical Issues*. Newbury Park, Calif.: Sage, 1992, pp. 31-64.
- Tymchuk, A. J. "Assent Processes." In B. Stanley and J. E. Sieber, eds. *Social Research on Children and Adolescents: Ethical Issues*. Newbury Park, Calif.: Sage, 1992, pp. 109-127.
- Veatch, R. M. *The Patient as Partner*. Bloomington: Indiana University Press, 1987.
- Weithorn, L. "Children's Capacities to Decide to Participate in Research." *IRB: A Review of Human Subjects Research* 5 (2, 1983): 1-5.
- Weithorn, L. A., and Campbell, S. B. "The Competency of Children and Adolescents to Make Informed Treatment Decisions." *Child Development* 53 (1982): 1589-159.

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