Brian Schrag'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

Scope and nature of the study

Judy proposes to study fourth, sixth and eighth graders who have been "exposed to violence in their community." The scope and nature of the study are important in thinking about the ethical considerations and implications of the study. The children range widely in age and maturity, and they will presumably mature considerably by the end of the four-year study. The subjects' capacity for informed consent and their concern for confidentiality and privacy may vary initially and may change over the course of the study.

What does the category of "community violence" include? Does it include domestic violence within their own nuclear families? Does it exclude domestic violence within the nuclear family, but include violence in the extended family and all other exposures to violence in their community? Does it exclude all family violence (nuclear and extended) but include all other violence in their immediate community? Does the study propose to investigate violence suffered directly by students at the hands of family, neighbors and strangers; does it propose to study the impact of merely observing or being aware of such violence; or will it attempt all of the above?

Through individual interviews and group-administered surveys, the study proposes to measure the subjects' amount and frequency of exposure to community violence as well as their psychological, behavioral and adaptational responses to violence. If the study includes experiences of violence in the nuclear or extended family, subjects may be probed about experiences of child abuse and other violence by family members, among other things. If it focuses only on violence witnessed by the students, including the family setting, the investigator may solicit information from subjects that may include information about domestic abuse in their families. In either case, this probing certainly constitutes invasion of privacy and has implications for obtaining informed consent from the parents or appropriate family members. Will parents clearly understand that their children's participation in the study may result in invasion of the family's privacy?

If the study focuses only on the student's direct involvement in violence outside the family, the investigator may solicit incidents of violence the subject has committed or which were committed against the subject. At the extreme, that may involve admitting to participation in gang activity, or criminal activity or being the victim of sexual assault. If the study focuses only on the student's awareness of violence in the community, students may admit witnessing violent criminal behavior. These questions make the students extremely vulnerable and have serious implications for the process of obtaining informed consent from both parents and students as well as for level of confidentiality maintained in the study.

Will students understand that they may reveal such information as subjects? Will they be clear about the degree of confidentiality maintained? Will parents expect to be informed of the subjects' behavior?

The study solicits students' psychological responses (depression, suicidal thoughts), behavioral responses (drinking) and their adaptational responses (delinquency and sexual promiscuity). These questions raise all sorts of issues of privacy, confidentiality, informed consent and researcher's responsibilities for the welfare of subjects. Judy may become aware of many instances of dangerous and even illegal behavior that she is legally required to report. Will students understand that they may reveal such information during the study? Will they expect it to be kept confidential? Will parents expect this information? Will the parents expect Judy's first concern to be the welfare of her subjects? Will parents assume Judy has the expertise needed to act for their child's welfare if she discovers the child is engaged in risky behavior? Does Judy have an obligation to intervene on behalf of the subjects even if that means weakening or ruining the study? Is Judy's paramount obligation not to the subjects' welfare but to carry out the research, in the best manner possible?

Judy can anticipate many of these issues before the protocol is designed. It may be possible to practice "preventive ethics" and design the protocol to avoid some of the ethical issues that may otherwise develop as the study progresses.

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Informed consent and assent

This research will be highly invasive of the privacy of the children and may be equally invasive of the privacy of other family members. The study may also place the subjects at considerable risk if their confidences about sensitive matters are violated. These facts alone are one argument for requiring the child's assent as well as the family's permission. The research is not likely to provide any direct benefit to either the children or their families, although it is possible that it will yield generalized knowledge of benefit to all children. In such circumstances, federal guidelines require that the researchers solicit the "assent" of minor children to participate in research if the children are capable of assent. (Title 45, Code of Federal Regulations 46.408 (a) 1991) Parental or guardian permission is also required. (45 CFR 46.408 (b) 1991) In this case, the quality of the subjects' assent and of the parents' permission is an extremely important moral issue.

The notion of assent of minors and how it relates to informed consent is unclear. (Macklin, 1992, 90) Fourth graders are not adults. They may not be capable of fully appreciating the limitations of the trust they should place in the researcher. They may not understand the risks when confidences are breached. They may underestimate how their attitude toward invasion of privacy may change as they mature. They may not be capable of balancing all these considerations as well as an adult, who will have greater experience and maturity. (See Macklin, 1992, 101, on understanding privacy.) Nevertheless, even fourth graders, and clearly sixth and eighth graders, are capable of understanding a great deal if information is presented appropriately. (Thompson, 1992, 61) It is morally significant that their assent be sought only after they receive that information.

The variability of ages, developing maturity levels and the length of the study all complicate the assent issue. Some subjects will enter the study as fourth graders; others will end the study as juniors or seniors in high school. Children become much more sensitive to privacy as they move into adolescence. (Thompson, 1992) Subjects may assent to invasions of privacy as fourth graders that they would not assent to as eighth graders. The law recognizes the capacity of young adolescents to make adult-like decisions. In some states, minors can legally self-refer themselves for medical treatment for venereal diseases, alcoholism, contraceptives and abortions without the knowledge or consent of their parents. (Brooks-Gunn, 1994, 116; Rogers et. al., 1994, 3)

Children in this study have a right to understand what they are assenting to. Judy should provide the subjects with at least the following age-appropriate information: 1) An explanation of the nature and purpose of the research and the nature and role of the researcher. The children should understand that the research activity is not intended to benefit them and that the researcher's primary concern is not to benefit them as subjects. This point is particularly important for younger children. They may tend to think that an authority figure who is called doctor (Ph.D.) and meets with them in the school setting has a role akin to their family physician or a teacher and is acting in their best interests. 2) A clear understanding of the sorts of information that they will be asked to share. 3) A clear understanding that they have a right to refuse to answer any of the questions raised in the study. 4) A clear understanding of the level of confidentiality of the information they share and the limits of that confidentiality. They should clearly understand the circumstances, if any, in which Judy will break their confidences and with whom she might share that information, including parents, health officials or legal authorities. 5) A clear indication that they can drop out of the study at any point. 6) Since the maturation levels of the subjects may change significantly over four years, Judy should consider the provision that the subjects' assent will be renegotiated at the beginning of each year of the study.

Parents have a right to know what they are giving permission for. A careful procedure for informing the parents is required. 1) Judy should take pains to ensure that parents understands that the research activity is not intended for the therapeutic benefit of their children. 2) Judy should tell parents specifically the sorts of information she will collect from the children and with whom it might be shared.

Parents should be clear about the kinds of information Judy is legally required to report to authorities, such as suspected child abuse. 3) Parents should understand what, if any, confidential information gained from their child Judy will or will not share with the parents about the child. In particular, parents should be clear how Judy will deal with information about serious psychological symptoms or risky behavior manifested by their child or whether she will disclose information about the child's self-referrals. If such information is not shared with the parents, can the parents expect that Judy will seek interventions on behalf of the child, where appropriate?

All of this implies that Judy must plan for a sophisticated process of informing potential subjects and their parents before obtaining assent and permission. Merely sending out permission slips to be signed and returned will not be sufficient. Judy needs to plan a more elaborate method of informing potential subjects and their parents in the consent process. She may also need to contact a much wider pool of potential subjects than otherwise anticipated. It is likely that when parents understand what she will be doing and students are clear about their rights to withdraw from the research, more parents will refuse to give their permission, and more subjects will withdraw or may be dropped during the course of the research.

We have argued that Judy has a moral obligation to make clear to both prospective subjects and their parents exactly what they can expect from Judy should she become aware that their child is in a high-risk situations. What exactly should she be prepared to do in such situations?

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Judy's moral obligation for subjects' welfare

1. The case for doing nothing

Judy may argue on three grounds that she has no moral obligation to do anything to safeguard the welfare of her subjects during the research. Judy's research simply involves watching what would have happened to these children anyway, whether or not she was conducting the research; her study is a kind of natural laboratory.

Whether or not Judy conducts the research, the same children would have engaged in the same risky behavior in exactly the same way, without their parents' knowledge. She has an obligation not to harm subjects but *she* is not causing any harm to the subjects.

If she intervenes, she may not be able to maintain the integrity of her research and research program. The long-term benefits of the study would outweigh anything that might happen to subjects because she did not intervene.

Suppose that Judy obtains permission from parents for their child to participate in the study with the clear understanding that should Judy discover that their child is engaging in high risk behavior, she will *not* act on that information in any way, unless required by law. The child also assents. Judy will *not* inform parents, she will *not* take steps to assist the child, even if she knows that she is the *sole* adult who is aware that the child is in a threatening situation or is engaging in self-destructive activity that presents a clear and present danger to the child (anorexic behavior, heavy drinking, drugs, sexual promiscuity or gang activity). Judy will simply carry on her research.

Judy may take the position that she is not morally obligated to do anything, given the fact that *she* is doing no harm to the children, that she is armed with parental permission and child assent to a noninterventionist policy on her part, and that, given such a policy, she will maximize benefits by conducting the best study possible. She has no obligation to intervene on behalf of children at risk; all things considered, she has an obligation to refrain from intervening in order to maximize benefits. She is satisfying the principle of beneficence as articulated in the Belmont Report, which provides ethical guideline for research on human subjects. (National Commission, 1979)

The first part of this argument parallels the argument given by researchers in the Tuskegee syphilis experiment (Jones, 1993). Unlike Judy's project, those adult subjects had not given their informed and voluntary consent to be experimental subjects. Nevertheless, Judy's position is subject to some of the same criticisms.

2. The case for doing something

To see why Judy is mistaken, consider for a moment how we would define the moral obligations of ordinary persons (who are not researchers) in a somewhat parallel situation. Imagine that Judy is not a researcher but an ordinary citizen who walks through a park and notices a fourth grader she knows, sitting alone, playing Russian roulette with a gun. She realizes that she is the only adult in the area aware of the child's activity, and yet she takes no action but walks on by. Normally, we would say Citizen Judy has an obligation to intervene to stop the child from harming himself, if she can do so at minimal risk to herself.

On what moral grounds would we make such a claim? The principle of beneficence is one moral principle that we recognize as applicable to all persons. That principle states that we all have an obligation to promote the good and to prevent or avoid doing harm.

Notice that an obligation to *maximize* benefit presupposes this obligation. Unless we already have an obligation to *promote the good and avoid harm*, we could not have an obligation to *maximize the good*. The obligation to promote good and avoid harm can actually be regarded as a set of prima facie obligations to: 1) avoid doing harm, 2) prevent harm, 3) remove harm and 4) promote good. Furthermore, these obligations are listed in their order of stringency. The stringency has in part to do with the fact that it takes less effort avoid doing harm than it does to prevent a harm, to remove a harm or to do good. I should not push children off the end of a pier; I have a less stringent obligation to buy them an ice cream cone. If we can prevent or remove a harm at little risk or cost to ourselves, we have an obligation to do so. If I am standing on the pier and notice that a child has fallen into the water, and if I can save it by throwing a lifeline, I have a moral obligation to do so. The implication of this articulation of the principle for Citizen Judy is that she not only has an obligation to avoid harming the child, she also has an obligation to try to prevent the harm about to happen, if she can do so at minimal risk. (Frankena, 1973, 45-47)

In her research, Judy may become aware that one of her subjects is engaging in risky behavior such as contemplating suicide, practicing unprotected sex, engaging in heavy drinking, abusing drugs or beginning to run with a gang. Suppose that Judy can, at minimal risk to herself, do something to prevent the child from coming to harm but decides to do nothing about it. Unless Judy can show how her status as a researcher excuses her from this obligation, she is mistaken in thinking she can simply do nothing. One might argue that the difference is that Judy is a scientist and, as such, she has professional moral obligations that override the obligation of ordinary morality to prevent harm to another. Judy might give three different claims to support that position.

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Three claims for excusing an obligation for subjects' welfare

1. The obligation to welfare is overridden by the obligation to do research.

Judy might argue that scientists have a professional obligation -- and indeed an overriding obligation -- to conduct their research in the most rigorous and scientifically sound manner possible. The best contribution a scientist can make to the general welfare is a contribution to the general knowledge, which will allow effective social policy. In a conflict of general and professional moral obligations, professional obligations are trump. In a research project designed to study the impact of violence in children, one is likely to encounter a higher incidence of children with risky behavior. To intervene to help a subject would threaten the integrity of the research project and thus society might lose the tremendous benefit of such research for children everywhere. Hence Judy ought not intervene.

However, a mere conflict of professional obligations with the obligations of ordinary morality does not excuse scientists from the obligations of ordinary morality. Simply being engaged in scientific activity does not excuse scientists, for example, from prima facie obligations not to steal, to tell the truth or to come to the aid of a person in distress even if doing so interferes with their scientific activity or jeopardizes the results of a particular research project. Professional moral obligations presuppose general moral obligations; they are not independent of them. (Bayles, 1989, Chapter 2)

2. The obligation to welfare is waived by parental permission.

Judy cannot be excused from obligations of ordinary morality in this case by the permission of parents and child. Recall the case of the child playing Russian roulette. Suppose, for some bizarre reason, the parent had given Judy permission to ignore their child in the event she ever saw the child playing Russian roulette. We would not say Judy was absolved from a moral responsibility to act simply because the parent gave her permission. (We would be more inclined to say that the parent was acting irresponsibly.) Would it make any difference if, as a researcher, Judy had obtained similar permission from the parent?

The Belmont Report articulates two principles guiding human research that are relevant here. First is the principle of treating subjects with the respect due humans: One must never treat humans solely as a means to one's own ends. Suppose that Judy, in virtue of her research, is the *sole* adult who is aware that a child is entertaining the possibility of suicide. She knows that if she does not act, no one will. If Judy takes no action because that would interfere with the research program, then she is treating the child solely as a means to her own ends and is violating the principle of respect for persons.

The second ethical principle is that of beneficence. As the Belmont Report puts it, the principle of beneficence is a twofold obligation:

> Two general rules have been formulated as complimentary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms.

I have already indicated that I do not think this articulation of the principle of beneficence is adequate because the claim that we have an obligation to *maximize* possible benefits already presupposes that we have a prior and more stringent obligation to do good and avoid evil. Judy has a stronger prima facie obligation to prevent harm to her subject than she has to maximize benefits.

3. The welfare obligation is overridden by the obligation of confidentiality.

Suppose Judy promises the subjects that she will never violate their confidence and never reveal to anyone, including parents, anything the subjects tell her. Normally we would say we have an obligation to maintain such a confidence because we have promised to do so. It is not clear on what grounds one would argue that keeping promises and confidentiality always trumps all other moral considerations, however. There may be situations in which other moral considerations outweigh an obligation to keep a promise -- for example, situations that threaten the life of the person promised. There are no compelling moral grounds for asserting that keeping confidences is always the highest moral obligation. It is also the case that Judy has legal obligations to report certain kinds of criminal behavior such as suspected child abuse. She should not make promises she knows she cannot keep.

I have argued that one must conclude that Judy cannot morally justify the position that she should never intervene by appealing to the mere fact that she is a researcher. If Judy's research proposal can reasonably be expected to give her knowledge that a child subject's health or welfare is seriously threatened and the situation requires immediate intervention, she must recognize that she has a prima facie obligation to take some action in some of these circumstances. She cannot morally defend a position of never doing anything. It is not clear that either the federal guidelines or the Belmont Report would reach this conclusion, but other standards do. The Society for Research in Child Development asserts:

> When, in the course of research , information comes to the investigator's attention that may jeopardize the child's well-being, the investigator has the responsibility to discuss the information with the parents, guardians or with those expert in the field in order that they may arrange the necessary assistance for the child. (SRCD, 1993, 339)

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Specifying an obligation to act.

It behooves Judy to take this moral responsibility into account as she designs, seeks funding for and carries out her research. She should make clear to the funding agent, and to parents and subjects, what interventions she is prepared to undertake on behalf of the children, even if those steps impair the quality of the research. However, the fact that Judy has an obligation to take *some* action to prevent harm to subjects, does not establish what action she ought to take.

There are certain parameters on what Judy should and should not do. 1) Judy has a legal obligation to report to appropriate authorities certain things such as suspected child abuse. (Some have argued that the specific issue of reporting suspected child abuse is a morally problematic requirement since less than half of all reported cases are substantiated and reporting suspected abuse when it has not happened may well do serious harm to both child and parents. [Scott-Jones, 1994, 101-103]) 2) If

Judy has some obligation to protect the welfare of the child, she should not report to parents things that may result in the parents harming the child. Notifying parents may only make things worse (for example, if there is a clear case of child abuse by a parent). 3) It is reasonable to argue that Judy should not report to parents the fact that their child has referred herself to agencies to seek medical help in those instances in which the law allows the child to do so without the knowledge or consent of parents. (Scarr, 1994, 153). Judy has an obligation to make clear in the process of obtaining informed consent from parents and subjects that she will operate within these parameters.

If we assume that Judy, parents and subjects all understand she will act within these three parameters, a large gray area remains of risky behavior of subjects she may uncover in the course of her research. Should she ever notify the parents about such activity, encourage students to refer themselves for help, or initiate action on behalf of the subjects?

Privacy, confidentiality and parental responsibility

A central issue here involves conflicts between maintaining the confidentiality and privacy of child subjects, interfering with the responsibilities of parents, protecting the subjects' welfare and maintaining a viable research program.

As a moral agent, Judy has a prima facie obligation to maintain her subjects' privacy. All persons, including children, have a right to privacy, and can be wronged when it is violated. Research suggests that children value privacy, even at a young age. (Melton, 1992) As children mature, privacy is increasingly important as an indicator of independence and self esteem; it is necessarily paralleled by a reduction of parents' right of control over the child. (Macklin, 1992, 103; Melton, 1992) Notice that one can morally wrong a person by invading his or her privacy whether or not confidentiality is involved. Violating confidences is only one way of invading privacy.

If Judy has promised the children to keep certain information from the study strictly confidential, then breaking that confidence both invades their privacy and violates a promise. An obligation to preserve the subject child's confidentiality is especially strong if breaking that confidence to parents or others is likely to result in harm to the interests of the subject.

As a scientist, Judy may be concerned that breaking confidentiality may also unravel the study. Once one child's confidence has been broken, that child is unlikely to be candid and may have to be dropped from the study. As other children learn that their information is not kept confidential, they may wish to drop out of the study. If children know in advance that their confidences may be breached, they may not agree to do the study.

Judy might consider informing subjects and parents that, subject to the parameters already identified, she will keep everything else she learns about the subject absolutely confidential. But she might conceal from them her intention to break a confidence, if extreme circumstances warrant it. This plan may initially reassure subjects of confidentiality and thus increase the likelihood that they will agree to participate, and it includes a plan for protecting the subjects' welfare or informing parents, if necessary.

This strategy is not a good idea. If Judy knows from the beginning that this is what she intends to do, then she is engaging in a deceptive practice that undercuts the moral legitimacy of the subjects' assent. If she breaks confidences more than once, the word may get around that Judy does not maintain the confidences she said she would maintain, and the study may unravel anyway. It would be better to tell all parties from the beginning that if Judy believes that the subject is in clear and present danger, she may break confidences and tell the parents or take other action.

This discussion has focused on preserving the subjects' privacy and confidentiality, maintaining the integrity of the study and meeting the researcher's obligation to protect the subjects' welfare. Parents' authority and responsibility to care for their children must also be considered. What claim do parents have to information about their child's risky behavior?

Return to the case of Citizen Judy walking by the fourth grader who is playing Russian roulette. Suppose she intervenes and stops the child from playing Russian roulette and then notices that his family, whom she also knows, is not far away and is unaware of what has just transpired. Instead of notifying the family, Judy says nothing to them and whisks the child off to see a counselor without the family's knowledge. She recognizes that she has an obligation to do something for the child's welfare but maintains that her obligation does not include notifying of the parents since that might violate the child's privacy rights.

Normally we would say that Citizen Judy has an obligation to make the family aware of the event because of the presumption that it is the family's business and responsibility to care for their children; that includes keeping children from harming themselves. Parents may well claim that the family is best able to judge what is in the child's best interests in these situations. It is also the family that will have to deal with the situation and the consequences of the child's action.

We have already indicated Citizen Judy may be right to avoid notifying the parents if she has good reason to think the parents would make the situation even more dangerous for the child. That important set of circumstances aside, why should Judy assume that the child's best interest is served by substituting her judgment for that of the family? Why should she assume that maintaining the child's privacy rights is preferable to notifying the family and allowing their judgment to take over?

There is something wrong with Citizen Judy assuming the role of protector of the child because it is precisely the responsibility of *parents* to care for and nurture their own children and to keep them from harming themselves. Parents have a prima facie claim to be informed when their children are engaged in harmful activity even if that notification is at the cost of the child's privacy, confidentiality and self-determination. Parents' claims may diminish with the maturity of the child, but the burden of proof ought to be on those who would ignore that prima facie claim. Even John Stuart Mill, one of the most ardent defenders of individual rights and the private right to private damage, recognized the limitations on the notion of self-determination as applied to children:

> Over himself and over his own body and mind, the individual is sovereign. it is perhaps hardly necessary to say that this doctrine is meant to apply only to humans being in the maturity of their faculties. We are not speaking of children or young persons below the age which the law may fix as that of manhood or womanhood. Those who are in a state that requires being taken care of by others, must be protected from themselves as well as against external injury. (Mill, 1961, 263)

Judy might argue that if she notices any risky behavior of such a serious nature, either the parents are already aware of it or, if they are not, that is evidence that they are not competent to deal with the problem. Therefore it is not in the child's best interest to notify the parents, and the parents do not have a right to be informed, at least not until other appropriate steps are taken. Once Citizen Judy is aware of a subject's risky behavior, she might counsel the child, offer to refer the child to competent professionals, or inform or consult with appropriate care givers or authorities. All of these options would address the child's welfare but preserve the child's privacy and confidentiality from their parents. Only at some later date, if ever, would the parents be notified.

The rationale for this approach, some have argued, presupposes a problematic view of the family and the relation of children's interests to the family and to parental and authority and responsibilities (Brown, 1982; Steinfels, 1982; Macklin, 1982). In particular the child is simply one member of an aggregate of individuals (family) bent on self-development and self-fulfillment. The interests of parents and children may conflict. Consequently, parents have only limited capacity to speak for the child's interests in the best of circumstances, and it is reasonable to think that a skilled professional may do as well as the parent. Hence the moral authority of parents over their children and the right to have information about their children is limited. It would not be wrong for an outsider to intervene to serve as interpreter, spokesman and protector of the child's interests. Resolving this issue is beyond the scope of this commentary. Notice that Citizen Judy knows some very important information about the child that the parents do not have. That fact gives her the power to prevent parents from carrying out their obligation to protect their child from harming himself.

Does the situation change if Judy is not just an ordinary citizen but a researcher? If she has this knowledge about the child, it is not by happenstance. Rather, it is because she is carrying on research with the parents' permission. What would good and reasonable parents agree to in such research? Would they expect a researcher to notify them if their child were engaged in risky behavior? They may expect it, precisely because they take seriously their responsibility to protect their children from harming themselves. Would they agree to having their children participate in an experiment if they knew such information would not be shared with them?

If Judy has a moral obligation to act on behalf of the welfare of the child, and if parents waive a claim to be informed of risky behavior, that constitutes ceding decision-making power to Judy to initiate treatment for the child. Would good and reasonable parents agree to that?

Parents might reason that any information about their child's risky behavior acquired by the researcher is information the parents would not have received otherwise. Parents might be willing to have a researcher act for the benefit of the child on the grounds that getting help for their child in this way is better than no help at all.

This case raises very complex issues for designing a protocol that is ethical and still allows the possibility of good research. Judy faces issues in Part 4 that could be avoided by full disclosure to prospective subjects and their parents of the degree to which she will share information of risky behavior with parents. It is perhaps an open question if enough subjects and parents will agree to participate to make the study possible, once they have been so informed. What Judy cannot do is to cut any of these corners in order to conduct the research.

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