

The Handbook of
ETHICAL RESEARCH
With
ETHNOCULTURAL
POPULATIONS & COMMUNITIES

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CHAPTER 11

With All Due Respect

Ethical Issues in the Study of Vulnerable Adolescents

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The United States government did something that was wrong, deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens.

—President Bill Clinton, from the apology for the
Tuskegee Study, May 16, 1997

While mental disorders may touch all Americans either directly or indirectly, all do not have equal access to treatment and services. The failure to address these inequities is being played out in human and economic terms across the nation—on our streets, in homeless shelters, public health institutions, prisons and jails.

—U.S. Surgeon General Dr. David Satcher,
Mental Health: Culture, Race and Ethnicity

There is little question but that scientific research with human populations has been responsible for both a great deal of good and a great deal of harm. Basic and applied research has played a

major role in the development of medical, pharmacological, and psychotherapeutic treatments that have not only extended life but enhanced its quality. Human research has also helped us learn more about ourselves,

AUTHOR'S NOTE: A special thanks also to Yvette Lohr, lead interviewer on SHARP and ethical and moral compass for that study.

how we interact with each other and are affected by social conditions. Nonetheless, one of the most shameful incidents in American history, the Tuskegee Study (1932–1972), which allowed 399 poor African American sharecroppers to go untreated for syphilis, all too clearly illustrates what can occur when a biased interpretation of what constitutes the scientific “greater good” results in the callous disregard for marginalized and vulnerable populations.

Ethics codes developed by professional and/or governmental entities have been revisited many times since 1972, and institutional review boards (IRBs) have been instituted to ensure that society could reap the benefits of scientific discovery while ensuring that individual research participants would be protected from undue harm; however, even as ethics codes and IRB regulations are refined and tightened—some would say needlessly or overzealously so—a researcher’s own moral compass continues to play a major role in how ethical concerns about human research are addressed in the lab or in the field. As such, we can learn much from each other as to how we grapple with and resolve ethical issues, an aspect of our work that is seldom described in our formal research papers.

This chapter will examine four crucial areas of ethical concern that are encountered in conducting scientific research with vulnerable populations: (a) setting the context for a respectful research relationship with the communities of those studied, (b) developing sensitive and appropriate consent procedures, (c) implementing appropriate confidentiality and disclosure policies, and (d) weighing the risk and benefits of a research study or program. The latter three concerns are standard ones that must be considered in virtually any research study; the first is especially important when working with vulnerable populations from lower-status communities that have historically lacked social and economic capital and access to political power.

In discussing these concerns, we will primarily draw from two research studies conducted in the first author’s lab over the last decades: the Families and Adolescent Study of School Transitions (FASST) and the Seattle Homeless Research Project (SHARP). An additional theme running through this discussion is the concern for how to ensure that a program of research, where appropriate, adequately reflects the lives of those being researched.

FASST AND SHARP: TWO STUDIES OF VULNERABLE YOUTH

Adolescence is an especially critical developmental period, characterized by rapid biological, emotional, and social changes, including puberty, the culmination of identity development, and shifting roles in social interaction with same-sex peers, opposite-sex peers, and adults (Brooks-Gunn & Reiter, 1990; Feldman & Elliot, 1990). How an adolescent navigates these developmental demands has critical implications for the rest of his or her life. Mistakes and mishaps here, like early pregnancy or drug abuse, can set up troubles that may haunt youths for years to come.

Although navigating adolescence presents challenges for all youth, additional stressors related to ethnic minority status, poverty, and homelessness may intensify these already difficult demands. It is imperative that we learn more about how adolescents deal with these additional challenges if we are to develop programs that will adequately meet their needs. It is also important that we construct our research programs in a manner that takes into account their multiple vulnerabilities due both to age and their “one-down” status in society.

More complete descriptions of the research background and goals of the FASST and SHARP studies are provided elsewhere (see Mason, Cauce, Gonzales, Hiraga, & Grove,

1994; Mason, Cauce, Gonzales, & Hiraga, 1994; Cauce, Gonzales, Hiraga, Grove, & Ryan-Finn, 1996; Cauce et al., 1994; Cauce et al., 1998; Cauce et al., 2000, for fuller descriptions of each). For the purpose of this chapter, it is worth noting that both studies were designed, at least in part, in order to help us better understand factors related to risk or resilience among these youth. But although FASST was a more classic social science research project that involved observations and interviews without intervention, the second, SHARP, was an intervention study.

In FASST, our specific interest was in family practices that enhanced or interfered with adolescent development in the years of transition from middle school to high school. One question we were especially interested in was what level of parental control related to optimal adolescent adjustment. Although much research with White youth suggested that high levels of control, sometimes referred to as "authoritarian" parenting, was related to higher levels of externalizing behavior or conduct problems, those working with African American families and youth had suggested that relatively high levels of control might be more normative and play a more positive role for this population. It is also worth noting that this was one of the first studies to bring African American families into the lab for parent-child conflict interactions that was videotaped and coded.

Participants in FASST were 144 African American adolescents who were in either the eighth or ninth grade at the start of the study. They were, on average, 13.5 years old. Adolescents were primarily recruited through local area schools and through formal and informal community systems (e.g. churches, youth groups). For inclusion in the study, at least one parent or equivalent had to agree to participate as well. Families were primarily working class, but socioeconomically diverse. Most of the mothers were high

school graduates (91%), although a few had graduated from college (11%). When household income was examined, most families could not be categorized as poor (58% reported incomes above \$20,000 in 1992 dollars), but relatively few reported incomes that would put them in the higher end of middle class (less than 20% reported incomes greater than \$40,000). A subset of 57 mothers and daughters participated in the interaction phase of the study. Only daughters were included because resources were limited and we wanted to ensure that we retained appropriate power for subsequent analyses.

This study has been referred to by others as a study of at-risk youth, but in fact it was a normative sample. Family income of participants was on average lower than would be the case for a comparable study of White youth but nonetheless representative of local African American families. Although the sample was normative and not chosen to be "at-risk," participants are considered vulnerable by virtue of their status as minors. They are doubly vulnerable by virtue of being members of an ethnic minority group.

Participants in SHARP were 364 runaway, homeless, and street youth between the ages of 13 and 21. The majority (82%) were between the ages of 15 and 18, with a mean age of 16.4. Although the majority of the youth were White, a substantial number (40%) were of ethnic-minority background. Moreover, many have noted that homeless youth are a subculture in their own right. Although this view may stretch the definition of culture beyond the point at which we feel entirely comfortable, there are certainly ways in which this is the case. For example, street youth will sometimes refer to a "code of the streets" or a code of honor that they aspire to.

Whether one ascribes subcultural status to street youth or not, there is no question but that this is a multiply vulnerable population. Not only do they lack the protection of a

familial or familial-like adult to look after their best interests, but previous research has suggested that a substantial number of these youth would have mental health problems of diagnosable proportions, most often depression and conduct disorder. In addition, a substantial number of these youth were expected to have experienced the violation of trust by an adult in the form of physical or sexual abuse. These expectations were more than met, with more than half (67%) of our SHARP sample qualifying for a mental disorder according to DSM III standards (41% met the criteria for conduct disorder, 28% met criteria for dysthymia or major depression, 5% met criteria for prodromal or residual schizophrenia), over half the sample (52%) reported that they had been physically abused prior to leaving their homes, and 60% of the girls and 23% of the boys reported that they had been sexually abused (Cauce et al., 2000).

It is important to note that the primary purpose of SHARP was to examine the efficacy of an intensive case management treatment model for meeting the needs of homeless youth (see Cauce et al., 1994, for a full description). In order to do this, a partnership was developed between the first author's research team at the University of Washington; YouthCare, a local social service agency serving runaway and homeless youth; and the State of Washington Division of Human and Social Services. YouthCare played the primary role in developing the intensive case management program, called Project Passage, and the UW played the primary role in developing the research and evaluation plan. The State of Washington's involvement was meant to ensure that funding for services would continue after grant funding ended. The National Institute of Mental Health grant that funded the project was obtained under a Public-Academic Liaison (PAL) program. So, although each of the partners brought special skills to the

table, all major decisions were made in partnership.

In order to evaluate Project Passage, youth in this new "experimental" program were compared with those in treatment-as-usual, regular case management services through YouthCare. Both programs were housed at YouthCare's Orion drop-in center. Youths in the study were randomly assigned to one of the two case management treatment conditions. It is important to note that there was no equivalent of a placebo condition and that no youth was denied treatment as a result of study participation. Youth either received regular case management, the best treatment available prior to this study, or the new intensive case management, which was considered state of the art and more resource intensive, but that had yet to be evaluated with this population. Although we considered having a no treatment condition, we opted not to because of our ethical concerns about withholding treatment from a population with this level of need.

In sum, both of the case study projects that we will discuss involved vulnerable populations by virtue of their age and because they come from groups that have traditionally been marginalized by society, in one case because of their ethnocultural group, the other because of their housing status (or lack thereof). The vulnerability of these populations required us to take special care in constructing and conducting our studies. This care began in our work with each respective community.

SETTING THE RESEARCH CONTEXT: ESTABLISHING A RELATIONSHIP WITH THE COMMUNITY

Perhaps the major concern of ethics codes, and the IRBs who implement them, is the desire to protect individuals from any harm

that might befall them as a result of research participation. This focus on the individual has, if anything, been emphasized in recent years. Indeed, although benefits to society at large have historically been taken into account when weighing the risks and benefits of a project, there is an increasing focus on the benefits that come directly to the individual participant.

The individualistic nature of most ethics codes is clearly in keeping with the individualistic nature of Anglo-American society. But, an individualistically oriented code may not do as well in protecting the interests of cultures or subcultures with more collectivist orientations. More specifically, U.S. ethnic minorities, whether African American, Latino American, Asian American, Native American, or Pacific Islander American, tend to hold values that place a great deal of importance on the good of the group (Boykin, 1986; Chun & Akutsu, 2003; Cauce, Domenech-Rodriguez, 2002). Collectivistic orientation has also been described as characteristic of street youth culture and has often been viewed as helping to protect these youth from the many exploitative adults who can so often be found surrounding them (Dachner & Tarasuk, 2002; Ruddick, 1996).

Dealing with research-related risks that may be posed at the group level, rather than at just the individual level, is especially important for ethnic minority adolescents and homeless youth because both have so often been portrayed in a manner that is stigmatizing. For example, ethnic minority youth are quite commonly portrayed by the media as gang members, perpetrators of violence, sexually promiscuous, or sexually irresponsible. Street youth are portrayed in a similar fashion, with the added stigma of being viewed as drug abusers and/or prostitutes. All too often scientific research has been conducted in ways that reify such portrayals and may be viewed as harmful to the larger communities that research participants come

from. For example, although the individual minority subjects who participated in the research described in the bell curve (Hermstein & Murray, 1994) may not have been individually harmed, the results reported have been seen by some as harmful to African Americans as a group.¹

We do not believe that one should shy away from research that documents real problems that exist within minority, poor, or otherwise marginalized communities, but it certainly seems preferable to construct research programs in ways that provide a fuller portrayal of the populations studied. When research does focus on problems, dysfunctions, or weaknesses, it would also be preferable if such studies were to do so with at least some intention of playing a role in remedying or alleviating these problems.

Consultation with members of the communities from which populations will be recruited can help ensure that the larger research program not only fails to harm but also provides some benefits to these populations at the level of the group. This type of consultation has the added benefit of helping the researcher construct recruitment and retention procedures that are not only respectful but effective. The same is the case when it comes to developing effective research paradigms or instrumentation. For example, our work with African American mothers proved invaluable in the design of our coding system. And, without the endorsement of a homeless youth-serving agency, it is unlikely that we would have attained the high rate of participation (95%) that we achieved.

The active engagement of community members in the design and conduct of research is the hallmark of participatory community research (Jason, Keys, Suarez-Balcazar, Taylor, & Davis, 2002). A goal of this approach is to construct research programs, especially prevention and intervention studies, in a manner that empowers participants and their communities (Balcazar, Keys,

Kaplan, & Suarez-Balcazar, 1998). We cannot say that we fully embraced this methodology in our research, which was carried out well before key writings in this area appeared in press, but many of the basic tenants of this approach were present in our approach, at least in some prototype form.

Identifying the community in question can, of course, raise difficult issues. Although decision-making authority is sometimes clearly delegated to a specific group, as is often the case among specific Native American communities, there was no clear group for us to go to in setting the context for FASST. Moreover, in 1989 when FASST was first being conceptualized and implemented, the creation of community boards as consultants to research projects was rare, and we did not think to create such a board in any formal manner. Instead, we brought together a group of about a half dozen African American women, most of whom were mothers and most of whom were working in mental health or social service agencies to help us think through the project as a whole and to provide help with specific aspects of the project, especially the coding scheme for the mother-daughter interaction.

We were already sensitized to issues of stigmatization among African American youth and from the outset had decided not to focus exclusively on an at-risk population or exclusively on negative behavior. For example, outcome measures focused on self-esteem and school achievement in addition to problem behavior; but it was not until our conversations with our community advisory group that we were sensitized to the fact that African American parenting, especially mothering, was also often portrayed in terms that were overwhelmingly negative. This did not deter us from the original plan to examine how parenting, mostly mothering, was related to negative adolescent behaviors, like externalizing; but it did lead us to be more sensitive about describing the context in

which parenting took place, especially the burdensome task of parenting youths growing up in high-risk circumstances, including high-crime neighborhoods. We were so influenced by the stories these women told us that we used them to frame our findings on the relationship between parental control and externalizing in one of our most cited publications (Cauce et al., 1996). Advice from this informal advisory work not only helped us in interpreting our findings but really sensitized us to some issues that the mothers might be bringing to the study, and we believe we were better able to engage with our sample as a result of this.

In contrast to FASST, SHARP presents an example of the dilemma faced by researchers working with a multicultural sample of youth, perhaps the most common situation in psychological research today. Youth in our studies typically come from multiple ethnic backgrounds, and no one group of ethnocultural experts may make sense as a consultation group. To the degree that we initially engaged in conversations with members of ethnic minority communities about youth homelessness, many viewed it as a "White" problem, on occasion insisting that their (e.g., the African American, Latino, Asian American, or Native American) community had informal structures that served to keep their youth off the street; but although it was true that we had trouble identifying homeless Asian American youth, the proportions of other youth of color in our sample seemed to mirror their ethnic representation within Seattle.

It did not make sense to set up an advisory board along ethnocultural lines, but as noted previously, we not only sought consultation from, but worked in full partnership with, YouthCare, the largest agency in town solely dedicated to serving runaway, homeless, and street youth (see www.youthcare.org/ for a fuller description of the agency). Throughout the implementation

of the research study, all key decisions were made by the principal investigator (first author of this paper), together with an advisory board that included the director of YouthCare, key clinical personnel from the agency, and representatives from the Washington State Department of Social and Health Services. Both agencies were partners in the study, and almost all key personnel, including the data analyst and all research interviewers, were housed in YouthCare and hired as YouthCare employees.

The involvement of YouthCare in every aspect of SHARP was critical, as we had negligible experience with homeless youth prior to this study. Although we did spend time at the agency talking to case managers and youth prior to developing the proposal that led to funding the study, there is no way that we could have garnered in this short time the type of insights and experience that staff had who had worked with these youths for years and, in some cases, decades. The involvement of YouthCare, and its personnel, ensured that the best interests of this vulnerable sample of youth would be given all due consideration at every step of the research process. It also ensured that the youth would be treated with all due respect.

Each of these studies called for a slightly different strategy for ensuring appropriate community cooperation and consultation. In SHARP, we worked with a community agency in full partnership. In FASST, our work was with community members, and the relationship was much more informal and best characterized as consultative. In both instances, however, community involvement was critical in setting the stage for the conduct of ethically appropriate and responsible research with these vulnerable youth. The importance of setting the stage will become abundantly clear as we focus our discussion on informed consent, confidentiality and disclosure, and the balance of risks to benefits.

MAKING SURE THAT YES MEANS YES: OBTAINING CONSENT FROM VULNERABLE YOUTH

There are a host of issues involved in making sure that vulnerable youth fully and completely consent, or assent, to research participation. Among the issues that have been raised are questions about whether youth from nonmainstream populations are familiar enough with research to know what they are consenting or assenting to. How easy or difficult is it for youth from a one-down position to say no to those who are viewed as authority figures (Fisher et al., 2002)? To what degree do promises of monetary reward provide a coercive environment, especially when youth lack monetary resources (Sieber, 1994; Macklin, 1989)?

Although these issues are legitimate ones for both FASST and SHARP, it is in the latter study that they were most salient. The required participation of at least one parent in FASST ensured that parental consent to adolescent participation was given under conditions in which parents were keenly aware of what such participation required. That is, in this study, not only were parents required to allow their children to participate in the study, answering questions, completing surveys, or engaging in interactions with research staff, but parents were required to themselves engage in similar procedures. In fact, the videotaped parent-child interaction—arguably the most sensitive procedure of all, in that it can elicit strong negative emotions—is one where the parent (mother) is there, sitting across from her child, with full authority to stop the interaction at any time. In this sense, we made the assumption that parents could and would protect their own children's best interests. Furthermore, the procedures of the study were such that parents were fully aware of what the research experience was like for their child, as procedures for parents and child closely paralleled each other.

Nonetheless, in recognition of the fact that the adolescents in our study were old enough to make independent judgments about their participation, assent from adolescents was also required for study participation. Assent forms were not only written in language that would be easy for adolescent to comprehend but were administered in person, and adolescents were given ample opportunity to ask questions about procedures before assenting.

In addition, both parents and adolescents were given the opportunity to withdraw from the study at any time. They were very clearly informed that if they withdrew from the study, even after the first question or two, they would keep the compensation given for participation (\$20 for each participant). Thus, compensation may have played a role in adolescent or parent's decision to participate, but we hoped that the role of compensation receded as the study progressed. It is important to note, however, that although some participants refused to answer an isolated question here or there or left portions of questionnaires unanswered, we did not have anyone totally withdraw from the study. We would like to think that this is because the interview experience was largely positive. It is also possible that once parents and adolescents agreed to participate in the study, they felt a sense of responsibility to continue, even if aspects of the study made them uncomfortable. Nonetheless, when participants were given the opportunity to give us feedback about the study after it was over, not one parent or child reported that they felt coerced or uncomfortable at any point. To the contrary, every indication suggested that the general experience had been a positive.

Issues about coercion and consent were much more salient in SHARP because there were no parents to look after the best interests of our minor participants. Moreover, although the majority of our homeless participants were not ethnic minorities, their

histories of abuse, the large number of youth with diagnosable mental disorders, and their glaring lack of access to even basic resources, including food and shelter, made them the more vulnerable population.

The role that homeless youth service providers and advocates played in the design and implementation of SHARP was important to ensure that our research agenda did not inadvertently override concerns for the well-being of youth participants. This was especially important because the lead researcher was, at the outset, not personally familiar with the population under study. The inherent danger in all studies, that research-related priorities may blind researchers to the best interests of study participants, is magnified in cases when the investigator may have limited knowledge of the specific vulnerabilities of the population under study.

Obtaining consent from the parents of runaway, homeless, or street youth is not feasible, as they are not an active part of youth's lives; and, given the histories of these youth, one cannot make the assumption that in most cases such parents would be able to protect their child's best interests or ensure their well-being. Therefore, it was especially important that we construct consent procedures in such a way that consent was maximally comprehensible and transparent to youth (youth who were unlikely to understand what research was about).

In SHARP, the challenge was to make sure that youths not only understood they would be asked painful questions—and that these questions would ask them to recall and speak about painful experiences—but to make sure that they also understood they were consenting to the possibility of being assigned to a treatment condition that some might view as intrusive, even if we believed it to represent a higher standard of care.

We did our best to ensure that youths were fully cognizant of every aspect of the study. Not only did we construct a consent form

that was detailed and written at a fifth-grade level or below, but the basic aspects of the study were also explained orally to all participants by investigative team members. Moreover, details of the study were presented to all case managers and all key YouthCare staff so that they could accurately answer questions that a youth might ask in an informal context. The fact that all research interviewers were YouthCare, as opposed to University of Washington, employees also helped to create a context in which the well-being of youths was paramount and in which there was minimal possibility that interviewers might feel the need to coerce youths to participate. That is, even research interviewers were part of an organization dedicated to the welfare of homeless youth, not one where research was paramount.

Despite these safeguards, the fact that monetary incentives were involved could be said to create a coercive environment for these youths because lack of resources are such a major issue for them. In deciding on a payment structure (\$25 for initial interview, \$15 for follow-up interviews), we had numerous discussions between researchers and service providers at the advisory board level and between researchers and the Washington State and University of Washington IRBs² about what payment rate would be appropriate. On one hand, there was some initial pressure from the IRBs to keep payment artificially low, well below what we were paying in other adolescent studies, in order to ensure that money was not the sole reason that youths participated in our study. Although there is certainly something to be said for this line of reasoning, there was also something that we found perverse about paying someone less money because they were poor. In addition, paying homeless youth less for their time than we would other youth seemed to communicate that they were somehow less worthy or that their time was less valuable than the time of others. Although we don't

believe that we would have had fewer participants in our study had we paid less, if we had, it would have sent a message to youth and to staff that is contrary to everything that this research intervention team was trying to communicate.

Another problem was deciding the form in which to provide compensation. Fears were expressed by some that if we paid youth in cash, they would be tempted to go out and buy alcohol or drugs. Although, again, we found such arguments to imply less than a respectful attitude or a positive message for our participants, we did consider other alternatives. We were not able to come up with another feasible avenue for payment. Providing them with a check, as was suggested by one IRB, did not make sense, as few youths had bank accounts or would be comfortable taking a check to the bank. Gift certificates for food did not seem a good alternative because it would require multiple meals to equal the price of payment. In the end, we went with cash, trusting youths to make reasonably good choices about how to spend it.

When we asked youths during their last set of interviews how they had been spending their money, food was the single item mentioned most frequently. None mentioned spending study money on illegal drugs, and only a handful mentioned alcohol, but cigarettes were mentioned quite frequently. This would not have been our choice for what youths should do with their money, but we are quite confident that nobody started to use alcohol or drugs or began to smoke as a result of receiving money in exchange for their time. Instead, we think that if some youths spent their money on drugs, cigarettes, or alcohol, study payment at least saved them from an evening of panhandling or worse activities that they otherwise might have engaged in for the money.

An additional safeguard that we put in place to ensure that youth were not participating in the study under coercive circumstances

was the requirement that at the start of each new major section of the interview, interviewers explicitly ask youth if they wanted to continue and remind them that they had already earned compensation if they decided to stop. Six youths (fewer than 3%) took us up on this option. All indications were that the vast majority of youth enjoyed their time with interviewers, although questions were on sensitive topics. In most cases, interviewers reported that youths seemed to be in no rush to end the interview and that many lingered for a while, conversing with the interviewer about the study or unrelated issues. Many asked about subsequent interviews and seemed eager for the next round. In fact, once the study was up and running, the buzz about it was remarkably positive, and it was not uncommon for youth to ask if they qualified for participation. In this vein, one more reason to construct sensitive and appropriate consent techniques is that such procedures are apt to help with recruitment and procedures. At times, the imperatives of good science and those of ethics run at cross-purposes, but often they are one and the same.

ESTABLISHING AND MAINTAINING TRUST: CONFIDENTIALITY AND DISCLOSURE

Issues about confidentiality are paramount during the adolescent years. Fear of disclosure of their private thoughts and fears is among the top reasons they give for failure to seek counseling or professional care, even when they have significant problems or are in need of treatment (Cauce et al., 2002; Cheng, Savageau, Sattler, & DeWitt, 1993; Ginsburg, Slap, Cnaan, Forke, Balsley, & Rouselle, 1995).

On the other hand, recent research has documented that a substantial number of

teenagers believe that disclosure of problems in a research context constitutes the equivalent of a cry for help (Fisher, 2003). That is, youth often believe that when adolescents disclose problems on research questionnaires, they are doing so with the hope that the researcher will intervene to obtain help for them.

Issues about confidentiality and disclosure were relatively minor concerns in FASST. The sample was a normative one, so participation in the study could not be viewed, in and of itself, as stigmatizing. Moreover, although we did examine adolescent problems like depression and externalizing behavior, diagnostic scales were not used and adolescents were not asked about suicidal behavior. Thus, we were not in a position to identify problem youth with any certainty. Given the risks of labeling and stigmatization, especially for African American youth, we believed that the dangers of false positives (e.g. identifying as problematic youths without problems) outweighed any benefits that might come from identifying youth who might actually be in need.

Still, we did not want to ignore the legitimate needs of youths with problems. So, we instituted a series of procedures to maximize the chances that youth in need would seek help if appropriate. First, we developed a one-page list of resources in the community available to deal with youth experiencing psychological problems. This list included our own psychology department clinic, which provides reduced-fee psychological services. This referral list was provided to every adolescent or parent of an adolescent who asked questions about services or how to seek treatment.

Participant parents were especially likely to use the research opportunity to ask questions about treatment and how to obtain it. Every time an interviewer gave out the referral list, the parent and/or teen was also given the option of obtaining the help of a

clinically licensed psychologist (the first author⁴) in deciding whether a referral might be appropriate. We did not keep track of how often this option was used, but we can recall speaking only to a handful of parents and no teens.

Midway through the study, parents and teens also received a newsletter that contained group-level information about teens' endorsement of items that could be viewed as symptoms of disorder. This newsletter also contained basic referral information. Thus, although we did not make any direct referrals to treatment, nor do we believe it was appropriate for us to do so, we did our best to facilitate effective treatment seeking among teens and parents who were concerned about problem behavior and interested in seeking help. At no point were we concerned about creating conditions that might increase treatment utilization. We did not view this as a serious threat to the validity of our research, although it was longitudinal in nature. Such concerns seemed misplaced in light of the fact that mere study participation might alter developmental trajectories.

Compared with those of FASST, the ethical dilemmas related to confidentiality and disclosure in SHARP were more vexing. Not only were we using diagnostic scales in SHARP, we also asked very detailed questions about suicidal ideation and behavior and about past and potentially ongoing sex with adults.

The latter two issues, suicide ideation and participation in exploitative relationships with adults, were ones we expected to deal with repeatedly. Detailed protocols for how to handle each were developed in consultation with YouthCare and with the Division of Child Protective Services, which is part of DSHS, one of our partners. Youths were told at the outset of the study during the consent stage that if during the course of the interview we became concerned about the possibility that they might hurt themselves or someone else, we would share the information

with their caseworker or seek immediate care. Youths were again reminded of this before beginning the section in which the suicide questions would be asked. In a similar vein, before asking youth about their previous or present history of sexual abuse or sex with adults, we reminded them that we would have to report any incident in which they gave us details about the perpetrator sufficient to identify them. In this sense, we tried to make sure that youth were very aware of the fact that we would, in effect, treat any communication about suicidal behavior as a cry for help. We also made it clear that if they gave us details about perpetrators of child abuse, this would be the equivalent of reporting it to authorities.

Reporting suicidal intent became routine in SHARP, with several dozen reports shared with caseworkers. In one case, when an interview took place during the evening and the adolescent appeared quite agitated, she was walked over to the closest emergency room where she was evaluated and held overnight. Although we never became aware of any youths attempting suicide during their time in the study, there were more than a few times when interviewers found it hard to walk away from youths, despite knowing that the youths were working with a case manager and receiving services.

One of the unexpected ethical (and practical) challenges we faced in this study was the need to develop a system of support for the interviewers. By the end of the first month, we had instituted twice-weekly meetings of the interview team when we discussed issues they might have faced while interviewing or ethical dilemmas they were still thinking over. These meetings often functioned as debriefing sessions during which interviewers had the opportunity to vent about the unfairness of the world and about the plight of victimized and homeless youth.

During the course of the study, we also made several dozen calls to Child Protective

Services to report incidents of previous child abuse. In virtually every case, however, there was not sufficient information to allow for a more complete investigation. Youth generally had no difficulty reporting that they had been abused but seldom provided enough detail for CPS to identify the perpetrator. When the perpetrator was the parent, reports had already been filed in all cases that we heard of. In fact, a third (33%) of all youths had been placed in foster care at least once, in almost all cases due to parental abuse or neglect.

We chose not to report youth's diagnostic status to case managers because they typically did their own psychological assessment as part of the intake process. In cases in which our assessment and that of case managers yielded different information, we were more confident in results obtained by the latter. Case managers also had the option of referring any youth for further psychiatric assessment when they were unsure about a diagnosis. In contrast, our diagnostic interviews were conducted by lay persons with no specialty training in mental health.

The fact that homeless youth were in case management helped to make potentially very difficult questions about disclosure much more mundane. And the fact that research interviewers and case managers were all members of the same staff, worked in the same building, and frequently interacted created an optimal environment, not only for communicating to youth that we all regarded their well-being as paramount but for making this a reality.⁵ It would be hard to imagine how to conduct this particular study without developing a public-academic partnership.

TO STUDY OR NOT TO STUDY: WEIGHING THE RISKS AGAINST THE BENEFITS

Assuming that a study is unlikely to result in serious harm, the key ethical question that

researchers ask themselves, and that IRBs will ask researchers, is are the benefits of the research likely to outweigh the risks? This is generally a question that is asked at the beginning of a project in making the decision about whether one should go forward. But, in this case, we will try to examine it in retrospect. The two studies we have described were conducted well over a decade ago. What was gained by the youths themselves? By the scientific community? By the therapeutic community? By the service provider community? What might have been lost, or what harm resulted to the youths? To their communities?

Not surprisingly, given that it was a normative sample and that no high-risk procedures were used, we are not aware of any negative consequences to youth or families that resulted from the FASST research. Youth overwhelmingly reported that they enjoyed spending time with the interviewers, despite being asked some questions that might be viewed as intrusive or negative. Although other studies have shown that youth themselves report that answering such questions on a survey might create distress (Fisher, 2003), it has been our experience throughout the years—and in the course of numerous studies, many of them with youth of color—that, at least in a face-to-face interview situation, whatever distress is generated is more than outweighed by the experience of having an adult give them undivided attention and really listen. In thinking about the benefits of research, we consistently underestimate how rare, and how validating, this type of experience is for young people, especially those who are vulnerable or have been marginalized. It is relatively rare in the course of an adolescent's life that an adult will just listen to them for an hour, never saying anything that is judgmental, offering unsolicited advice, or talking about what life was like when they were young.

In the FASST study, our interviewers, who were primarily college students, many of

them students of color, reported instances when adolescents showed them their sketch pads or insisted on playing an instrument for them. Youths showed off their rooms to interviewers and bragged about their accomplishments. They complained about little sisters or older brothers and in one case about an abusive uncle, triggering a report to Child Protective Services. With that one exception, they did not reveal serious problems to our team of interviewers, but we did receive some questions from the youths about where they could find help if needed, questions that we gladly answered. Perhaps the most common area of questioning had to do with college. One unintended, or at least unplanned, benefit of this study was that it exposed adolescents to college-attending positive role models, and a significant number of youth took this opportunity to learn a little more about college life and how to best prepare for it.

The warmth that interviewers experienced in their interactions with the adolescents was also evident in their encounters with parents. The parents we interviewed, most of them mothers, seemed overwhelmingly pleased to be spending time talking to someone about their child or about their parenting. They also often asked our interviewers about college and what was needed to be accepted there and do well. Compared with the youths, parents were much more likely to take this opportunity to talk about their children's problems and seek advice. Although our interviewers were not in a position to make professional judgments, they were able to provide referrals and encourage the parents to follow them up. This was an added, and unplanned, benefit of the study.

Although this is not the kind of question that IRBs ask, or that is highlighted by ethics codes, perhaps the biggest risk posed by this study, which focused exclusively on African American youth, was that our research could reinforce negative views or stereotypes about them. Interestingly, this is a concern that

some parents also expressed in no uncertain terms. More than once we were asked, "Please, don't *just* say bad things" about our children or about our parenting. It was a message we took very seriously.

The FASST study yielded many publications, and it serves as one of the first short-term longitudinal studies to focus exclusively on African American youth. It was also one of the first to conduct a videotaped parent-child interaction with this population, a technique that had long been considered the gold standard in studies of White youth. It made methodological contributions by raising questions about how such interactions should be coded and suggesting that one should pay attention to the ethnicity of the interviewers (Gonzales, Cauce, & Mason, 1997), and it made contributions to our understanding of how parental control affects externalizing behavior (Mason, Cauce, & Gonzales, 1997) and school achievement (Gonzales, Cauce, Friedman, & Mason, 1996), suggesting that one cannot talk about optimal levels of control without taking into account the neighborhood context in which youth grow up. But the single event that made us feel most strongly that the benefits had outweighed the risks came during a talk the first author gave at UNC-Chapel Hill (based on work reported in Cauce et al., 1996). An African American woman in the audience, who described herself as the mother of a teenager and a junior high school teacher, approached the first author afterwards to thank her profusely and enthusiastically for "getting it right" and portraying African American mothers in a positive light rather than simply blaming them for the risks faced by their children. One of the most important and seldom mentioned benefits from survey or interview research is that when gotten right, it can give voice to sectors of the population who are seldom included in public conversations. Although we're sure there are many things we missed and

might have done better, there is little doubt that when taken as a whole, this was an enterprise that produced much more good than harm.

As we've noted throughout, the risks involved in SHARP were more salient than those in FASST. As an intervention study, so also was the possibility of gain. To minimize the risks, we developed extensive protocols to deal with suicidal behavior and reporting of child abuse. We also very carefully structured our interviews so that, for example, following the section on child abuse, we asked more upbeat questions about plans for the future. Sections when youths were asked to report about potentially difficult past experiences were generally followed by questions that were more neutral or positive. We also trained our interviewers to look for signs of distress and fatigue and empowered them to end the interview or to skip to the next section of the interview if they believed that a youth seemed distressed.

What was more unexpected than the few interviews that were terminated was the length of others. Initial interviews had been structured to last about 60 minutes for each session, and interviewers were instructed to end the interview at about 90 minutes, even if sections had not been completed. During the piloting, we found that the latter was happening so often that we finally divided the interview into two parts, and it was still not unusual for them to last almost 90 minutes each. What took so long wasn't answering the questions themselves, but the chit-chat that was taking place throughout. In more cases than not, youths were enjoying their conversations with interviewers, and they were obviously working to prolong that contact.

Youths repeatedly expressed positive feelings about the study and the interview process, and there were no instances of which we were aware of harm befalling any of the participants as a result of our study. Still, case managers involved with the project did not

always understand why we wouldn't try to intervene, on the spot, when a youth was showing obvious signs of depression, and they clearly would have preferred that they (the case managers) do the interviews instead of researchers. The job of the researcher was often portrayed within the agency as a relatively "cushy" one. At times, it was also portrayed as a heartless one, requiring the ability to walk away from youths that were in obvious need.

For the duration of our interview staff's time in the field, biweekly or weekly meetings were necessary (as we previously described), both to discuss the interviews and any issues that had come up and to bolster the morale of the interview team. Interviewers often found it hard to walk away from young people, not knowing if they had a place to stay that night. More than once an interviewer said they had been tempted to bring a street youth home. Knowing that the youths were receiving services wasn't always enough to allay the interviewers' anxieties about youths' well-being; and being portrayed, even teasingly, by clinical staff as heartless didn't help things.

Things did turn around about halfway through the process. Our lead interviewer, Yvette Lohr, wrote a short story called, "The Boy in the Polka Dot Pajamas" that she read to our interview team. In it, she spoke about a young boy she had interviewed repeatedly. Each time he seemed fairly distant, answering questions directly, but offering little in the way of elaboration. Unexpectedly and remarkably, during the third interview, he told Yvette that she was the first adult that he had ever trusted because "You didn't want anything from me." This revelation led to an extended conversation about treatment providers, their expectations, and about his hopes and dreams and future goals. There is no way of knowing whether this happened or not, but he agreed that he would be more open with his case manager and share with her some of what he had shared with Yvette.

We would reprint the story here but didn't keep a copy, and Yvette, still in her early 30s, has passed away. But the fact that Yvette, a very kind-hearted person, came to believe in the power of nonintervention and *just* listening really helped to bolster the morale of our interview team. They came to see that in their own way, they were playing a role in making things better for the youths they were growing to care about so deeply. Like Yvette, we too have come to believe that for vulnerable youths who are marginalized and neglected, merely listening can have a curative function. Thus, what is often considered a risk (e.g., asking youth about sensitive issues, then just listening) is often a benefit.

In addition to whatever validation youths may have experienced from being listened to and heard, we were also able to provide more than a hundred youths with state-of-the-art case management services, services that would not otherwise have been available. Initially, even this had been a point of contention with the clinical case management staff. In the early stages of project design, they had lobbied hard to be able to pick which youth were assigned to intensive case management. They assumed it was the better program and that youth with more problems should be assigned to that condition. It was argued by some that to do anything less was unethical, or at least not altogether ethical.

It is easy to understand their point of view, and it took some convincing to help some of the case managers to understand that we shouldn't simply assume that more (treatment) was necessarily better. We're not quite sure that some were ever convinced. What they did come to realize was that the only thing that made the intensive case management services possible in the first place was the study. (YouthCare did not have the money to provide such services otherwise.) So if we did not have rigor in our design, nobody would have received intensive case management services.

In the end, our study suggested that youth in both types of case management, regular (treatment as usual) and intensive (the experimental condition), improved over the course of treatment in various domains, including mental health and housing status. There was also some evidence that, especially for girls, intensive case management led to a greater degree of improvement than regular case management. Case vignettes that describe the types of services that youths received and their response to treatment are provided elsewhere (see Caucé et al., 1994, 1998) and clearly illustrate the high level of immediate and responsive care that intensive case managers were able to give their clients. Such services included (a) providing a diary and writing material to young girls struggling with issues of self-esteem related to a history of abuse, (b) taking a group of urban boys on an outward bound-type program, or (c) simply helping youths find a bed in a local shelter.

Although validation and treatment were those benefits that most directly affected the participating youth, the community of homeless youth as a whole might have gained the most from the research findings themselves. Quite a number of publications have resulted from this study, and they have been cited extensively, not only by other researchers but in a host of policy papers. Closer to home, this research was cited in a series of public meetings and legislative hearings that led to the Hope Act, passed in 1999, championed by Jim Theofilis, one of the case management directors in our study. The Hope Act provided increased temporary residential placements and comprehensive assessments for homeless street youth under 18 (see www.wsipp.wa.gov/rptfiles/HOPEfinal.pdf).

We are certainly not unbiased observers, but it seems quite clear to us that despite considerable risks, SHARP was a study in which benefits greatly outweighed harm. All indications suggest that if there was harm, it

was not serious enough to reach anyone's attention. By contrast, the benefits, both to the youths in the study itself and to the broader community of street youth, are quite apparent.

CONCLUSIONS

Almost all health and mental health status indicators suggest that poor youth and youth of color lag behind their White middle-class counterparts (Cauce et al., 2002). In order to begin to bridge this gap, we must not only continue but expand our efforts to conduct health and mental health research that focuses on these health disparities. Minority, poor, and other vulnerable communities' distrust of research and the motivation of researchers have been considered important barriers to such efforts (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Poussaint & Alexander, 2000). More recently, some have argued that the tightening of ethical codes and IRB restrictiveness constitute yet another barrier (Azar, 2002; Mueller, 2004). Although addressing this second concern is beyond the scope of this paper, it is worth noting that to the degree that IRBs are tightening up on the research they approve, they may not be focusing on those risks that may be most salient to these vulnerable communities.

Ethical codes and IRBs generally focus their attention on the harms or risks that accrue to individual participants in research projects, with little or no attention given to community-level risk or harm. They also make at least some assumptions about participants in research that may not be true. For example, it is typically believed that study participants will experience discomfort and distress when asked questions about painful incidents in their lives (e.g., child abuse) or about distressing thoughts or problems (e.g., suicidal thoughts, about lying

or cheating). This is also an assumption made by some members of the public (Fisher, 2003); however, it has been our experience that many, perhaps most, individuals from marginalized groups welcome the opportunity to talk about themselves and their problems. Moreover, they find the nonjudgmental listening in which research interviewers are trained to be validating, producing more comfort than distress.

In contrast, one of the concerns we heard most often from participants, especially ethnic minorities, was fear for how they would be portrayed in research studies. They wondered whether the portrayal of their communities by researchers would be overwhelmingly negative and how might this affect them. This is not a concern that IRBs address, nor do we believe it is one that they can address, at least not effectively.

The underlying premise of this chapter is that we can, indeed that we must, carry out research that deals with sensitive issues with vulnerable populations. The cost of not doing so is too high. We've already seen some of the consequences that come from, for example, not using children as subjects in studies that look at the effectiveness of medication for depression and what can happen when women are excluded from studies on coronary health. We cannot develop competent and effective treatments for those communities most in need if we exclude them from our research.

The challenge is finding ways in which to conduct important, and sensitive, research while treating vulnerable populations and the communities they come from with all due respect. In this chapter, we have tried to illustrate some ways in which we have tried to do this in our research. The key, as we see it, is involving community members in as many phases of the study as possible, beginning with the study design. The creation of public-academic or university-community partnerships can go a long way toward addressing

the kinds of ethical dilemmas most likely to be salient when working with poor and/or minority populations (see Suarez-Balcazar et al., 2002, for a discussion of important characteristics in such partnerships). These formal partnerships are especially important when conducting intervention research.

In lieu of official partnerships, even informal consultation with key community members or the conduct of focus groups with individuals similar to those who will be participating in the study can be extremely helpful. We do not believe that it would be especially useful or effective to mandate that all studies have community advisory boards.

We are not even sure that like-minded researchers would always agree as to the type of board or partnership that would be optimally desirable. What we do believe is that over time most researchers will find that in most cases, community advisory boards will be in their best interests and in the best interests of their research, not to mention the best interests of the participants. The best route for arriving at this goal is not through coercion but through dialogue. Too often we focus only on the results of our work and not on the process that has gotten us there. It is wonderful to have this opportunity to do the latter.

NOTES

1. This is used as an example because most of the readership is apt to be familiar with the bell curve; however, much of the research in this book actually came from databases that had not been expressly collected with the analyses that Hernstein and Murray (1994) had in mind.
2. Because of the involvement of UW researchers and the Washington State Department of Social and Health Services, the study had to be approved by two separate IRBs.
3. Each interview had between four and six sections.
4. Since then the first author has let her license expire because she is no longer a treatment provider.
5. We have not been able to recreate this relationship in some subsequent studies with this population.

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