CHAPTER 4

The Ethics and Politics of Social Work Research

What You'll Learn in This Chapter

In this chapter, you'll see how ethical and political considerations must be taken into account alongside scientific ones in the design and execution of social work research. Often, however, clear-cut answers to thorny ethical and political issues are hard to come by.

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INTRODUCTION

Before they can implement their studies, social workers and other professionals who conduct research that involves human subjects may confront questions about the ethics of their proposed investigations. They must resolve these questions not only to meet their own ethical standards, but also to meet the standards of committees that have been set up to review the ethics of proposed studies and to approve or disapprove the studies' implementation from an ethical standpoint.

Concern about the ethics of research that involves human subjects has not always been as intense as it is today. The roots of this concern date back many decades to an era in which studies on human subjects could be conducted with little scrutiny of their ethics—an era in which some research became notorious for its inhumane violations of basic ethical standards. The most flagrant examples were the Nazi atrocities in medical experimentation that were conducted during the Holocaust.

Another notorious example was the Tuskegee syphilis study that started in 1932 in Alabama. In that study, medical researchers diagnosed several hundred poor African American male sharecroppers as suffering from syphilis, but did not tell them they had syphilis. Instead, they told the men that they were being treated for "bad blood." The researchers merely studied the disease's progress and had no intentions of treating it. Even after penicillin had been accepted as an effective treatment for syphilis, the study continued without providing penicillin or telling the subjects about it. The subjects were even kept from seeking treatment in the community—since the researchers wanted to observe the full progression of the disease. At times, diagnostic procedures such as spinal taps were falsely presented to subjects as cures for syphilis. Thirteen journal articles reported the study during this time, but it continued uninterrupted. As reported by James Jones in his book on the Tuskegee experiment, *Bad Blood: The Tuskegee Syphilis Experiment* (1981:190), "none of the health officers connected with the Tuskegee Study expressed any ethical concern until critics started asking questions." In fact, when a member of the medical profession first objected to the study (in 1965), he got no reply to his letter to the Centers for Disease Control, which read:

> I am utterly astounded by the fact that physicians allow patients with a potentially fatal disease to remain untreated when effective therapy is available. I assume you feel that the information which is extracted from observations of this untreated group is worth their sacrifice. If this is the case, then I suggest that the United States Public Health Service and those physicians associated with it need to reevaluate their moral judgments in this regard.
>
> (JONES, 1981:190)

Jones reported that this letter was simply filed away with the following note stapled to it by one of the authors of one of the articles that reported the study: "This is the first letter of this type we have received. I do not plan to answer this letter." In December 1965, Peter Buxtun, who was trained as a social worker while in the U.S. Army, was hired by the Public Health Service as a venereal disease interviewer. Buxtun soon learned of the Tuskegee study from co-workers, and after studying published articles on it, he became relentless in his efforts to intervene. A series of letters to, and difficult meetings with, high-ranking officials ultimately prompted them to convene a committee to review the experiment, but that committee decided against treating the study's subjects.

Buxtun then went to the press, which exposed the study to the public in 1972. This exposure prompted U.S. Senate hearings on the study. Subsequently, in the mid-1970s, the men were treated with antibiotics, as were their wives, who had contracted the disease; and their children, who had it congenitally (Royse, 1991). According to Jones (1981:203), it was the social worker Peter Buxtun—aided by the press—who deserves the ultimate responsibility for stopping the Tuskegee study.

INSTITUTIONAL REVIEW BOARDS

In response to notoriously unethical research experiments such as the Tuskegee study, federal law now governs research ethics in studies involving humans. Any agency (such as a university or a hospital) wishing to receive federal research support must establish an Institutional Review Board (IRB), a panel of faculty (and possibly others) who review all research proposals involving human subjects and rule on their ethics. Their aim is to protect the subjects' rights and interests. The law applies specifically to federally funded research, but many universities apply the same standards and procedures to all research, including that funded by nonfederal sources and even research done at no cost, such as student projects.

SOURCE: The National Archives and Records Administration

Photo from the Tuskegee Syphilis Study

The chief responsibility of an IRB is to protect the rights and interests of human participants in research and ensure that the risks they face by participating are minimal and justified by the expected benefits of the research. In some cases, the IRB may refuse to approve a study or may ask the researcher to revise the study design. IRBs may continue to oversee studies after they are implemented, and they may decide to suspend or terminate their approval of a study.

The sections that follow describe the key ethical guidelines that IRB panelists consider when reviewing and deciding whether to approve a proposed study. When we consider research such as the Tuskegee study, it is not hard to find the ethical violations and to agree that the research was blatantly unethical. However, some ethical violations in social work research can be subtle, ambiguous, and arguable. Sometimes there is no correct answer to the situation, and people of goodwill can disagree. Consequently, reasonable people might disagree about whether some studies are ethical—and whether the risks are outweighed by the expected benefits. Thus, there is no guarantee that every IRB decision will be the "correct" or best decision about the ethics of a proposed project. Later in this chapter, after we examine these ethical issues, we'll look at various IRB regulations that researchers must comply with and IRB forms which researchers must complete.

Voluntary Participation and Informed Consent

Social work research often, though not always, represents an intrusion into people's lives. The interviewer's knock on the door or the arrival of a questionnaire in the mail signals the beginning of an activity that the respondent has not requested and that may require a significant portion of his or her time and energy. Participation in research disrupts the subject's regular activities.

Social work research, moreover, often requires that people reveal personal information about themselves—information that may be unknown to their friends and associates. And social work research often requires

that such information be revealed to strangers. Social work practitioners also require such information, but their requests may be justified on the grounds that the information is required for them to serve the respondent's personal interests. Social work researchers cannot necessarily make this claim, perhaps only being able to argue that their efforts will ultimately help the entire target population of people in need.

A major tenet of research ethics is that participation must be voluntary. No one should be forced to participate. All participants must be aware that they are participating in a study, be informed of all the consequences of the study, and consent to participate in it. This norm might not apply to certain studies. For example, if a community organization measures the amount and speed of automobile traffic at a busy intersection near a school as part of an effort to convince the city to erect a traffic light, it would not need to obtain informed consent from the drivers of every automobile it observes passing through the intersection.

The norm of voluntary participation is far easier to accept in theory than to apply in practice. Again, medical research provides a useful parallel. Many experimental drugs are tested on prisoners. In the most rigorously ethical cases, the prisoners are told the nature—and the possible dangers—of an experiment; that participation is completely voluntary; and, further, that they can expect no special rewards, such as early parole, for participation. Even under these conditions, some volunteers clearly are motivated by the belief that they will personally benefit from their cooperation.

When the instructor in a social work class asks students to fill out a questionnaire that he or she hopes to analyze and publish, students should always be told that their participation in the survey is completely voluntary. Even so, most students will fear that nonparticipation will somehow affect their grade. The instructor should be especially sensitive to such beliefs in implied sanctions and make special provisions to obviate them. For example, the instructor could leave the room while the questionnaires are being completed. Or, students could be asked to return the questionnaires by mail or drop them in a box near the door just before the next course meeting.

You should be clear that this norm of voluntary participation goes directly against several scientific concerns we'll be discussing later in this text. One such concern involves the scientific goal of *generalizability,* which is threatened to the extent that the kinds of people who would willingly participate in a particular research study are unlike the people for whom the study seeks generalizations. Suppose the questionnaire assesses student attitudes about the feminization of poverty, and only a minority of students voluntarily participate—those who care the most deeply about feminism and the poor. With such a small group of respondents, the instructor would have no basis for describing student attitudes in general, and if he or she did generalize the findings to the entire student population, then the generalizations might be seriously misleading.

The need, in some studies, to conceal the nature of the study from those being observed is another scientific concern that is compromised by the norm of voluntary participation and informed consent. This need stems from the fear that participants' knowledge about the study might significantly affect the social processes being studied among those participants. Often the researcher cannot reveal that a study is even being done. Rosenhan (1973), for example, reported a study in which the research investigators posed as patients in psychiatric hospitals to assess whether hospital clinical staff members, who were unaware of the study, could recognize "normal" individuals (presumably the investigators) who (presumably) did not require continued hospitalization. (The results suggested that they could not.) Had the subjects of that study—that is, the clinical staff members—been given the opportunity to volunteer or refuse to participate, then the study would have been so severely compromised that it would probably not have been worth doing. What point would there be to such a study if the clinical staff was aware that the investigators were posing as patients?

But the fact that the norm of voluntary participation and informed consent may be impossible to follow does not alone justify conducting a study that violates it. Was the study reported by Rosenhan justified? Would it have been more ethical not to conduct the study at all? That depends on whether the long-term good derived from that study—that is, observations and data on the identification, understanding, and possible amelioration of problems in psychiatric diagnosis and care—outweighs the harm done in denying clinical staff the opportunity to volunteer or refuse to participate in the study. The need to judge whether a study's long-term benefits will outweigh its harm from ethically questionable practices also applies to ethical norms beyond voluntary participation, and thus we will return to it later. The norm of voluntary participation and informed consent is important. In cases where you feel ultimately justified in violating it,

it is all the more important that you observe the other ethical norms of scientific research, such as bringing no harm to the people under study.

Regardless of how you may feel about the norm of voluntary participation and informed consent, if your study involves human subjects then you will probably have to obtain the approval of its ethics from your IRB, which will probably require participants to sign a **consent form** before they participate in your study. The consent form should provide full information about the features of the study that might affect their decision to participate, particularly regarding the procedures of the study, potential harm, and anonymity and confidentiality.

IRB consent forms can be quite detailed. Separate forms are required if children are research participants. If you conduct a study involving parents and children, for example, you will probably have to use one consent form for parents that might be several pages long, another form for parents to consent to their child's participation, and a third form for the child to sign. The latter form usually is called an assent form and will be briefer and use simpler language that a child can understand. Likewise, to obtain truly informed consent, you should consider the reading level of prospective research participants and have a translated version if they do not speak English. Figure 4-1 displays (in condensed fashion) excerpts from the sample consent forms used by the University of Texas at Austin's Institutional Review Board. (We have not reproduced the entire forms because of their length.)

No Harm to the Participants

Research should never injure the people being studied, regardless of whether they volunteer for the study, and your IRB will need to be persuaded that you have minimized the risk that harm will come to participants from your study. Perhaps the clearest instance of this norm in practice concerns the revealing of information that would embarrass them or endanger their home lives, friendships, jobs, and so forth.

Research participants can be harmed psychologically in the course of a study, and the researcher must be aware of the often subtle dangers and guard against them. Research participants are often asked to reveal deviant behavior, attitudes they feel are unpopular, or personal characteristics they may feel are demeaning such as low income, the receipt of welfare payments, and the like. Revealing such information is likely to make them feel at least uncomfortable.

Social work research projects may also force participants to face aspects of themselves that they do not normally consider. That can happen even when the information is not revealed directly to the researcher. In retrospect, a certain past behavior may appear unjust or immoral. The project, then, can be the source of a continuing personal agony for the participant. If the study concerns codes of ethical conduct, for example, the participant may begin questioning his or her own morality, and that personal concern may last long after the research has been completed and reported.

Although the fact often goes unrecognized, participants can be harmed by data analysis and reporting. Every now and then, research participants read the books published about the studies in which they have participated. Reasonably sophisticated participants will be able to locate themselves in the various indexes and tables. Having done so, they may find themselves characterized—though not identified by name—as bigoted, abusive, and so forth. At the very least, such characterizations are likely to trouble them and threaten their self-images. Yet the whole purpose of the research project may be to explain why some people are prejudiced and others are not.

By now, you should have realized that just about any research you might conduct runs at least some slight risk of harming people somehow. Like voluntary participation, not harming people is an easy norm to accept in theory but often difficult to ensure in practice. Although there is no way for the researcher to eliminate the possibility of harm, some study designs make harm more likely than others. If a particular research procedure seems likely to produce unpleasant effects for participants—asking survey respondents to report deviant behavior, for example—the researcher should have the firmest of scientific grounds for doing it. If the research design is essential and also likely to be unpleasant for participants, then you will find yourself in an ethical netherworld and may find yourself forced to do some personal agonizing. Although agonizing has little value in itself, it may be a healthy sign that you have become sensitive to the problem. And even if after your agonizing you are convinced that your study's benefits far outweigh its minimal risks of harm, your IRB may disagree with you. Some IRB panelists at times can be overzealous in refusing to approve valuable research projects whose benefits far outweigh

Condensed Excerpts from Sample Consent Forms Used by the University of Texas at Austin's Institutional Review Board

You are being asked to participate in a research study. This form provides you with information about the study. The Principal Investigator (the person in charge of this research) or his/her representative will also describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part. Your participation is entirely voluntary and you can refuse to participate without penalty or loss of benefits to which you are otherwise entitled.

Title of Research Study:

Principal Investigator(s) (include faculty sponsor), UT affiliation, and Telephone Number(s):
[Do not use "Dr." as it might imply medical supervision. Instead, use "Professor or Ph.D. or Pharm.D, etc."]

Funding source:

What is the purpose of this study? *[Please include the number of subjects]*

What will be done if you take part in this research study?

What are the possible discomforts and risks?
[Studies that involve psychological risk . . .

The principles that apply to studies that involve psychological risk or mental stress are similar to those that involve physical risk. Participants should be informed of the risk and told that treatment will not be provided. They should be given the names and telephone numbers of agencies that may alleviate their mental concerns, such as a crisis hot line. If the principal investigator or the faculty sponsor of a student investigator is qualified to treat mental health problems, that person may be listed as a resource.]

What are the possible benefits to you or to others?

If you choose to take part in this study, will it cost you anything?

Will you receive compensation for your participation in this study?

What if you are injured because of the study?

If you do not want to take part in this study, what other options are available to you?

Participation in this study is entirely voluntary. You are free to refuse to be in the study, and your refusal will not influence current or future relationships with The University of Texas at Austin *[and or participating sites such as AISD or any other organization].*

How can you withdraw from this research study and who should I call if I have questions?

If you wish to stop your participation in this research study for any reason, you should contact: at (512) . You are free to withdraw your consent and stop participation in this research study at any time without penalty or loss of benefits for which you may be entitled. Throughout the study, the researchers will notify you of new information that may become available and that might affect your decision to remain in the study.

In addition, if you have questions about your rights as a research participant, please contact *[name]* Chair, The University of Texas at Austin Institutional Review Board for the Protection of Human Subjects, *[phone number].*

How will your privacy and the confidentiality of your research records be protected?

Authorized persons from The University of Texas at Austin and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. If the research project is sponsored

SOURCE: Reprinted with permission of the University of Texas at Austin Institutional Review Board.

Figure 4-1 Condensed Excerpts from Sample Consent Forms Used by permission of the University of Texas at Austin's Institutional Review Board

then the sponsor also has the legal right to review your research records. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

[Please note that for studies with audio or video recordings, participants must be told: (a) that the interviews or sessions will be audio or videotaped; (b) that the cassettes will be coded so that no personally identifying information is visible on them; (c) that they will be kept in a secure place (e.g., a locked file cabinet in the investigator's office); (d) that they will be heard or viewed only for research purposes by the investigator and his or her associates; and (e) that they will be erased after they are transcribed or coded. If you wish to keep the recordings because of the requirements of your professional organization with respect to data or because you may wish to review them for additional analyses at a later time, the statement about erasing them should be omitted and you should state that they will be retained for possible future analysis.

If you wish to present the recordings at a convention or to use them for other educational purposes, you should get special permission to do so by adding, after the signature lines on the consent form, the following statement,

"We may wish to present some of the tapes from this study at scientific conventions or as demonstrations in classrooms. Please sign below if you are willing to allow us to do so with the tape of your performance."

And add another signature line prefaced by, "I hereby give permission for the video (audio) tape made for this research study to be also used for educational purposes." This procedure makes it possible for a participant to agree to being taped for research purposes and to maintain the confidentiality of the information on that tape.]

Will the researchers benefit from your participation in this study *[beyond publishing or presenting the results]***?**

Signatures:

Other circumstances in which addenda may need to be included:

1. (For your information only. This explanatory section should NOT be placed into the consent form.)

[When informed consent cannot be obtained from the subject because the subject is an adult who does not have the ability to read and understand the consent form (for example, the subject has advanced Alzheimer's Disease or another cognitive problem), then the study should be explained verbally using language the subject can understand. The Subject should then be asked if she/he agrees to participate. If the subject does not want to participate, she/he should not be enrolled unless it is determined by the person legally responsible that it is in the subject's best interest.

When appropriate, the following text should be added as an addendum to the Informed Consent Form before the Signature section:]

If you cannot give legal consent to take part in this study because you may have trouble reading or understanding this consent form, then the researcher will ask for your assent. Assent is your agreement to be in the study. The researcher will explain the study to you in words that you can understand. You should ask questions about anything you don't understand. Then you should decide if you want to be in the research study. If you want to participate, you or someone who can sign a legal document for you must also give their permission and sign this form before you take part.

You agree to participate:

Subject's signature	**Date**
Signature of Principal Investigator or Representative	**Date**
Witness (if available)	**Date**

Figure 4-1 (*continued*)

If you are not the subject, please print your name:

_____ and indicate one of the following:

_____ **The subject's guardian**

_____ **A surrogate**

_____ **A durable power of attorney**

_____ **A proxy**

_____ **Other, please explain:**

If the child is between 13 and 17, a child signature line may be added to the consent form. If the child is between 7 and 12, the child should sign a separate assent form.

Sample Parental Consent Form for the Participation of Minors: Selected Elements
(Use this in conjunction with the consent form template for adults.)

CONSENT FORM
TITLE of STUDY

Your (son/daughter/child/infant/adolescent youth) is invited to participate in a study of (describe the study). My name is _____ and I am a _____ at The University of Texas at Austin, Department of _____. This study is (state how study relates to your program of work or your supervisor's program of work). I am asking for permission to include your (son/daughter/child/infant/adolescent youth) in this study because _____. I expect to have (number) participants in the study.

If you allow your child to participate, (state who will actually conduct the research) will (describe the procedures to be followed. If the study will take place in a school setting refer to the material under the subheadings in the consent form for minors section of *Procedures and Forms* for examples of information that should be included about the specific activities for which consent is being sought, the time when the study will be conducted, arrangements for students who do not participate, and access to school records.)

Any information that is obtained in connection with this study and that can be identified with your (son/daughter/child/infant/adolescent youth) will remain confidential and will be disclosed only with your permission. His or her responses will not be linked to his or her name or your name in any written or verbal report of this research project.

Your decision to allow your (son/daughter/child/infant/adolescent youth) to participate will not affect your or his or her present or future relationship with The University of Texas at Austin or (include the name of any other institution connected with this project). If you have any questions about the study, please ask me. If you have any questions later, call me at xxx-yyyy. If you have any questions or concerns about your (son/daughter/child/infant/adolescent youth)'s participation in this study, call *[name]*, Chair of the University of Texas at Austin Institutional Review Board for the Protection of Human Research Participants at *[number]*.

You may keep the copy of this consent form.

You are making a decision about allowing your (son/daughter/child/infant/adolescent youth) to participate in this study. Your signature below indicates that you have read the information provided above and have decided to allow him or her to participate in the study. If you later decide that you wish to withdraw your permission for your (son/daughter/child/infant/adolescent youth) to participate in the study, simply tell me. You may discontinue his or her participation at any time.

_____
Printed Name of (son/daughter/child/infant/adolescent youth)

_____ _____
Signature of Parent(s) or Legal Guardian Date

_____ _____
Signature of Investigator Date

Figure 4-1 *(continued)*

Assent for Minors
If the minor is between 7 and 17, his or her assent to participate in the study should be obtained by one of two ways. If the minor is old enough to read and comprehend the parental consent form (more or less between 13 and 17) use the assent signature line method shown at the top of the page titled "Sample Assent Forms for Minors . . ." If the minor is not old enough to comprehend the parental consent form, but is old enough to realize that he or she is participating in a research project (more or less from 7 to 12) use a separate assent form. A sample assent form is at the bottom of the page with the sample forms.

Sample Assent Forms for Minors

Assent Signature Line
If the minor is between the ages of 13 and 17 and capable of understanding the consent form signed by the parents(s), add the following paragraph to the end of that form, underneath the line for the signature of the investigator.

I have read the description of the study titled (give title) that is printed above, and I understand what the procedures are and what will happen to me in the study. I have received permission from my parent(s) to participate in the study, and I agree to participate in it. I know that I can quit the study at any time.

_____ _____
Signature of Minor Date

Assent Form
If a research participant is a minor between the ages of 7 and 12, use an assent form. A sample assent form is printed below. Modify it for your study. The title may be a simplified version of the title on the parental consent form.

ASSENT FORM
(Title of Study)

I agree to be in a study about (give general topic of study). This study was explained to my (mother/father/parents/guardian) and (she/he/they) said that I could be in it. The only people who will know about what I say and do in the study will be the people in charge of the study (modify if information will be given to parents, teachers, doctors, etc.).

(Provide here an overview, from the child's perspective, of what he or she will do in the study. Write this so that a child of seven can understand it, e.g., "In the study I will be asked questions about how I solve problems. I will also be asked how I feel about my family and myself."

Writing my name on this page means that the page was read (by me/to me) and that I agree to be in the study. I know what will happen to me. If I decide to quit the study, all I have to do is tell the person in charge.

_____ _____
Child's Signature Date

_____ _____
Signature of Researcher Date

Figure 4-1 (*continued*)

their minimal risks of harm. IRB requirements not only guard against unethical research but also can reveal ethical issues that have been overlooked by even the most scrupulous of researchers.

Anonymity and Confidentiality

The protection of participants' identities is the clearest concern in the protection of their interests and wellbeing in survey research. If revealing their survey responses would injure them in any way, adherence to this norm becomes all the more important. Two techniques—*anonymity* and *confidentiality*—will assist you in this regard, although the two are often confused.

Anonymity A respondent has **anonymity** when the researcher cannot identify a given response with a given respondent. This means that an interview survey respondent can never be considered anonymous, because an interviewer collects the information from an identifiable respondent. (We assume here that standard sampling methods are followed.)

An example of anonymity would be a mail survey in which no identification numbers are put on the questionnaires before their return to the research office.

As we will see in Chapter 15 (on survey research), ensuring anonymity makes it difficult to keep track of who has or has not returned the questionnaires. Despite this problem, you may be advised to pay the necessary price in some situations. If you study drug abuse, for example, assuring anonymity may increase the likelihood and accuracy of responses. Also, you can avoid the position of being asked by authorities for the names of drug offenders. When respondents volunteer their names, such information can be immediately obliterated on the questionnaires.

Confidentiality In a survey that provides **confidentiality**, the researcher is able to identify a given person's responses but essentially promises not to do so publicly. In an interview survey, for instance, the researcher would be in a position to make public the income reported by a given respondent, but the respondent is assured that this will not be done.

You can use several techniques to ensure better performance on this guarantee. To begin, interviewers and others with access to respondent identifications should be trained in their ethical responsibilities. As soon as possible, all names and addresses should be removed from questionnaires and replaced with identification numbers. A master identification file should be created that links numbers to names to permit the later correction of missing or contradictory information, but this file should not be available to anyone else except for legitimate purposes. Whenever a survey is confidential rather than anonymous, it is the researcher's responsibility to make that fact clear to respondents. Never use the term *anonymous* to mean *confidential.*

As in social work practice, situations can arise in social work research in which ethical considerations dictate that confidentiality not be maintained. Suppose in the course of conducting your interviews you learn that children are being abused or respondents are at imminent risk of seriously harming themselves or others. It would be your professional (and perhaps legal) obligation to report this to the proper agency. Participants need to be informed of this possibility as part of the informed consent process before they agree to participate in a study.

There may be other situations in which government agents take legal action to acquire research data that you believe should remain confidential. For example, they may subpoena data on participants' drug use and thus legally force you to report this information. In 2002, the U. S. Department of Health and Human Services announced a program to issue a "Certificate of Confidentiality" to protect the confidentiality of research subject data against forced disclosure by the police and other authorities. Not all research projects qualify for such protection, but it can provide an important support for research ethics in many cases.

> Under section 301(d) of the Public Health Service Act (42 U.S.C. 241(d)) the Secretary of Health and Human Services may authorize persons engaged in biomedical, behavioral, clinical, or other research to protect the privacy of individuals who are the subjects of that research. This authority has been delegated to the National Institutes of Health (NIH).
>
> Persons authorized by the NIH to protect the privacy of research subjects may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify them by name or other identifying characteristic.
>
> (HTTP://GRANTS.NIH.GOV/GRANTS/POLICY/COC/INDEX.HTM)

The box "Certificates of Confidentiality" provides an example of the language used in these certificates.

Deceiving Participants

We've seen that handling participants' identities is an important ethical consideration. Handling your own identity as a researcher can be tricky also. Sometimes it's useful and even necessary to identify yourself as a researcher to those you want to study. You'd have to be a master con artist to get people to complete a lengthy questionnaire without letting on that you were conducting research.

Even when it's possible and important to conceal your research identity, there is an important ethical dimension to consider. Deceiving people is unethical, and within social research, deception needs to be justified by compelling scientific or administrative concerns. Even then, the justification will be arguable, and your IRB may not buy your justification.

Sometimes, researchers admit they are doing research but fudge about why they are doing it or for whom. Suppose you've been asked by a public welfare agency to conduct a study of living standards among aid recipients. Even if the agency is looking for ways of improving conditions, the recipient participants are likely to fear a witch hunt for "cheaters."

CERTIFICATES OF CONFIDENTIALITY

The following was downloaded from the website of the U.S. Department of Health & Human Services at: http://grants.nih.gov/grants/policy/coc/appl_extramural.htm.

When a researcher obtains a Certificate of Confidentiality, the research subjects must be told about the protections afforded by the certificate and any exceptions to that protection. That information should be included in the informed consent form. Examples of appropriate language follow. Researchers may adapt the language to the needs of the research participants and to the subject matter of the study. However, the language used must cover the basic points.

Researchers should also review the language about confidentiality and data security that is routinely included in consent forms to be certain that it is consistent with the protections of the Certificate of Confidentiality.

Example:

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

[The researchers should include language such as the following if they intend to make voluntary disclosure about things such as child abuse, intent to hurt self or others, or other voluntary disclosures.] The Certificate of Confidentiality does not prevent the researchers from disclosing voluntarily, without your consent, information that would identify you as a participant in the research project under the following circumstances. [The researchers should state here the conditions under which voluntary disclosure would be made. If no voluntary disclosures will be made, the researchers should so state.]

They might be tempted, therefore, to give answers that make themselves seem more destitute than they really are. Unless they provide truthful answers, however, the study will not produce accurate data that will contribute to an effective improvement of living conditions. What do you do? One solution would be to tell participants that you are conducting the study as part of a university research program—concealing your affiliation with the welfare agency. Doing that improves the scientific quality of the study but raises a serious ethical issue in the process.

Analysis and Reporting

As a social work researcher, then, you have several ethical obligations to the participants in your study. At the same time, you have ethical obligations to your professional colleagues. A few comments on those latter obligations are in order.

In any rigorous study, the researcher should be more familiar than anyone else with the study's technical shortcomings and failures. You have an obligation to make them known to your readers. Even though you may feel foolish admitting mistakes, you should

do it anyway. Negative findings should be reported if they are at all related to your analysis. There is an unfortunate myth in scientific reporting that only positive discoveries are worth reporting (and journal editors are sometimes guilty of believing that as well). In science, however, it is often just as important to know that two variables are not related as to know that they are. If, for example, an experiment finds no difference in outcome between clients treated and not treated with a tested intervention, then it is important for practitioners to know that they may need to consider alternative interventions—particularly if the same null finding is replicated in other studies. And replication would not be possible if the original experiment were not reported.

The ethical importance of reporting negative findings in studies evaluating the effectiveness of interventions, programs, or policies is particularly apparent in the evidence-based practice process (as discussed in Chapter 2). Suppose you are conducting an evidence-based practice search looking for interventions with the best evidence supporting their effectiveness for the problem presented by your client and you find a well-designed study supporting the effectiveness of a relevant intervention that we'll call Intervention A. If you find no other studies with contradictory findings, you might be tempted to deem Intervention A the one with the best evidence base for your client's problem. But suppose several other studies found Intervention A to be ineffective for that problem but were not reported because the investigators believed that no one is interested in hearing about interventions that don't work. In reality, then, interventions other than Intervention A might have better, more consistent evidence supporting their effectiveness, and if you knew of the studies with negative findings about Intervention A you might propose one of those other interventions to your client. Moreover, suppose your client is African American or Hispanic, and that the one study supporting Intervention A involved only Caucasian clients whereas the other studies—the ones with negative results—involved African American or Hispanic clients. The ethical implications of not reporting those other studies should be apparent to you; not reporting them would mislead you into proposing the wrong, unhelpful intervention to your client.

Researchers should also avoid the temptation to save face by describing their findings as the product of a carefully preplanned analytic strategy when that is not the case. Many findings arrive unexpectedly—even though they may seem obvious in retrospect. So they uncovered an interesting relationship by accident—so what? Embroidering such situations with descriptions of fictitious hypotheses is dishonest and tends to mislead inexperienced researchers into thinking that all scientific inquiry is rigorously preplanned and organized.

In general, science progresses through honesty and openness, and it is retarded by ego defenses and deception. Researchers can serve their fellow researchers—and scientific discovery as a whole—by telling the truth about all the pitfalls and problems they have experienced in a particular line of inquiry. Perhaps that candor will save their colleagues from the same problems.

Weighing Benefits and Costs

We have noted that ethical considerations in the conduct of social work research often pose a dilemma. The most ethical course of action for researchers to take is not always clear cut. Sometimes it is difficult to judge whether the long-term good to be derived from a study will outweigh the harm done by the ethically questionable practices that may be required for adequate scientific validity. Consider, for example, the study in which a team of researchers deceptively posed as hospitalized mental patients, concealing their identity from direct care staff members to study whether the staff could recognize their normalcy.

Earlier we asked whether the potential benefits of the study—regarding psychiatric diagnosis and care—justified violating the norm of voluntary participation by direct staff. What if the purpose of that study had been to verify whether suspected physical abuse of patients by staff was taking place? Suppose an appalling amount of staff neglect and abuse of patients really was occurring and that the researchers uncovered it. Would the potential benefits to current and future patients to be derived from exposing and perhaps reforming the quality of care outweigh using deception in the research?

If alternative ways to conduct the research are available—that is, ways that can provide equally valid and useful answers to the research question without engaging in ethically questionable research practices—then the dilemma will be resolved and an alternate methodology can be chosen. Indeed, IRBs can be zealous in identifying a possible alternative methodology and perhaps insisting that it be used even if you think it is much less likely to produce valid and unbiased results.

But sometimes no such alternatives appear. If not, then how researchers resolve this dilemma will depend on the values they attach to the various costs and benefits of the research and whether they believe that some ends can ever justify some means. No objective formula can be applied to this decision; it is inherently subjective. Some individuals would argue that the end never justifies the means. Others might disagree about which particular ends justify which particular means. Even if you resolve this dilemma in your own mind, you will probably find it very difficult to get all the members of your IRB to agree with you.

The box, "An Illustration: Living with the Dying—Use of Participant Observation," provides one example of how the long-term good to be derived from a study may have justified violating ethical guidelines. This study, which involved deceiving participants and not obtaining their informed consent to participate, might be of special interest to students who are interested in practicing social work in a medical or hospice setting.

Right to Receive Services versus Responsibility to Evaluate Service Effectiveness

Perhaps the most critical ethical dilemma in social work research pertains to the right of clients in need to receive services and whether the benefit of improving the welfare of clients in the long run ever justifies delaying the provision of services to some clients in the short run. Practitioners engaged in the evidence-based practice process will search for the best available evidence about the effectiveness of services. As mentioned in Chapter 2, at the top of the evidence-based practice research hierarchy for evaluating service effectiveness are studies (and reviews of such studies) with the strongest designs for making inferences about whether the service provided or something else most plausibly explains variations in client outcome. Those designs involve experiments that evaluate the effectiveness of services by comparing the fates of clients who receive the service being evaluated and those from whom the service is withheld. (We will examine experiments in depth in Chapter 11.) Two values are in conflict here: doing something to try to provide immediate help to people in need, and the professional's responsibility to ensure that the services clients receive have had their effects—either beneficial or harmful—scientifically tested.

Some researchers argue that individuals in need should never be denied service for any period or for any research purposes. Others counter that the service being delayed is one whose effects, if any, have not yet been scientifically verified—otherwise, there would be no need to test it. How ethical, they ask, is it to provide the same services perennially without ever scientifically verifying whether those services are really helping anyone or are perhaps harmful? And if they are potentially harmful, are those who receive them actually taking a greater risk than those who are temporarily denied them until their effects are gauged? Using another medical parallel, would you think your physician was ethical if he or she treated you with a drug knowing that the beneficial or harmful effects of that drug were as yet untested? If you were being paid to participate in a medical experiment to test the effectiveness of a drug whose benefits and negative side effects were as yet unknown, which group would you feel safer in: the group receiving the drug or the group not receiving it?

The seriousness of the client's problem is one factor that bears on this dilemma. It would be much harder to justify the delay of service to individuals who are experiencing a dangerous crisis or are at risk of seriously harming themselves—suicidal clients, for example—than to those in less critical need. Another factor is the availability of alternative interventions to which the tested intervention can be compared. Perhaps those who are denied the tested service can receive another one that might prove to be no less beneficial.

If alternative interventions are available, then the conflict between the right to service and the responsibility to evaluate can be alleviated. Instead of comparing clients who receive a new service being tested to those who receive no service, we can compare them to those who receive a routine set of services that was in place before the new one was developed. This is a particularly ethical way to proceed when insufficient resources are available to provide the new service to all or most clients who seek service. This way, no one is denied service, and the maximum number that resources permit receives the new service.

Another way to reduce the ethical dilemma when resources don't permit every client to receive the new service is to assign some clients to a waiting list for the new service. As they wait their turn for the new service, they can be compared to the clients currently receiving the new service. Ultimately, everyone is served, and the waiting list clients should be free to

AN ILLUSTRATION: LIVING WITH THE DYING—USE OF PARTICIPANT OBSERVATION

Robert Buckingham and his colleagues (1976) wanted to compare the value of routine hospital care with hospice care for the terminally ill. (As we mentioned in Chapter 3, the emphasis in hospice care is on minimizing discomfort and maximizing quality of life, and this might entail eschewing medical procedures that prolong life but hinder its quality. Routine hospital care, in contrast, is more likely to emphasize prolonging life at all costs, even if that requires a lower quality of life for the dying patient. The routine approach is less attentive to the psychosocial and other nonmedical needs of the patient and family.)

Buckingham wanted to observe and experience the treatment of a terminally ill patient in two wards of a hospital: the surgical-care (nonhospice) ward and the palliative-care (hospice) ward. For his observations to be useful, it was necessary that staff members and other patients on his ward not know what he was doing. The steps that he took to carry out his deception are quite remarkable. Before entering the hospital, he lost 22 pounds on a six-month diet. (He was naturally thin before starting his diet.) He submitted himself to ultraviolet radiation so he would look as if he had undergone radiation therapy. He had puncture marks from intravenous needles put on his hands and arms so he would look as if he had undergone chemotherapy. He underwent minor surgery for the sole purpose of producing biopsy scars. He learned how to imitate the behavior of patients dying with pancreatic cancer by reviewing their medical charts and maintaining close contact with them. Finally, for several days before entering the hospital, he grew a patchy beard and abstained from washing.

Buckingham stayed in the hospital 10 days, including two days in a holding unit, four days in the surgical-care unit, and four days in the hospice unit. His findings there supported the advantages of hospice care for the terminally ill. For example, on the surgical-care ward he observed staff communication practices that were insufficient, impersonal, and insensitive. Physicians did not communicate with patients. Staff members in general avoided greeting patients, made little eye contact with them, and often referred to them by the names of their diseases rather than by their personal names. Complacent patients did not receive affection. The negative aspects of the patients' conditions were emphasized.

Buckingham's observations on the hospice ward, however, were quite different. Staff maintained eye contact with patients. They asked questions about what the patients liked to eat and about other preferences. They asked patients how they could be more helpful. They listened to patients accurately, unhurriedly, and empathically. Physicians spent more time communicating with patients and their families. Staff encouraged family involvement in the care process. It is not difficult to see the value of Buckingham's findings in regard to enhancing the care of the terminally ill and their families. In considering whether the benefits of those findings justify Buckingham's particular use of deception, several other aspects of the study might interest you.

Before entering the hospital, Buckingham engaged the hospital's top medical, administrative, and legal staff members in planning and approving the study. (They had no IRB at that time.) The heads of both the surgery ward and the hospice ward also participated in the planning and approved the study. In addition, the personnel of the hospice ward were informed in advance that their unit was going to be evaluated, although the nature of the evaluation was not revealed. Finally, an ad hoc committee was formed to consider the ethics of the study, and the committee approved the study. In light of these procedures and this study's benefits, it may not surprise you to learn that no ethical controversy emerged in response to this study.

refuse participation in the study without being denied services eventually.

NASW Code of Ethics

If decisions about the ethics of research involve subjective value judgments in which we must weigh the potential benefits of the research against its potential costs to research participants, and if we must make those decisions in light of various idiosyncratic factors, then those decisions pose dilemmas for which there may be no right or wrong answers. But researchers can do some things to be as ethical as possible. They can obtain collegial feedback as to the ethics of their proposed research. They should carefully consider whether there are ethically superior alternatives and strive to ensure that their research proposal is the most ethical one that they can conceive. And, of course, they must obtain approval from their IRB.

To guide them in this endeavor, various professional associations have created and published formal codes of conduct to cover research ethics. Figure 4-2 shows the codes from the "Evaluation and Research" section of the Code of Ethics of the National Association of Social Workers. Although those codes provide ethical guidelines for conducting research, another section—on

Section 5.02 Evaluation and Research

(a) Social workers should monitor and evaluate policies, the implementation of programs, and practice interventions.

(b) Social workers should promote and facilitate evaluation and research to contribute to the development of knowledge.

(c) Social workers should critically examine and keep current with emerging knowledge relevant to social work and fully use evaluation and research evidence in their professional practice.

(d) Social workers engaged in evaluation or research should carefully consider possible consequences and should follow guidelines developed for the protection of evaluation and research participants. Appropriate institutional review boards should be consulted.

(e) Social workers engaged in evaluation or research should obtain voluntary and written informed consent from participants, when appropriate, without any implied or actual deprivation or penalty for refusal to participate; without undue inducement to participate; and with due regard for participants' well-being, privacy, and dignity. Informed consent should include information about the nature, extent, and duration of the participation requested and disclosure of the risks and benefits of participation in the research.

(f) When evaluation or research participants are incapable of giving informed consent, social workers should provide an appropriate explanation to the participants, obtain the participants' assent to the extent they are able, and obtain written consent from an appropriate proxy.

(g) Social workers should never design or conduct evaluation or research that does not use consent procedures, such as certain forms of naturalistic observation and archival research, unless rigorous and responsible review of the research has found it to be justified because of its prospective scientific, educational, or applied value and unless equally effective alternative procedures that do not involve waiver of consent are not feasible.

(h) Social workers should inform participants of their right to withdraw from evaluation and research at any time without penalty.

(i) Social workers should take appropriate steps to ensure that participants in evaluation and research have access to appropriate supportive services.

(j) Social workers engaged in evaluation or research should protect participants from unwarranted physical or mental distress, harm, danger, or deprivation.

(k) Social workers engaged in the evaluation of services should discuss collected information only for professional purposes and only with people professionally concerned with this information.

(l) Social workers engaged in evaluation or research should ensure the anonymity or confidentiality of participants and of the data obtained from them. Social workers should inform participants of any limits of confidentiality, the measures that will be taken to ensure confidentiality, and when any records containing research data will be destroyed.

(m) Social workers who report evaluation and research results should protect participants' confidentiality by omitting identifying information unless proper consent has been obtained authorizing disclosure.

(n) Social workers should report evaluation and research findings accurately. They should not fabricate or falsify results and should take steps to correct any errors later found in published data using standard publication methods.

(o) Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary.

(p) Social workers should educate themselves, their students, and their colleagues about responsible research practices.

Figure 4-2 NASW Code of Ethics

social workers' ethical responsibilities as professionals—reminds us that we can violate our ethical responsibilities as professionals not only when we conduct research, but also when we refrain from using it to guide our practice. It is worded as follows:

> Social workers should critically examine and keep current with emerging knowledge relevant to social work. Social workers should routinely review the professional literature. . . . Social workers should base practice on recognized knowledge, including empirically based knowledge, relevant to social work and social work ethics.
>
> (NASW, 1999, SECTION 4.01)

IRB Procedures and Forms

IRBs vary in the amount and format of materials they require to describe the proposed research. In the process of deciding whether to approve a research proposal, an IRB may require certain modifications to make the research acceptable, such as providing additional information to participants before their consent to participate is obtained. For example, some social work research studies might involve situations in which ethical considerations dictate that confidentiality not be maintained, such as when child abuse is unexpectedly encountered or when respondents are at imminent risk of seriously harming themselves or others. You may need to add this contingency to your own consent form and IRB application form. You may also need to assure your participants and your IRB that you will arrange for services to be offered to any subject you encounter who needs them. Because they vary so much, we suggest that you examine your university's IRB forms and procedures, which may be accessible online. Alternatively, you can examine Figure 4-3, which presents condensed and partial excerpts from the template used by the University of Texas at Austin to guide investigators as to what materials to submit in their applications for IRB approval. It will give you an idea of the kinds of things that are commonly required by other IRBs.

Training Requirement

One regulation that does not vary is the responsibility of IRBs to require education on the protection of human research participants for each individual investigator and research assistant working on studies involving human subjects. Your institution might offer its own educational program on the protection of research participants. Alternatively, you can obtain free online training at the following National Institutes of Health ethics tutorial website, http://cme.cancer.gov/clinicaltrials/learning/humanparticipant-protections.asp. The tutorial takes about three hours to complete and contains seven modules, four of which are followed by quizzes. After you complete all the modules and correctly answer the required number of quiz questions you will receive a certificate of completion that you can submit with your IRB proposal to verify that you have obtained the required training. Even if you are not involved presently in a study to be submitted for IRB approval you might want to complete the online training anyway. The certificate might come in handy later on if you become a research assistant or need IRB approval for your research. You might also ask your instructor if extra credit could be granted for obtaining this certificate. In fact, be sure to examine your research course syllabus carefully in this regard; it might already include a provision for such extra credit!

Expedited Reviews

If you are fortunate enough to have a research instructor who requires that you design and carry out a research project, then you may find that you have to get your study approved by your university's IRB before you can begin collecting data. Moreover, if your research project is to be carried out in an agency that receives federal money, you may have to obtain approval from both your school's IRB and the agency's IRB. Just what you needed, right? Don't panic. Perhaps your study will qualify for an exemption from a full review and you'll be able to obtain approval within a relatively short time (perhaps as short as a few days). Federal regulations allow IRBs to grant exemptions to certain kinds of studies, although institutions vary considerably in interpreting the federal regulations. Exempt studies receive an expedited review. The box "Federal Exemption Categories for Expedited Reviews" lists the guidelines for qualifying for an exemption from a full review.

Most student research (with the exception of doctoral dissertations) qualifies for at least one exemption. Note that studies that appear to meet one or more exemptions might still require a full review if subjects can be identified, if knowledge of their responses could

I. **Title**
II. **Investigators (co-investigators)**
III. **Hypothesis, Research Questions, or Goals of the Project**
IV. **Background and Significance**
V. **Research Method, Design, and Proposed Statistical Analysis**
VI. **Human Subject Interactions**

A. Identify the **sources of potential participants,** derived materials, or date. Describe the characteristics of the subject population such as their anticipated number, age, sex, ethnic background, and state of health. Identify the criteria for inclusion and/or exclusion. Explain the rationale for the use of special classes of participants whose ability to give voluntary informed consent may be in question. Such participants include students in one's class, people currently undergoing treatment for an illness or problem that is the topic of the research study, people who are mentally retarded, people with a mental illness, people who are institutionalized, prisoners, etc. When do you expect human subject involvement in this project to begin and when do you expect it to end?

If the participants are prisoners or residents of correction facilities, the composition of the IRB must be augmented by a prisoner's advocate. Please inform the IRB if this applies to your project.

If some of the potential participants or the parents of child participants are likely to be more fluent in a language other than English, the consent forms should be translated into that language. Both English and the other language versions of the form should be provided, with one language on one side of a page and the other on the other side of the page. This translation may be completed after IRB approval of the study and consent forms. Specify here your intentions with respect to the languages of the consent forms. (If you plan to conduct your study with students from the Austin Independent School District, you will be required to provide a Spanish language version of your parental consent form.)

B. Describe the **procedures for the recruitment of the participants.** Append copies of fliers and the content of newspaper or radio advertisements. If potential participants will be screened by an interview (either telephone or face-to-face) provide a script of the screening interview.

If the potential participants are members of a group that may be construed as stigmatized (e.g., spousal abusers, members of support groups, people with AIDS, etc.) your initial contact with the potential participants should be through advertisements or fliers or through people who interact with the potential participants because of their job duties. These people may describe your study to the potential participants and ask them to contact you if they are interested in talking to you about the study.

C. Describe the **procedure for obtaining informed consent.**

D. Research Protocol. What will you ask your participants to do? When and where will they do it? How long will it take them to do it? Describe the type of research information that you will be gathering from your subjects, i.e., the data that you will collect. *Append copies of all surveys, testing materials, questionnaires, and assessment devices. Append copies of topics and sample questions for non-structured interviews and focus group discussions.*

VII. Describe any **potential risks** (physical, psychological, social, legal, or other) and assess their likelihood and seriousness.

Describe the procedures for protecting against (or minimizing) any potential risks and include an assessment of their effectiveness. Discuss the procedures that will be used to maintain the confidentiality of the research data.

If your study involves deception, describe the procedures for debriefing the participants.

VIII. Describe and assess the **potential benefits** to be gained by participants (if any) and the benefits that may accrue to society in general as a result of the planned work. Discuss the risks in relation to the anticipated benefits to the participants and to society.

IX. Indicate the specific **sites or agencies involved in the research project** besides The University of Texas at Austin. These agencies may include school districts, day care centers, nursing homes, etc. Include, as an attachment, approval letters from these institutions or agencies on their letterhead. The letter should grant you permission to use the agency's facilities or resources; it should indicate knowledge of the study that will be conducted at the site. If these letters are not available at the time of IRB review, approval will be contingent upon their receipt.

SOURCE: Reprinted with permission of the University of Texas at Austin Institutional Review Board.

Figure 4-3 Excerpts from the Template to Guide Research Proposals Used by the University of Texas at Austin's Institutional Review Board

FEDERAL EXEMPTION CATEGORIES FOR EXPEDITED REVIEWS

Studies that may qualify for an expedited review are as follows:

(1) Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:

(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

(3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if:

(i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

(5) Research and demonstration projects which are conducted by or subject to the approval of Department or Agency heads, and which are designed to study, evaluate, or otherwise examine:

(i) Public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

(6) Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

place them at risk of some sort of harm, or if the data are sensitive. Of course, if your study involves some controversial procedures—such as pretending to faint every time your instructor mentions statistics so you can see whether research instructors are capable of exhibiting compassion or whether this is an effective way to influence exam content—then obtaining IRB approval may be problematic (not to mention what it will do to your grade when the instructor reads your report). Other (more realistic) problematic examples include surveys on sensitive topics such as drug abuse or sexual practices or on traumatic events that may be painful for respondents to remember.

Whether or not you seek an expedited review, and no matter how sure you are that your proposed research is ethical, it would be prudent to submit your IRB application as early as possible. Suppose you hope to complete your data collection before the end of the spring semester—perhaps during the month of May—and your IRB meets to review proposals at the end of each month. Suppose further that it will take you one month to complete your data collection. If you submit

your application in March, and it gets an expedited review, you are probably in the clear. But what if your IRB perceives (or perhaps misperceives) something controversial in your proposal and does not grant an expedited review. Suppose further that it gets a full review at the end of March and rather than approving it, your IRB raises questions and requires you to make significant modifications. Conceivably, that might delay obtaining approval until its next meeting at the end of April or perhaps even later. That might make it impossible to complete your data collection by the end of the spring semester, but had you submitted your IRB proposal a month or more earlier, you would still be able to meet your target date.

Overzealous Reviewers

In our experience, we have found most IRB panelists and their support staff to be very reasonable people who make every effort to help investigators (especially students) obtain timely approval for their social work research projects. Occasionally, however, we have run into some IRB panelists who can at times be overzealous in their roles as protectors of research participants and in their interpretations of ethical guidelines.

One proposal, for example, included express mailing from Texas a videotape of five one-hour therapy sessions (with five different clients) to a psychologist in Colorado and another psychologist in New York. The two psychologists were nationally known experts in the particular therapy being evaluated, and their task was to view each therapy session and rate the extent to which the therapist implemented the therapy appropriately. None of the therapy clients were named on the videos. Given that each therapy session was one hour long, and in light of the busy schedules of the psychologists, it was expected that it might take them a week or more to find the time to rate all the sessions.

Upon reviewing the proposal, three IRB panelists insisted that the videotape not be express mailed. Instead, they wanted the investigator to carry the video with him on separate trips to Colorado and New York, stay there until the psychologists completed their ratings, and then personally carry the video back to Texas. Their rationale was that the video might get lost in the mail (despite being carefully labeled on the video itself with the researcher's address, etc.), and if so, mail staff might watch it and recognize one of the clients.

Though far fetched, such an eventuality was not impossible, and the IRB approval got delayed one month—until the next IRB meeting. At that next meeting, the investigator appeared and explained how he was conducting the project without funding as a volunteer at the request of a local residential treatment center (information that was already in the written proposal!) and that in light of that and the potential benefits of the study it was unreasonable to require him to travel to those two sites and wait there for days instead of using express mail. The chair of the IRB enthusiastically agreed with the investigator and convinced most of the panelists to approve of the study. Nevertheless, in the final vote, the three panelists remained unmoved and voted in the minority against approval.

Lest you think that we are cherry picking an aberrant incident, you may want to go to the IRBwatch website at www.irbwatch.org. The purpose of the site is to chronicle abuses by IRBs. According to the site, "IRB's have increasingly harassed researchers and slowed down important research, without protecting any human research participants." One of many interesting links at that site is to a study by Christopher Shea (2000), "Don't Talk to the Humans: The Crackdown on Social Science Research," *Lingua Franca* 10, no. 6, 27–34.

But don't think that these critiques minimize the importance of IRBs in protecting human participants in research. Also, as we noted earlier, we have found most IRB panelists and their support staff to be very reasonable people who make every effort to help investigators obtain timely approval for their social work research projects. We just want you to realize that some IRB members can be overzealous, and that means you should submit your IRB proposal as early as possible and not be cavalier about the prospects for its swift approval.

FOUR ETHICAL CONTROVERSIES

As you may already have guessed, the advent of IRBs and the dissemination of professional codes of ethics have not prevented reasonable people from disagreeing about whether some research projects are ethically justified. In this section, we will describe four research projects that have provoked ethical controversy and discussion. These are not the only controversial projects that have been done, but they illustrate ethical issues in the real world, and we thought you'd find them interesting and perhaps

provocative. The first two are from psychology and sociology. They were conducted before the advent of IRBs and are often cited as examples of the need for IRBs. The latter are from social work and were conducted later. As you read each, imagine how you would have responded had you been reviewing their proposals as an IRB member. We'll start with the notorious Milgram study.

Observing Human Obedience

One of the more unsettling rationalizations to come out of World War II was the German soldiers' common excuse for atrocities: "I was only following orders." From the point of view that gave rise to this comment, any behavior—no matter how reprehensible—could be justified if someone else could be assigned responsibility for it. If a superior officer ordered a soldier to kill a baby, then the fact of the order was said to exempt the soldier from personal responsibility for the action.

Although the military tribunals that tried the war crime cases did not accept the excuse, social scientists and others have recognized the extent to which this point of view pervades social life. Often people seem willing to do things they know would be considered wrong by others if they can cite some higher authority as ordering them to do it. Such was the pattern of justification in the My Lai tragedy of Vietnam, when U.S. soldiers killed more than 300 unarmed civilians—some of them young children—simply because their village, My Lai, was believed to be a Vietcong stronghold. This sort of justification appears less dramatically in day-to-day civilian life. Few would disagree that this reliance on authority exists, yet Stanley Milgram's study (1963, 1965) of the topic provoked considerable controversy.

To observe people's willingness to harm others when following orders, Milgram brought 40 adult men—from many different walks of life—into a laboratory setting that he designed to create the phenomenon under study. If you had been a subject in the experiment, you would have had something like the following experience.

You would have been informed that you and another subject were about to participate in a learning experiment. As the result of drawing lots, you would have been assigned the job of "teacher" and your fellow subject the job of "pupil." Your pupil then would have been led into another room, strapped into a chair, and had an electrode attached to his wrist. As the teacher, you would have been seated in front of an impressive electrical control panel covered with dials, gauges, and switches. You would have noticed that each switch had a label giving a different number of volts, ranging from 15 to 315. The switches would have had other labels, too, some with the ominous phrases "Extreme-Intensity Shock," "Danger—Severe Shock," and "XXX."

The experiment would run like this. You would read a list of word pairs to the learner and then test his ability to match them. You couldn't see him, but a light on your control panel would indicate his answer. Whenever the learner made a mistake, you would be instructed by the experimenter to throw one of the switches—beginning with the mildest—and administer a shock to your pupil. Through an open door between the two rooms, you'd hear your pupil's response to the shock. Then, you'd read another list of word pairs and test him again.

As the experiment progressed, you'd be administering ever more intense shocks until your pupil was screaming for mercy and begging for the experiment to end. You'd be instructed to administer the next shock anyway. After a while, your pupil would begin kicking the wall between the two rooms and screaming. You'd be told to give the next shock. Finally, you'd read a list and ask for the pupil's answer—and there would only be silence from the other room. The experimenter would inform you that no answer was considered an error and instruct you to administer the next higher shock. This process would continue up to the "XXX" shock at the end of the series.

What do you suppose you really would have done when the pupil first began screaming? When he began kicking on the wall? Or, when he became totally silent and gave no indication of life? You'd refuse to continue giving shocks, right? And surely the same would be true of most people.

So we might think—but Milgram found out otherwise. Of the first 40 adult men Milgram tested, nobody refused to continue administering the shocks until they heard the pupil begin kicking the wall between the two rooms. Of the 40, five did so then. Two-thirds of the subjects, 26 of the 40, continued doing as they were told through the entire series—up to and including the administration of the highest shock.

As you've probably guessed, the shocks were phony, and the "pupil" was another experimenter. Only the "teacher" was a real subject in the experiment.

You wouldn't have been hurting another person, even though you would have been led to think you were. The experiment was designed to test your willingness to follow orders—presumably to the point of killing someone.

Milgram's experiments have been criticized both methodologically and ethically. On the ethical side, critics particularly cited the effects of the experiment on the subjects. Many seem to have personally experienced about as much pain as they thought they were administering to someone else. They pleaded with the experimenter to let them stop giving the shocks. They became extremely upset and nervous. Some had uncontrollable seizures.

How do you feel about this research? Do you think the topic was important enough to justify such measures? Can you think of other ways in which the researcher might have examined obedience? There is a wealth of discussion regarding the Milgram experiments on the web. Search for *Milgram experiments, human obedience experiments,* or *Stanley Milgram.*

Trouble in the Tearoom

The second illustration was conducted by a graduate student and published in a 1970 book called *Tearoom Trade: Impersonal Sex in Public Places.* Researcher Laud Humphreys wanted to study homosexual acts between strangers meeting in public restrooms in parks; the restrooms are called "tearooms" by those who used them for this purpose. Typically, the tearoom encounter involved three people: the two men actually engaged in the homosexual act and a lookout.

To gather observations for his study, Humphreys began showing up at public restrooms and offering to serve as a lookout whenever it seemed appropriate. Humphreys wanted to go beyond his observations as lookout and learn more about the people he was observing. Many of the participants were married men who wanted to keep their homosexuality secret and thus avoid being stigmatized and losing their status in their communities. They probably would not have consented to being interviewed. Instead of asking them for an interview, Humphreys tried to note the license plate numbers of their vehicles and then track down their names and addresses through the police. Then disguising himself enough to avoid recognition, he visited the men at their homes and announced that he was conducting a survey. In that fashion, he collected the personal information he was unable to get in the restrooms.

Humphreys' research provoked considerable controversy both within and outside the social scientific community. Some critics charged Humphreys with a gross invasion of privacy in the name of science. What men did in public restrooms was their own business and not his. Others were mostly concerned about the deceit involved: Humphreys had lied to the participants by leading them to believe he was only participating as a voyeur. Some were more concerned with Humphreys' follow-up survey than with what he did in public facilities. They felt it was unethical for him to trace the participants to their houses and interview them under false pretenses. Still others justified Humphreys' research. The topic, they said, was worth study and could not be studied any other way. They considered the deceit to be essentially harmless, noting that Humphreys was careful not to harm his subjects by disclosing their tearoom activities.

The tearoom trade controversy, as you might imagine, has never been resolved. It is still debated, and probably will be for a long time, because it stirs emotions and contains ethical issues about which people disagree. What do you think? Was Humphreys ethical in doing what he did? Are there parts of the research you feel were acceptable and other parts that were not? Whatever you feel in the matter, you are sure to find others who disagree with you.

"Welfare Study Withholds Benefits from 800 Texans"

That was the front-page headline that greeted readers of the Sunday, February 11, 1990, edition of the *Dallas Morning News.* Then they read the following: "Thousands of poor people in Texas and several other states are unwitting subjects in a federal experiment that denies some government help to a portion of them to see how well they live without it."

This was pretty strong stuff, and soon the story was covered on one of the national TV networks. Let's examine it further for our third illustration.

The Texas Department of Human Services received federal money to test the effectiveness of a pilot program that had been designed to wean people from the state's welfare rolls. The program was targeted to welfare recipients who found jobs or job training. Before the new program was implemented, these recipients received four months of free medical care and some child care after they left the welfare rolls. The new program extended these benefits to one year of Medicaid coverage and subsidized child care.

The rationale was that extending the duration of the benefits would encourage recipients to accept and keep entry-level jobs that were unlikely to offer immediate medical insurance or child care.

The federal agency that granted the money attached an important condition: Receiving states were required to conduct a scientifically rigorous experiment to measure the program's effectiveness in attaining its goal of weaning people from welfare. Some federal officials insisted that this requirement entailed randomly assigning some people to a control group that would be denied the new (extended) program and would instead be kept on the old program (just four months of benefits). The point of this was to maximize the likelihood that the recipient group (the experimental group) and the nonrecipient (control) group were equivalent in all relevant ways except for the receipt of the new program. If they were, and if the recipient group was weaned from welfare to a greater extent than the nonrecipient group, then it could be safely inferred that the new program, and not something else, caused the successful outcome. (We will examine this logic further in Chapters 10 and 11.)

If you have read many journal articles reporting on experimental studies, you are probably aware that many of them randomly assign about half of their participants to the experimental group and the other half to the control group. This routine procedure denies the experimental condition to approximately one-half of the participants. The Texas experiment was designed to include all eligible welfare recipients statewide, assigning 90 percent of them to the experimental group and 10 percent to the control group. Thus, only 10 percent of the participants, which in this study amounted to 800 people, would be denied the new benefits if they found jobs. Although this seems more humane than denying benefits to 50 percent of the participants, the newspaper account characterized the 800 people in the control group as "unlucky Texans" who seemed to be unfairly left out of a program that was extending benefits to everyone else who was eligible statewide and who numbered in the many thousands. Moreover, the newspaper report noted that the 800 control participants would be denied the new program for two years to provide ample time to compare outcomes between the two groups. To boot, these 800 "unlucky Texans" were not to be informed of the new program or of the experiment. They were to be told of only the normal four-month coverage.

Advocates of the experiment defended this design, arguing that the control group would not be denied benefits. They would receive routine benefits, and the new benefits would not have been available for anyone in the first place unless a small group was randomly assigned to the routine policy. In other words, the whole point of the new benefits was to test a new welfare policy, not merely to implement one. The defenders further argued that the design was justified by the need to test for unintended negative effects of the new program, such as the possibility that some businesses might drop their child care or insurance coverage for employees, knowing that the new program was extending these benefits. That, in turn, they argued, could impel low-paid employees in those businesses to quit their jobs and go on welfare. By going on welfare and then getting new jobs, they would become eligible for the government's extended benefits, and this would make the welfare program more expensive.

Critics of the study, on the other hand, argued that it violated federal ethics standards such as voluntary participation and informed consent. Anyone in the study must be informed about it and all its consequences and must have the option to refuse to participate. One national think tank expert on ethics likened the experiment to the Tuskegee syphilis study (which we discussed earlier), saying, "It's really not that different." He further asserted, "People ought not to be treated like things, even if what you get is good information."

In the aftermath of such criticism, Texas state officials decided to try to convince the federal government to rescind the control group requirement so that the state could extend the new benefits to the 800 people in the control group. Instead of using a control group design, they wanted to extend benefits to everyone and find statistical procedures that would help ferret out program defects (a design that might have value, but which would be less conclusive as to what really causes what, as we will see in later chapters). They also decided to send a letter to the control group members that explained their special status.

Two days after the *Dallas Morning News* broke this story, it published a follow-up article reporting that the secretary of the U.S. Department of Health and Human Services, in response to the first news accounts, instructed his staff to cooperate with Texas welfare officials so that the project design would no longer deny the new program to the 800 control group members. Do you agree with his decision? Did the potential benefits of this experiment justify its controversial ethical practices?

A control group probably could not have been formed had recipients been given the right to refuse to participate. Who would want to be denied extended free medical and child care benefits? Assuming it were possible, however, would that influence your opinion of the justification for denying them the new program? Do you agree with the expert who claimed that this study, in its original design, was not that different from the Tuskegee syphilis study? Instead of assigning 90 percent of the participants to the experimental group, what if the study assigned only 10 percent to it? That way, the 800 assigned to the experimental group may have been deemed "lucky Texans," and the rest might not have been perceived as a small group of unlucky souls who were being discriminated against. In other words, perhaps there would have been fewer objections if the state had merely a small amount of funds to test out a new program on a lucky few. Do you think that would have changed the reaction? Would that influence your own perception of the ethical justification for the experiment?

Social Worker Submits Bogus Article to Test Journal Bias

Our final illustration is the first well-publicized ethical controversy to involve a social worker's research. National news media ran several stories on it, including two stories in the *New York Times* (September 27, 1988, pp. 21, 25; and April 4, 1989, p. 21) and one in the *Chronicle of Higher Education* (November 2, 1988, pp. A1, A7). The information for this illustration was drawn primarily from those three news articles.

The social worker, William Epstein, started with the hypothesis that journal editors were biased in favor of publishing research articles whose findings confirmed the effectiveness of evaluated social work interventions and biased against publishing research articles whose findings failed to support the effectiveness of tested interventions. To test his hypothesis, Epstein fabricated a fictitious study that pretended to evaluate the effectiveness of a social work intervention designed to alleviate the symptoms of asthmatic children. (Some might deem asthma to be a psychosomatic illness.) Epstein concocted two versions of the bogus study. In one version, he fabricated findings that supported the effectiveness of the intervention; in the other version, he fabricated data that found the intervention to be ineffective.

Epstein submitted the fictitious article to 146 journals, including 33 social work journals and 113 journals in allied fields. Half of the journals received the version that supported the effectiveness of the intervention, and half received the other version. Epstein did not enter his own name as author of his fabricated article, instead using a pair of fictitious names.

In his real study, Epstein interpreted his findings as providing some support for his hypothesis: Journal editors were biased in favor of publishing the version of the bogus article with positive findings and against publishing the version with negative findings. Among the social work journals, for example, eight accepted the positive version and only four accepted the negative version. Nine journals rejected the positive version, and 12 rejected the negative version. Among the journals in allied fields, 53 percent accepted the positive version, and only 14 percent accepted the negative version. A statistical analysis indicated that the degree of support these data provided for Epstein's hypothesis was "tentative" and not statistically significant.

After being notified of the acceptance or rejection of his fictitious article, Epstein informed each journal of the real nature of his study. Later, he submitted a true article under his own name that reported his real study to the *Social Service Review,* a prestigious social work journal. That journal rejected publication of his real study, and its editor, John Schuerman, led a small group of editors who filed a formal complaint against Epstein with the National Association of Social Workers. The complaint charged Epstein with unethical conduct on two counts: (1) deceiving the journal editors who reviewed the bogus article, and (2) failing to obtain their informed consent to participate voluntarily in the study.

Schuerman, a social work professor at the University of Chicago and an author of some highly regarded research articles, recognized that sometimes the benefits of a study may warrant deceiving subjects and not obtaining their informed consent to participate. But he argued that in Epstein's (real) study, the benefits did not outweigh the time and money costs incurred for many editors and reviewers to read and critique the bogus article and staff members to process it.

When an article is submitted for publication in a professional social work journal, it is usually assigned to several volunteer reviewers, usually social work faculty members who do not get reimbursed for their review work. The reviewers do not know who the author is so that the review will be fair and unbiased. Each reviewer is expected to read each article

carefully, perhaps two or three times, recommend to the journal editor whether the article should be published, and develop specific suggestions to the author for improving the article. The journal editor also is usually a faculty member volunteering his or her own time as an expected part of one's professional duties as an academician. Schuerman noted that, in addition to the time and money costs mentioned, Epstein's experiment had exacted an emotional cost: "the chagrin and embarrassment of those editors who accepted the [bogus] article" (*New York Times,* September 27, 1988, p. 25).

Epstein countered that journal editors are not the ones to judge whether the benefits of his (real) study justified its costs. In his view, the editors are predisposed to value their own costs dearly. Thus, they are unlikely to judge any study that would deceive them as being worth those costs. Epstein argued that the journals are public entities with public responsibilities. Testing whether they are biased in deciding what to publish warranted his deception and the lack of informed consent to participate, actions that were necessary to test for their bias.

One might argue that if journal editors and reviewers are biased against publishing studies that fail to confirm the effectiveness of tested interventions, then the field may not learn that certain worthless interventions in vogue are not helping clients. Moreover, if several studies disagree about the effectiveness of an intervention, and only those that confirm its effectiveness get published, then an imbalanced and selective set of replications conceivably might be disseminated to the field. This would mislead the field into believing that an intervention is yielding consistently favorable outcomes when, in fact, it is not. This could hinder the efforts of social workers to provide the most effective services to their clients—and therefore ultimately reduce the degree to which we enhance clients' well-being.

One could argue that Epstein's study could have been done ethically if he had forewarned editors that they might be receiving a bogus paper within a year and obtained their consent to participate in the study without knowing the specifics of the paper. An opposing viewpoint is that such a warning might affect the phenomenon being studied, tipping off the reviewers in a manner that predisposes them to be on guard not to reveal a real bias that actually does influence their publication decisions.

Some scholars who have expressed views somewhat sympathetic of Epstein's thesis have argued that journal editors and reviewers exert great influence on our scientific and professional knowledge base and therefore need to have their policies and procedures investigated. Schuerman, who filed the charges against Epstein, agreed with this view, but he argued that Epstein's study was not an ethical way to conduct such an investigation.

In an editorial in the March 1989 issue of the *Social Service Review,* Schuerman elaborated his position. He noted that journals have low budgets and small staffs and depend heavily on volunteer reviewers "who see their efforts as a professional responsibility" and receive little personal or professional benefit for their work (p. 3). He also portrayed Epstein's research as "badly conducted," citing several design flaws that he deemed to be so serious that they render the anticipated benefits of the Epstein study as minimal, and not worth its aforementioned costs. Schuerman also cited Epstein as admitting to serious statistical limitations in his study and to characterizing his research as only exploratory. "It is at this point that issues of research design and research ethics come together," Schuerman argued (p. 3). In other words, Schuerman's point is that the methodological quality of a study's research design can bear on its justification for violating ethical principles. If the study is so poorly designed that its findings have little value, it becomes more difficult to justify the ethical violations of the study on the grounds that its findings are so beneficial.

The initial ruling of the ethics board of the National Association of Social Workers was that Epstein had indeed violated research rules associated with deception and failure to get informed consent. It could have invoked serious sanctions against Epstein, including permanent revocation of his membership in the professional association and referral of the case to a state licensing board for additional sanctions. But Epstein was permitted to appeal the decision before any disciplinary action was taken. His appeal was upheld by the executive committee of the association, which concluded that his research did not violate its ethical rules. The committee exonerated Epstein, ruling that the case was a "disagreement about proper research methodology," not a breach of ethics. It did not publicize additional details of its rationale for upholding Epstein's appeal and reversing the initial ruling. Epstein speculated that the reversal may have been influenced by the publicity the case received in the press.

If Epstein's speculation is valid, then one might wonder whether the reversal was prompted by the

executive committee's sincere judgment that the research really did not violate ethical rules or by expediency considerations, perhaps connected to concerns about potential future publicity or other costs. What do you think? What ideas do you have about the two rulings and about the ethical justification for Epstein's study? Which ruling do you agree with? Do you agree with Schuerman's contention that methodological flaws in the research design can bear on research ethics? Is it possible to agree with Schuerman on that issue and still agree with the executive committee that this case was a disagreement about methodology and not a breach of ethics? If, just for the sake of discussion, you assume that Epstein's study had serious design flaws that prevented the possibility of obtaining conclusive findings, then how would that assumption affect your position on the ethical justification for Epstein's study?

Suppose Epstein had obtained the advance approval of an IRB at his university for his study using a bogus article to test for journal bias. (Epstein told us that his university had no IRB at that time, but that he did obtain informal feedback from some of his colleagues, who agreed that his study was ethical.) Had Epstein been able to obtain an IRB approval, even those who later depicted his study as unethical would have had no basis for charging him with unethical conduct. Instead, their complaint would have been with the IRB if it had approved his study. By not making the decision himself—and thus avoiding the chances that his own vested interests or ego involvement, if any, could have influenced his decision—Epstein would have been operating responsibly, regardless of how some might later judge the ethics of the research method. Even if we deem Epstein's study to have been ethical, we can say that obtaining IRB approval (had it been possible for him to do so) would have protected Epstein from any ensuing ethical controversy. The case has an epilogue: Epstein completed a replication of his earlier study (Epstein, 2004). This time he obtained permission from his university's IRB to waive informed consent.

BIAS AND INSENSITIVITY REGARDING GENDER AND CULTURE

In several chapters of this book, you will encounter examples of how gender and cultural bias and insensitivity can hinder the methodological quality of a study and therefore the validity of its findings. Much has been written about these problems in recent years, and some theorists have suggested that when researchers conduct studies in a manner that may be insensitive to issues of women or culture, they are not just committing methodological errors but also going awry ethically.

The question of ethics arises because some studies are perceived to perpetuate harm to women and minorities. Feminist and minority scholars have suggested a number of ways that such harm can be done. Interviewers who are culturally insensitive can offend minority respondents. If they conduct their studies in culturally insensitive ways, then their findings may yield implications for action that ignore the needs and realities of minorities, may incorrectly (and perhaps stereotypically) portray minorities, or may inappropriately generalize in an unhelpful way. By the same token, studies with gender bias or insensitivity may be seen as perpetuating a male-dominated world or failing to consider the potentially different implications for men and women in one's research.

Various authors have recommended ways to avoid cultural and gender bias and insensitivity in one's research. We will cover these recommendations in greater depth in later chapters on methodology—especially Chapter 5 on culturally competent research—but we'll also mention them here in light of their potential ethical relevance. Among the more commonly recommended guidelines regarding research on minorities are the following:

- Spend some time immersing yourself directly in the culture of the minority group(s) that will be included in your study (for example, using qualitative research methods described in Chapters 17 and 18) before finalizing your research design.
- Engage minority scholars and community representatives in the formulation of the research problem and in all the stages of the research to ensure that the research is responsive to the needs and perspectives of minorities.
- Involve representatives of minority groups who will be studied in the development of the research design and measurement instruments.
- Do not automatically assume that instruments successfully used in prior studies of one ethnic group can yield valid information when applied to other ethnic groups.
- Use culturally sensitive language in your measures, perhaps including a non-English translation.

- Use in-depth pretesting of your measures to correct problematic language and flaws in translation.
- Use bilingual interviewers when necessary.
- Be attuned to the potential need to use minority interviewers instead of nonminorities to interview minority respondents.
- In analyzing your data, look for ways in which the findings may differ among different categories of ethnicity.
- Avoid an unwarranted focus exclusively on the deficits of minorities; perhaps focus primarily on their strengths.
- In addition to looking for differences among different ethnic groups, look for differences among varying levels of acculturation within specific minority groups.
- Assess your own cross-cultural competence.
- Look for cross-cultural studies in your literature review.
- Use specialized sampling strategies (discussed in Chapters 5 and 14) that are geared toward adequately representing minority groups.

In her book *Nonsexist Research Methods,* Margrit Eichler (1988) recommended the following feminist guidelines to avoid gender bias and insensitivity in one's research:

- If a study is done on only one gender, make that clear in the title and the narrative and do not generalize the findings to the other gender.
- Do not use sexist language or concepts (for example, males referred to as "head of household," and females referred to as "spouses").
- Avoid using a double standard in framing the research question (such as looking at the work–parenthood conflict for mothers but not for fathers).
- Do not overemphasize male-dominated activities in research instruments (such as by assessing social functioning primarily in terms of career activities and neglecting activities in homemaking and child rearing).
- In analyzing your data, look for ways in which the findings might differ for men and women.
- Do not assume that measurement instruments used successfully with males are automatically valid for women.
- Be sure to report the proportion of males and females in your study sample.

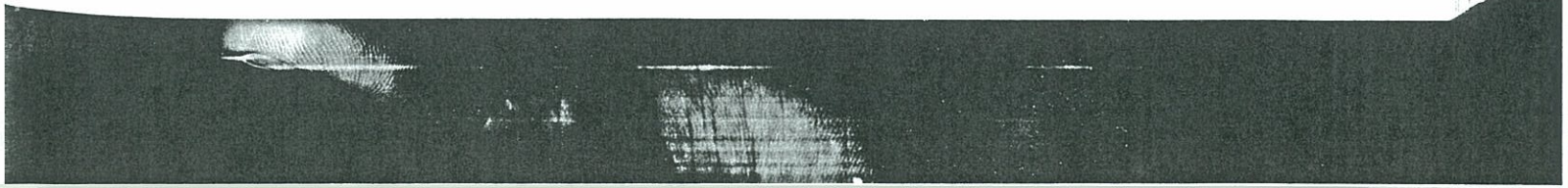
THE POLITICS OF SOCIAL WORK RESEARCH

At this point, you may have gleaned that a fine line can be found between ethical and political issues in social work research. Both ethics and politics hinge on ideological points of view. What is unacceptable from one point of view may be acceptable from another. Thus, we will see that people disagree on political aspects of research just as they disagree on ethical ones. As we change topics now, we will distinguish ethical from political issues in two ways.

First, although ethics and politics are often closely intertwined, the ethics of social work research deals more with the methods employed, whereas political issues are more concerned with the practical costs and use of research. Thus, for example, some social workers raise ethical objections to experiments that evaluate the effectiveness of social work services by providing those services to one group of clients while delaying their provision to another group of clients. Those who voice these objections say that the harm done to clients in delaying service provision outweighs the benefits to be derived from evaluating the effectiveness of those services.

A political objection, on the other hand, might be that if the results of the evaluation were to suggest that the services were not effective, then those negative results might hurt agency funding. Another political objection might be that withholding services would reduce the amount of fees for service or third-party payments received, not to mention the bad publicity that would be risked regarding agency "neglect" of people in need.

Second, ethical aspects can be distinguished from political aspects of social work research because there are no formal codes of accepted political conduct that are comparable to the codes of ethical conduct we discussed earlier. Although some ethical norms have political aspects—for example, not harming subjects clearly relates to our protection of civil liberties—no one has developed a set of political norms that can be agreed on by social work researchers. The only partial exception to the lack of political norms is in the generally accepted view that a researcher's personal political orientation should not interfere with or unduly influence his or her scientific research. It would be considered improper for you to use shoddy techniques or lie about your research as a way to further your political views. As you can imagine, however, studies are often enough attacked for allegedly violating this norm.



Objectivity and Ideology

In Chapter 3, we suggested that social research can never be totally objective, because researchers are humanly subjective. Science attempts to achieve objectivity by using accepted research techniques that are intended to arrive at the same results, regardless of the subjective views of the scientists who use them. Social scientists are further urged to seek facts, regardless of how those facts accord with their cherished beliefs or personal politics.

But many scholars do not believe that social research is ever entirely value-free. They argue that values can influence any phase of the research process, such as the selection of a research question or sample or the definition of a variable. For example, planners working for a state bureaucracy that is researching the effectiveness of a new state program or policy may focus the research on whether the new approach saves the state money, such as when a new case management program reduces state hospitalization costs for its mentally ill citizens. In their zeal to meet budget-balancing priorities, planners may not think to study indicators of client well-being. Perhaps many people in need of hospitalization are worse off under the new program, for example. Clinical researchers, on the other hand, may evaluate the effectiveness of the new program in terms of its effects on the symptomatology or quality of life of the mentally ill individuals, perhaps believing that those concerns are more important than saving taxpayer money on services that are already underfunded and inadequate. In their zeal to maximize client well-being, they may not think to examine the program costs that are required to produce specific increments of benefit to clients.

In another example, researchers of homelessness may be influenced by their values in the way they define homelessness, which in turn influences whom they include in their sample of homeless individuals. Do the homeless include only people living in the streets? Or do they also include people "doubling up" with friends or relatives or living in substandard temporary quarters who cannot find a decent place they can afford? It is difficult to make such decisions independently of our values. Researchers who have been active in social action efforts to alleviate homelessness may be predisposed to choose the broader definition, which will indicate a greater number of the homeless; researchers who believe social welfare spending is wasteful and incurs too much dependency among the poor may be predisposed to choose the narrower definition.

Scholars who believe that social research is never really value-free typically recommend that we should be aware of and describe our values upfront rather than kid ourselves or others that we are completely objective. Indeed, not all social scientists agree that researchers should try to separate their values from their research activities. Some, such as those whose views reflect the critical social science paradigm (as discussed in Chapter 3), argue that social science and social action cannot and should not be separated.

Social work has a long tradition of using research as a tool to try to make society more humane. Zimbalist (1977), for example, describes how the profession embraced the social survey movement at the turn of the 20th century as a way to convince society to enact environmental reform to alleviate a host of urban problems. In its overriding concern to spur social reform, the social survey movement was frequently selective in what facts it would present, attempting to "make a case" rather than providing a scientifically disciplined and balanced presentation and interpretation of data.

Social work researchers today may attempt to be more objective than they were a century ago, but even contemporary positivist researchers often hope that their research findings will spur social action. There is nothing wrong with viewing research as a tool that can be used to alleviate human suffering and promote social welfare. Indeed, in the social work profession, that is what research is all about. From a scientific standpoint, however, it is one thing to let our values spur us to undertake specific research projects in the hope that the truth we discover will foster the achievement of humanitarian aims. It is quite another to let our values or ideological beliefs spur us to hide from or distort the truth by biasing the way we conduct our research or interpret its findings. Attempting to be completely objective and value-free in the way we conduct research is an impossible ideal, and it is risky to kid ourselves into thinking that we are completely neutral. Contemporary positivists, argue, however, that this does not mean that we should not try to keep our beliefs from distorting our pursuit of truth. Being aware of our biases throughout all phases of our research helps us minimize their impact on our work, and being up-front in describing our predilections to others better prepares them to evaluate the validity of our findings.

You may find this a bit unsettling. How will we ever know what's true if the goal of being completely objective is so hard to attain and if we are constantly

producing new research that disagrees with previous research? In Chapter 1, we noted that science is an open-ended enterprise in which conclusions are constantly being modified. Inquiry on a given topic is never completed, and the eventual overturning of established theories is an accepted fact of life. In light of this, many social work practitioners may simply opt to be guided exclusively by tradition and authority. Rather than use research findings to help guide their practice (in keeping with the evidence-based practice process), they merely attempt to conform to the traditional ways of operating in their particular agency or to the ordinations of prestigious, experienced practitioners whom they respect. However, according to NASW's Code of Ethics, refusing to utilize research to guide their practice is unethical. Moreover, they should realize that various practice authorities themselves are unlikely to be completely objective.

Social Research and Race

In light of the foregoing discussion, you may not be surprised to learn that some social science research studies have stimulated considerable controversy about whether their findings were merely intrusions of a researcher's own political values. Nowhere have social research and politics been more controversially intertwined than in the area of race relations.

For the most part, social scientists during the 20th century supported the cause of African American equality in the United States. Many were actively involved in the civil rights movement, some more radically than others. Thus, social scientists were able to draw research conclusions that support the cause of equality without fear of criticism from colleagues. To recognize the solidity of the general social science position in the matter of equality, we need to examine only a few research projects that have produced conclusions that disagree with the predominant ideological position.

Most social scientists—overtly, at least—supported the end of even de facto school segregation. Thus, an immediate and heated controversy was provoked in 1966 when James Coleman, a respected sociologist, published the results of a major national study of race and education. Contrary to general agreement, Coleman found little difference in academic performance between African American students attending integrated schools and those attending segregated ones. Indeed, such obvious things as libraries, laboratory facilities, and high expenditures per student made little difference. Instead, Coleman reported that family and neighborhood factors had the most influence on academic achievement. Coleman's findings were not well received by many of the social scientists who had been active in the civil rights movement. Some scholars criticized Coleman's work on methodological grounds, but many others objected hotly on the grounds that the findings would have segregationist political consequences.

Another example of political controversy surrounding social research in connection with race concerns the issue of IQ scores of black and white people. In 1969, Arthur Jensen, a Harvard psychologist, was asked to prepare an article for the *Harvard Educational Review* that would examine the data on racial differences in IQ test results (Jensen, 1969). In the article, Jensen concluded that genetic differences between African Americans and Caucasians accounted for the lower average IQ scores of African Americans. He became so identified with that position that he appeared on college campuses across the country discussing it.

Jensen's position was attacked on numerous methodological bases. It was charged that many of the data on which Jensen's conclusion was based were inadequate and sloppy—there are many IQ tests, some worse than others. Similarly, critics argued that Jensen had not sufficiently accounted for social-environment factors. Other social scientists raised other appropriate methodological objections.

Beyond the scientific critique, however, Jensen was condemned by many as a racist. He was booed, and his public presentations were drowned out by hostile crowds. Jensen's reception by several university audiences was not significantly different from the reception received by abolitionists a century before, when the prevailing opinion favored leaving the institution of slavery intact.

A similar reaction erupted in response to a book titled *The Bell Curve,* published in 1994 and coauthored by Charles Murray, a sociologist known as a leading thinker on the political right, and the late Richard J. Herrnstein, a psychologist and distinguished professor at Harvard University. A small portion of the lengthy book argues that ethnic differences in intelligence can be attributed in part (but not exclusively) to genetic factors.

In their book, Murray and Herrnstein see intelligence as a crucial factor that influences whether Americans will prosper or wind up in an underclass culture of poverty and other social ills. Based on the thesis that intelligence is so hard to change, the book

recommends against spending money on a variety of social programs, including those aimed at improving the intellectual performance of disadvantaged youths.

Critics have pointed to serious methodological shortcomings in the procedures and conclusions in the Murray and Herrnstein study. But as with the earlier controversy involving Jensen, what is most germane to this chapter is not the methodological critique of *The Bell Curve,* but its political condemnation. When the book first appeared, its early critics gave more attention to political objections than to the study's serious methodological shortcomings. It was attacked in a *Boston Globe* editorial before it was even published. The *Washington Post* reported that former Education Secretary William Bennett, a conservative supporter and friend of Murray, strongly praised the book but was made nervous by the section on race and intelligence. Because of that section, Bennett reportedly characterized Murray as a "marked man."

New Republic magazine devoted its October 31, 1994, issue to the book. The issue contains a 10-page article by Murray and Herrnstein, based on the section of their book that dealt with intelligence and genetics. Preceding that article are 17 pages of editorials by 20 different authors about both *The Bell Curve* and Murray and Herrnstein's *New Republic* article. Some of the editorials debate whether the magazine was ethical in even considering publishing the article, and most sharply attack the article or criticize the magazine's decision to publish it. One editorial depicts Murray and Herrnstein as dishonest. Another portrays them as seeking to justify oppression. Others liken them to racists trying to justify their racism or to bigots practicing pseudoscientific racism. One harsher editorial, titled "Neo-Nazis," implies that the relevant chapter from Murray and Herrnstein's book is "a chilly synthesis" of the findings of previous works published by neo-Nazis.

In an editorial that justified the decision to publish the Murray and Herrnstein article on grounds of free inquiry, the magazine's editor argued that the burden of proof for suppressing debate on the topic rests with those who seek to suppress the debate. The editorial argues for judging the issue on scientific and logical grounds, not tarring and feathering the authors by impugning their motives or by associating them with Nazis. The editorial also responds to critics who claim that *The Bell Curve* hurts the feelings of African Americans, especially African American children, who don't want to be called genetically inferior. The editor depicts the view that African Americans are vulnerable people who must be shielded from free and open intellectual exchange as itself inherently racist.

Many social scientists limited their objections to the Coleman, Jensen, and Murray and Herrnstein research to scientific and methodological grounds. The purpose of our account, however, is to point out that political ideology often gets involved in matters of social research. Although the abstract model of science is divorced from ideology, the practice of science is not.

When political and ideological forces restrict scientific inquiry in one area, this can have unfortunate spin-off effects that restrict needed inquiry in related areas. For example, in 1991 Lovell Jones, director of Experimental Gynecology–Endocrinology at the University of Texas's M. D. Anderson Cancer Center, expressed concern regarding the dearth of health research about the higher rate of mortality seen in African American women with breast cancer as compared to Caucasian women with breast cancer. Jones postulated that one plausible factor that might contribute to the higher mortality rate among African American women is that they have more breast tumors that are "estrogen receptor negative," which means that those tumors tend to be more aggressive. Jones found it striking that there had been no concrete studies to investigate this possibility; based on feedback he had received from Caucasian research colleagues, he thought he knew why. His colleagues told him that they did not want to pursue this line of inquiry because it would be too controversial politically. They said the research would have to delve into racial differences in genetic predispositions to breast tumors. They feared that they would therefore be accused, like Jensen was, of racial bias—if not for their own findings on breast tumors, then for making it easier for other investigators to study more politically sensitive differences in genetic predispositions between African Americans and whites (differences connected to intelligence, for example).

Jones also observed that for 10 years (as of 1991) we had known that Caucasian women with a family history of breast cancer have a higher risk of developing breast cancer than do Caucasian women with no family history. Jones reasoned that the field should have quickly followed up this research by investigating whether the same holds true for African American women with and without family histories of breast cancer. But not until 10 years after the research on

Caucasian women first appeared did the first study on African American women come out. Jones attributed this time lapse to the political risk that faced researchers in conducting such an investigation; the researchers feared that if they were to find that the risk of African American women getting breast cancer is higher than that of Caucasian women, they would be attacked as racists.

Jones further recounted how he was once told by a staff member of a national news program that a spokesperson for the National Cancer Institute suggested that they would prefer that the word *genetics* not be used in commenting on cancer among African Americans. In a somewhat related incident, Jones recalled how he once wrote an editorial for a prominent newspaper, an editorial that discussed cancer among minority populations. The paper's editor called him to say that the paper could not run the editorial because it would be accused of racial bias if it did. But when the editor learned that Jones was African American, he said, "Well then, we can use it."

Jones's comments* illustrate how politically rooted taboos against certain lines of inquiry may do a disservice to the very people they seek to protect. What is your opinion about such taboos? Are some or all of them justified? Or is the benefit of ensuring that some research findings will not be misused for harmful purposes outweighed by the risk that such taboos will keep others from conducting much-needed research in related areas?

Main Points

- Social work research projects are likely to be shaped not only by technical scientific considerations but also by administrative, ethical, and political considerations.
- What's ethically "right" and "wrong" in research is ultimately a matter of what people agree is right and wrong.
- Any agency wishing to receive federal research support must establish an Institutional Review Board (IRB) to review all research proposals involving human subjects and rule on their ethics.
- Scientists agree that participation in research should, as a general norm, be voluntary. This norm, however, can conflict with the scientific need for generalizability.
- Probably all scientists agree that research should not harm those who participate in it, unless the participants willingly and knowingly accept the risks of harm.
- *Anonymity* refers to the situation in which even the researcher cannot identify an individual by the specific information that has been supplied.
- *Confidentiality* refers to the situation in which the researcher—although knowing which data describe which participants—agrees to keep that information confidential.
- In some instances, the long-term benefits of a study are thought to outweigh the violation of certain ethical norms. But determining whether a study's ends justify its means is a difficult and often highly subjective process. Nowadays, IRBs make such determinations in approving studies.
- Certificates of Confidentiality protect the confidentiality of research subject data against forced disclosure by the police and other authorities.
- IRBs require education on the protection of human research participants for each individual investigator and research assistant working on studies involving human subjects.
- Federal regulations allow IRBs to grant exemptions to certain kinds of studies. Exempt studies receive an expedited review.
- Some IRB panelists at times can be overzealous in refusing to approve valuable research projects whose benefits far outweigh their minimal risks of harm.
- Bias and insensitivity about gender and culture have become ethical issues for many social scientists.
- Guidelines have been proposed by feminist and other scholars.
- Although science is neutral on political matters, scientists are not.
- Even though the norms of science cannot force individual scientists to give up their personal values,

*Lovell Jones's comments were presented in part at the Texas Minority Health Strategic Planning Conference, Austin, Texas, July 18, 1991, in his presentation titled "The Impact of Cancer on the Health Status of Minorities in Texas." Jones elaborated on his conference remarks in a telephone conversation with Allen Rubin on July 25, 1991. Some of the material included in his comments is covered in Jerome Wilson, "Cancer Incidence and Mortality Differences of Black and White Americans: A Role for Biomarkers," in Lovell Jones (ed.), *Minorities and Cancer*, 1989, Springer Verlag, pp. 5–20.

the use of accepted scientific practices provides a safeguard against "scientific" findings being the product of bias alone.

• Ideological priorities can restrict inquiry out of a fear that certain truths can be misperceived or misused in a manner that will harm certain vulnerable groups; this restriction can lead to incomplete or distorted knowledge building that risks harming the people it seeks to protect.

Review Questions and Exercises

1. Suppose a social work researcher decides to interview children who were placed for adoption in infancy by their biological parents. The interviewer will focus on their feelings about someday meeting their biological parents. Discuss the ethical problems the researcher would face and how those might be avoided.

2. Suppose a researcher personally opposed to transracial adoption wants to conduct an interview survey to explore the impact of transracial adoption on the self-images of adoptees. Discuss the personal involvement problems he or she would face and how those might be avoided.

3. Consider the following real and hypothetical research situations. Identify the ethical component in each. How do you feel about it? Do you feel the procedures described are ultimately acceptable or unacceptable? It might be useful to discuss some of these with classmates.

a. A social work professor asks students in a social policy class to complete questionnaires that the instructor will analyze and use in preparing a journal article for publication.

b. After a field study of a demonstration of civil disobedience, law enforcement officials demand that the researcher identify those people who were observed breaking the law. Rather than risk arrest as an accomplice after the fact, the researcher complies.

c. After completing the final draft of a book reporting a research project, the researcher and author discovers that 25 of the 2,000 survey interviews were falsified by interviewers, but the author chooses to ignore that fact and publishes the book anyway.

d. Researchers obtain a list of abusive parents they wish to study. They contact the parents with the explanation that each has been selected at random from among the general population to take a sampling of public opinion.

e. A social work doctoral student is conducting dissertation research on the disciplinary styles of abusive parents with toddlers. Each parent and his or her child enter a room with toys scattered around it, and the parent is asked to have the child straighten up the toys before playing with them. The parent is told that the researcher will observe the parent–child interactions from behind a one-way mirror.

f. In a study of sexual behavior, the investigator wants to overcome subjects' reluctance to report what they might regard as deviant behavior. To get past their reluctance, subjects are asked the following question: "Everyone masturbates now and then. About how much do you masturbate?"

g. A researcher discovers that 85 percent of the students in a particular university smoke marijuana regularly. Publication of this finding will probably create a furor in the community. Because no extensive analysis of drug use is planned, the researcher decides to ignore the finding and keep it quiet.

h. To test the extent to which social work practitioners may try to save face by expressing clinical views on matters about which they are wholly uninformed, the researcher asks for their clinical opinion about a fictitious practice model.

i. A research questionnaire is circulated among clients as part of their agency's intake forms. Although clients are not told they must complete the questionnaire, the hope is that they will believe they must—thus ensuring a higher completion rate.

j. A participant-observer pretends to join a group that opposes family planning services so she can study it, and she is successfully accepted as a member of the inner planning circle. What should the researcher do if the group makes plans for: (1) a peaceful, though illegal, demonstration against family planning services? (2) the bombing of an abortion clinic during a time when it is sure to be unoccupied?

Internet Exercises

1. Find an article that discusses ethical issues in social research. (You might enter one of the following search terms: *research ethics, informed consent,* or

institutional review boards. Read an article that piques your interest. Write down the bibliographical reference information for the article and summarize the article in a few sentences.

2. Repeat Internet Exercise 1, this time entering the term *research politics* as the search term.

3. Search for *informed consent* and then narrow your search to *research*. Skim the resulting articles and begin to identify groups of people for whom informed consent may be problematic—people who may not be able to give it. Suggest some ways in which the problem might be overcome.

4. Visit the National Institutes of Health (NIH) Human Subjects/Research Ethics Tutorial site at http://cme.cancer.gov/clinicaltrials/learning/humanparticipant-protections.asp. If you take the online tutorial at this site, you will receive a certificate of completion that might come in handy later on if you become a research assistant or need IRB approval for your research. You might also ask your instructor if extra credit could be granted for obtaining this certificate.

5. Search for *Tuskegee syphilis study* and visit some of the sites on that topic. Do the same for the search term *Nazi medical experiments*.

6. Go to the IRBwatch website at www.irbwatch.org. Examine some of the reports of abuses by IRB's. Write down one or two reports that you agree really do represent abuses and one or two that you believe were not really abuses. Briefly state your reasons.

Additional Readings

Jones, James H. 1981. *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press. This remarkable book provides a fascinating account of the Tuskegee study we discussed in this chapter. Its account of the history of that study may astound you, and you may be inspired by the tale of a social worker whose relentless battles over several years with public health authorities and ultimately his willingness to use the press got the study stopped.

Potocky, Miriam, and Antoinette Y. Rodgers-Farmer (eds.). 1998. *Social Work Research with Minority and Oppressed Populations*. New York: Haworth Press. This collection of articles contains innovative ideas for avoiding cultural bias and insensitivity in research with minority and oppressed populations; these groups include people living with HIV or AIDS, low-income urban adolescents, women of color, nonwhite ethnic elders, and African American children.