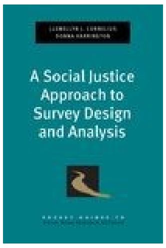

A Social Justice Approach to Survey Design and Analysis

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CHAPTER

2 Preparing to Conduct Social Justice Survey Research

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Abstract

This chapter provides an overview of tasks central to engaging in social justice research. It includes an examination and awareness of the benefits and trade-offs of including the community in all aspects of the research project—running from discussions regarding informed consent (privacy, confidentiality) to questionnaire design and survey administration. It also requires an awareness of the continuum of community involvement in research (ranging from minimum involvement, engaging the community, or involving the community as co-producers/collaborators). The initial design of the study should include developing a sampling frame that strikes a careful balance between including hard-to-reach persons in the sample, while hindering researchers from determining the identity of the respondent, using statistical techniques.

Keywords: informed consent, ethics, community engagement, privacy

Subject: Social Work Research and Evidence-based Practice

Building on the theories and models presented in Chapter 1, this chapter presents social justice research as a transactional process that requires the continuous transformation of both engaging in social justice research and becoming a social justice researcher. Social justice research places a premium on the use of (wherever possible) approaches that foster the intensive involvement of the community in the design and execution of the study. We begin this chapter with a vignette, then develop the foundation for engaging in social justice research and discuss the process of becoming a social justice researcher. This chapter also addresses many of the foundations for social justice research, including ethics, informed consent, and sampling issues.

Vignette: Joint African American, Asian American, and Latino American consumer and researcher engagement in the development of a consumer cultural competency assessment tool[1]

- *Affected populations*: African Americans, Latinos, Vietnamese, persons in recovery
- *Type of inequity/exclusion/discrimination*: Perceived discrimination, governance, exploitation
- *Social justice research issues*: Survey design, questionnaire development, question validation, data analysis, collaboration, transparency, community partnership
- *Case description*: In 1997, Maryland implemented a new managed-care mental health system. Consumer satisfaction, evaluation, and cultural competency were considered high priorities for the new system. Although standardized tools for measuring consumer satisfaction were readily available, no validated, reliable, and standardized tool existed to measure the perception of people from minority groups receiving mental health services. The Mental Hygiene Administration/Maryland Health Partners Cultural Competency Advisory Group (CCAG) formulated a partnership that resulted in the design and dissemination of a consumer assessment tool for cultural competency. The CCAG is an independent advisory group of people in recovery, clinicians, and administrators who advise the state regarding the delivery of public mental health services. In 1997, they began a multi-year process of designing and validating a cultural competency assessment tool. During this time, the CCAG revised the instrument nine times based on concepts from the literature on cultural awareness and consumer satisfaction with services, as well as based on the methods of examining the wording of questions, the placement of questions, and so on.

Following this extensive editing process, the instrument was reviewed by the CCAG, along with several external mental health researchers, to determine whether the wording made sense based on their cultural experiences. This was done to determine the face validity of the instrument. Once the group determined that the instrument was logical and coherent, they proceeded with reciprocal translations of the instrument into Spanish and Vietnamese to target Latino and Vietnamese immigrants. This was followed by the training of survey administrators in the administration of the survey tool and then the administration of the survey to a statewide sample of 238 mental health consumers, with a focus on African American, Afro-Caribbean, Latino, and Vietnamese consumers. This was followed by the computation of a series of correlation matrices and an exploratory factor analysis of the questionnaire to examine the concurrent validity of the instrument. This resulted in the generation of a report from the factor and correlation analyses that noted that the questions in the cultural competency questionnaire aligned ("loaded") on six factors along with the finding that the scale had a ***Cronbach's alpha*** of .92 (Cronbach's alpha is used to examine the internal-consistency reliability of an instrument). Following the publication of the empirical work on the instrument, the CCAG witnessed both acceptance within the consumer and mental health research communities as well as criticism from other mental health researchers who had not been involved in the instrument development process. This led to development of a second study between 2004 and 2010 to document the validity of the original study findings. The core findings of the original assessment were affirmed in this second report.

- *Discussion*: This case highlights multiple issues that are central to the process of becoming a social justice researcher. Critical to the success of this initiative was the creation of a process where persons in recovery carried the same and sometimes even more weight than the investigators in the design and implementation of the project. That led to greater investment by them in the process, as well as greater dissemination of the results of the project across the community. There is also an implied issue about the time required to conduct this type of process; it took eight years for the project to reach its full level of maturation, the first four of which occurred without the involvement of the researchers. This raises the need to be aware of the possibility that social justice research may follow a different timeline and path than the standard academic model.

- *Comments relating to the process of reducing inequities/discrimination, etc.*: This example also provides an example of using ***Community Based Participatory Research*** (CBPR) to foster processes that give voice to experiences of felt stigma and discrimination.

The vignette for this chapter emphasizes the importance of including stakeholders throughout the process of designing and executing research. This inclusiveness focuses on our transforming ourselves so that the work we do is responsive, not just to the academic community, but also to our community stakeholders. This vignette focuses on an ongoing partnership between mental health administrators, mental health consumers, and ↳ p. 26

p. 27 ↳

researchers (called the Cultural Competency Advisory Group [CCAG], which is an advisory group of the Maryland Department of Health and Mental Hygiene, Mental Health Administration).[2] The research part of the CCAG collaboration focused on engaging in a protracted iterative process of designing and validating a consumer-based Cultural Competency Assessment tool. This multi-phase process required the researchers and the administrators and consumers to engage in a co-educational process. For the researchers, this educational process required that they increase their understanding of consumers’ need to feel that their provider respected their cultural background, and the need for consumers to feel that they played a significant role in the clinical management of their behavioral health ↳ p. 28 needs. In order to achieve this goal, it was necessary for the researchers to become immersed in the specific challenges encountered by the mental health consumers as they entered the behavioral healthcare delivery system. For the consumers and administrators, this educational process required that they become immersed in principles of survey design, data analysis, and report dissemination. Although the vignette is an example of a successful researcher–stakeholder research collaboration, the important takeaway message is that by expanding the team involved in the design of a study, you increase the chances that the community becomes involved in the research collaboration process, as well as increase the chances that the findings will be disseminated to a broader audience.

Developing a Foundation for Engaging in Social Justice Research

In the last chapter, it was noted that it is important to examine needs as part of an empirical assessment of social justice. More specifically, this includes examining instrumental, functional, and intrinsic needs. Although one can examine each of these types of needs independently, part of what makes social justice research unique for social workers is the person-in-environment focus. This conceptual approach is transactional and assumes that activities are occurring on multiple levels at the same time and therefore that the social change process needs to address issues on these multiple levels. As it relates to social justice research, determining the instrumental needs (i.e., unmet needs) involves not only measuring the unmet needs; it also involves creating processes where populations become active players in ensuring that their voices are heard.

Within the context of designing and conducting social justice survey research, this transaction process requires attending to both our capacity to hear these unheard voices as well as our capacity to create a transparent communication and collaboration process. This in fact speaks to the ***Emic*** (insider) perspective that is typically used in discussing cultural anthropology. In this case, the Emic perspective focuses on engaging in a process of immersion into the host culture in order to capture the nuances of the host culture, thus reflecting their worldview. It focuses not just on analyzing the information but also on examining the context in which the information is presented. The ***Etic*** (objective outsider) perspective focuses on p. 29 examining a situation from the outside and attempting to generalize ↳ the findings to other, similar situations (Morris, Leung, Ames, & Lickel, 1999). We are suggesting that, in order to move to developing and executing research using the Etic perspective, researchers must first engage in a process wherein they are influenced and shaped by the contingencies that create the need for such a study. Thus, before engaging in social justice research, we may want to develop and undergo our own social justice clarification exercise. We will also want to go through a process that will assist us in clarifying the theories, conceptual models, and frameworks that we choose as the foundation for conducting social justice research.

Where Does One Start?

Self-Preparation for Becoming a Social Justice Researcher

A great example of an academic trailblazer who had to balance witnessing injustices with being a committed empiricist is Rachel Carson, a marine biologist, conservationist, naturalist, and ecologist. Since World War II, synthetic chemical pesticides had been used to control the spread of insects that were damaging crops. In 1956, the U.S. Department of Agriculture pressed forward with its plan to spray nearly a million acres of land in New Jersey, New York, and Pennsylvania with DDT insecticide as part of its plan to eradicate the gypsy moth, in spite of the effects of DDT on fish and wildlife (Carson, 1962). This resulted in a group of Long Island citizens suing the U.S. Department of Agriculture to prevent the spraying of DDT. It also led to the launching of a study by Rachel Carson that documented the extensive effects of synthetic pesticides on crops and animals. As a committed naturalist, her combined love of nature and animals, training in zoology, and reputation as a scientist made Carson the ideal candidate for conducting a study that would fundamentally transform our attitudes about the widespread use of synthetic chemical pesticides and contribute to launching the scientific discipline called *environmentalism* (Doremus & Tarlock, 2005). In her work *Silent Spring*, Carson (1962) summed up her view of the importance of the scientific inquiry process by quoting Carl P. Swanson, who said:

> Any science may be likened to a river. . . . It has its obscure and unpretentious beginning; it quietly stretches along with its rapids; its periods of drought as well as its fullness. It gathers momentum p. 30 with the work of ↳ many investigators as it is fed by other streams of thought; it is deepened and broadened by the concepts and generalizations that are gradually evolved. (Carson, 1962, p. 245)

In addition to documenting the effects of the use of pesticides on nature, Rachel Carson documented the efforts of the federal government to ignore the concerns of activists about the application of environmental pesticide. Carson concluded her study regarding the harmful effects of pesticides with the following warning:

> The control of nature is a phrase conceived in arrogance, born of the Neanderthal age of biology and philosophy, when it was supposed that nature exists for the convenience of man. The concepts and practices of applied entomology for the most part date from that Stone Age of science. It is our alarming misfortune that so primitive a science has armed itself with the most modern and terrible weapons and that in turning them against the insects it has also turned them against the earth. (Carson, 1962, pp. 261–262)

Rachel Carson received the *New York Times* Best Seller book award, the Albert Schweitzer award from Animal Welfare Institute, and the American Academy of Arts and Letters award for her book *Silent Spring.* It remained on the *New York Times*'s bestseller list for 31 weeks. Her findings resulted in the publication of more than 50 newspaper editorials and 20 columns, as well as the introduction of more than 40 bills in state legislatures governing the regulation of pesticide use (Litmans & Miller, 2004; Van Emden & Peakall, 1999). Along with praise for her work came intense criticism. This criticism included verbal abuse, character assassination, and debates regarding whether science should be used for advocacy. Nonetheless, 50 years later her work is still praised (Wharton, 2012).

Carson's scholarship seems to fit the classic quote "No good deed goes unpunished." It serves as a reminder that sometimes the pursuit of social justice research will bring more attention than a publication in a peer review journal. Some may argue that researchers such as Rachel Carson are an exception to the rule. However, in fact, this level of dedication to social justice research may be more normative. For example, disparities research was conducted for decades before its elevation to a national research priority. Likewise, as noted by the case vignette in Chapter 1, the issue of pay equity for women is an old concept, yet we have not achieved the goal of closing the gap. These examples remind us that the motivation for engaging in social justice research is not fame or notoriety; rather, is it commitment to the principles of social justice.

As noted by Rountree and Pomeroy (2010), we may have two roles to perform as researchers: (1) as a front-line practitioner witness to injustices experienced by the oppressed, and (2) as an empiricist who documents these transgressions. These two roles may create a need to balance several issues at once. First, it may require that we clarify what we personally and professionally mean by "social justice." Second, we need to emulate the social justice principles that were presented in the last chapter (or that fit with one's own social justice principles). Third, we need to discover and understand our intention for conducting research in general. Is it our intention to engage in research because we are fascinated with the plight of the population we are studying, or because we have easy access to that population? Are we serving our own interests, or trying to serve those of the population we are asking to participate in the research? Are we prepared to do the work of getting to know how to form a transparent partnership with the community? And, even more important, are we are ready to bear the brunt of criticism or opposition from power brokers who are displeased with our research findings, in spite of the quality of the work? Fourth, we need to conduct the research. Fifth, we need to examine and analyze the data. Finally, we need to report the findings in a socially responsible and just manner.

These issues suggest that becoming a social justice researcher may require a process of self-reflection. It may also require a self-assessment of where you are on a continuum between thinking about becoming such a researcher and engaging in social justice research. A model one can use to think about the process of moving from thinking about change to engaging in a new endeavor is the concept of readiness for change that is part of the Transtheoretical Model of Intentional Behavior Change (DiClemente, Schlundt, & Gemmell, 2004). This model is based on the idea that there are five stages of the change process. DiClemente and colleagues believe that being motivated or ready to perform a behavior is critical to performance and outcome. The five stages of change are:

1. *Precontemplation*, where individuals are not motivated to change;
2. *Contemplation*, where individuals are examining their patterns of behavior; ↳ p. 32
3. *Preparation*, where individuals make a commitment to change and develop a plan and strategy for change;
4. *Action*, where the person implements the behavior change; and
5. *Maintenance*, where the changed behavior is sustained for an extended period of time.

You may start your own process of becoming a social justice researcher by thinking about where you are on the continuum of readiness to change. Are you reading this book because someone told you to (perhaps in the precontemplation stage), because you are examining your own patterns of behavior in terms of research (perhaps in the contemplation stage), or because you are in the process of evaluating your own research to strengthen your use of social justice principles (perhaps in the preparation, action, or maintenance stage)?

Implied in the presentation of the DiClemente and colleagues (2004) model is the notion that change is a developmental process. Therefore, in order to become a social justice researcher, one should recognize that there different stages of becoming a social justice researcher. This self-development may come via reading content that gives us an awareness regarding inequities. It may also come from exposure to the plight of an effected population, and it may also occur via immersion in a community that is affected by an issue. These are all forms of internal developmental processes that may require some continued action and reflection on our part in order to crystallize.

It is this reflective action process that Freire (2000) speaks of in his classic work, *Pedagogy of the Oppressed. Pedagogy of the Oppressed* was originally designed to help teachers understand the power dynamics of the learning process and how they may inadvertently reinforce oppressive values in the name of calling themselves a vehicle for empowering the students. It has been used since then as an approach to help change agents undergo the transformational process required for creating co-learning opportunities with others. Freire summarizes the dilemma of oppression by saying that

> the oppressor consciousness tends to transform everything surrounding it into an object of its domination. The earth, property, production, the creations of people, people themselves, time—everything is reduced to ↳ p. 33 the status of objects at its disposal. In their unrestrained eagerness to possess, the oppressors develop the conviction that it is possible for them to transform everything into objects of their purchasing power; hence their strictly materialistic concept of existence. Money is the measure of all things, and profit the primary goal. For the oppressors, what is worthwhile is to have more—always more—even at the cost of the oppressed having less or having nothing. For them, *to be is to have* and to be the class of the “haves.” (p. 58)
>
> . . . More and more, the oppressors are using science and technology as unquestionably powerful instruments for their purpose: the maintenance of the oppressive order through manipulation and repression. The oppressed, as objects, as “things,” have no purposes except those their oppressors prescribe for them. (p. 60)

He notes that, sometimes unknown to us in our process of engaging oppressed communities, we may directly and other times indirectly create directive processes that keep the disadvantaged at bay. To overcome this tendency, he suggests that the transformation process can only occur when we work in concert with others.

> Our converts, on the other hand, truly desire to transform the unjust order; but because of their background they believe that they must be the executors of the transformation. They[3] talk about the people, but they do not trust them, and trusting the people is the indispensable precondition for revolutionary change. A real humanist can be identified more by his trust in the people, which engages him in their struggle, than by a thousand actions in their favor without that trust. (p. 60)
>
> . . . Revolutionary leaders cannot think *without* the people, nor *for* the people, but only *with* the people. (p. 129)

Freire (2000) notes that, while the transformation process does not change our past, it changes our future, as we are now teammates, working in concert with the oppressed. Freire calls this process “praxis,” wherein we engage in a process of reflective action with the community. It is anticipated that the result of this self-developmental process would be an increased sensitivity to the use of research collaboration models that are partnership-based. These models are explored later in this chapter. ↳ p. 34

Social Justice Research Ethics

Although an exhaustive discussion of research ethics is beyond the scope of this book, we want to address several issues with particular relevance to social justice research. In particular, we highlight issues related to power dynamics and how the institutional review board (IRB) process helps ensure that participation is voluntary (i.e., not coerced), the purpose of the research is clearly stated, and participants’ rights are protected. Many of the principles and practices for human research protections, including IRBs, were developed in response to unjust treatment of research participants. In 1974, the National Research Act (Pub. L. 93–348) was signed into law, creating the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The commission was charged with identifying the underlying basic ethical principles and developing guidelines for conducting research. The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) summarizes the principles identified by the commission and is “a statement of basic ethical principles and guidelines that should assist in resolving the ethical problems that surround the conduct of research with human subjects” (http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html, summary).

The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) identified three basic ethical principles: (1) respect for persons, (2) beneficence, and (3) justice. “Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, Part B.1). The expectations to do no harm, maximize possible benefits, and minimize possible risks come from the principle of beneficence. For the principle of justice, the report states:

> Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of "fairness in distribution" or "what is deserved." An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of conceiving the principle of justice is that equals ↳ ought to be treated equally. However, this statement requires explication. Who is equal and who is unequal? What considerations justify departure from equal distribution? Almost all commentators allow that distinctions based on experience, age, deprivation, competence, merit and position do sometimes constitute criteria justifying differential treatment for certain purposes. It is necessary, then, to explain in what respects people should be treated equally. There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are (1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit. (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, Part B.3)

In their discussion of the principle of justice, the Belmont Report continues:

> Questions of justice have long been associated with social practices such as punishment, taxation and political representation. Until recently these questions have not generally been associated with scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients. Subsequently, the exploitation of unwilling prisoners as research subjects in Nazi concentration camps was condemned as a particularly flagrant injustice. In [the U.S.], in the 1940's, the Tuskegee syphilis study used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available.
>
> Against this historical background, it can be seen how conceptions of justice are relevant to research involving human subjects. For example, the selection of research subjects needs to be scrutinized in order to determine whether some classes (e.g., welfare patients, particular racial ↳ and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied. Finally, whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries of subsequent applications of the research. (Part B.3)

We have quoted at length from the Belmont Report because it provides the foundation and historical context for our current human research protections. In addition, although written more than 30 years ago, their statement about justice is still timely. The Belmont Report also identified three applications: (1) informed consent, (2) assessment of risk and benefits, and (3) selection of participants.

Three issues integral to ***informed consent*** are disclosure of information, voluntariness, and competency (Grisso & Appelbaum, 1998; Moreno, Caplan, & Wolpe, 1998; Palmer & Kaufman, 2003). All three components need to be present for an individual to be able to provide informed consent to participate in research. A person is sufficiently informed to give consent only if he or she knows what the purpose of the study is, what will occur during the study, the potential risks and benefits, any alternatives to participation, and what will happen if he or she does not consent to participate. This consent process should also focus on the use of culturally and linguistically appropriate materials that are easy for the respondent to understand and provide a means for accommodating persons with disabilities as well as persons who are from low-literacy populations. In Chapter 3, we discuss the issue of the cultural context of surveys, including the processes that are involved in ensuring that similar concepts are used in translating surveys into different languages and using approaches that make questions easier to understand for all respondents.

Consent is meaningful only when it is given voluntarily, not coerced. Although researchers may not intentionally coerce someone into participating in a study, it is important to consider factors that may influence a person's decision. For example, large monetary payments for participation may be coercive for
p. 37 low-income participants. Implied in ↳ the discussion regarding the "pedagogy of the oppressed" is the need to become sensitive to the power of the research process itself, particularly as it relates to the ethics of research and participants' free choice of whether to participate or not. Finally, informed consent presupposes that the person who gives consent is competent to do so.

Obtaining informed consent is especially problematic when the unit of analysis is a community, neighborhood, or other organization. Hardina (2004) suggests that the best method for ensuring that most participants agree with an approach is to hold a "meeting in which all members debate risks and benefits of the proposed action and attempt to reach a consensus" (p. 599). This approach can be time-consuming, and there is no guarantee that consensus can be reached; however, "constituents should be fully informed about the consequences of their actions, especially when personal sacrifices (such as job loss, arrest, or social stigma) are great" (Hardina, 2004, p. 599).

Obtaining informed consent can also be challenging when multiple levels of consent are needed. For example, for research with school children it may be necessary to obtain approval and consent from the school district, the individual school(s), classroom teachers, and the children's parents. Once these levels of consent are obtained, then the researcher may also need assent from the individual children to participate. In another example, recruitment in populations whose individual members are reluctant to participate in research may require building trust and obtaining consent from community leaders before recruiting participants. Although the community leaders may not provide written consent, their approval may be necessary to recruit through their organization or to lend legitimacy to the research.

Researchers need to provide potential participants with a clear statement of the possible benefits and risks of participation. Benefits can be at the individual, group, community, or societal level, but (when applicable) it is important to acknowledge that there may be no direct benefit to the participant. In addition, the potential benefits of the research for individual participants or the community should not be overstated. Risks need to be clearly identified so that participants are aware of any possible negative consequences of participation. Personal questions or questions that remind participants of negative events in their lives can
p. 38 be upsetting, and loss of privacy and confidentiality are always potential risks in survey research. ↳

Privacy refers to individuals' right to decide what, if any, information about them is shared with others. ***Confidentiality*** refers to the professional obligation of the researcher not to reveal information received from a research participant without the participant's informed consent. Researchers, especially those who are also social workers, have legal obligations to breach confidentiality under certain circumstances, such as duty to inform if participants threaten harm to themselves or others or in cases of abuse or neglect. Researchers should carefully investigate what their responsibilities are because the limitations and circumstances vary by jurisdiction or location.

Social justice researchers should minimize potential risks to the greatest extent possible. As we will discuss in Chapter 6, there are many ways that the confidentiality of data can be protected. But, in addition, researchers can ensure that interviews or surveys are conducted in private settings and resources or referrals are available if questions may be upsetting for participants. If asking about illegal behaviors, researchers can obtain certificates of confidentiality to protect data from being subpoenaed (see http://www.hhs.gov/ohrp/policy/certconf.html for more information on certificates of confidentiality).

Finally, as highlighted in the quote from the Belmont Report above, participant selection needs to ensure that vulnerable individuals are not selected as participants because they are a "convenient" population to recruit from. Those who are asked to take the risks of participating in research, no matter how minor, should also have the potential to benefit from the findings of the research.

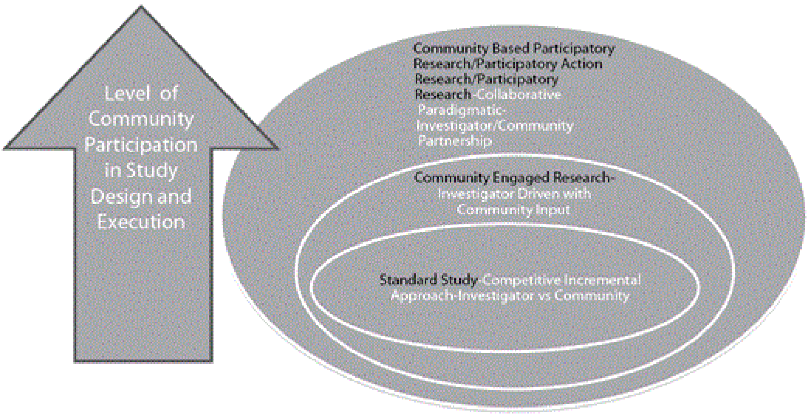
Building Community-Based Partnerships

While the previous sections focused on strategies that support becoming a social justice researcher, this section focuses on another issue—building a partnership for designing the survey and conducting the research. One of the key premises of this book is that you will need to build the conceptual and analytical approach that serves as the platform for conducting social justice research while you are designing the survey instrument and conducting the research. Implied in this activity is a need for transparency with the community[4] regarding the scope and direction of the study. It is also suggested that in the ideal circumstances the process ↳ would involve the formation of a partnership between you and the community. The reason for this premise is that social justice research reflects a need to clarify up front the focus of the study, its expected outcomes, who is involved in the research endeavor, and who owns the data and decides how it is to be used. It is based on the notion that social justice research requires an approach that builds equity and fairness into the discussions regarding the study, the development of key study questions, study design, analyses, study implementation, and so on. In other words, as we interface with the larger community, we must be transparent that we were fair and equitable behind the scenes in the same way we are in developing the partnership with our stakeholders.

Sranko (2011) suggests that we can expect different government and community efforts based on the power dynamics in the process. In analyzing social and environmental movements, Sranko (2011) also suggests that change processes are reflected by four contrasting types of partnerships. In the *competitive incremental* partnership, officials and stakeholders approach a problem based on their self interests, which probably results in only incremental change. *Collaborative incremental* partnerships involve up-front buy-in regarding values, principles, and goals, resulting in a series of self-sustaining activities. Government retains control in *competitive paradigmatic* partnerships, resulting in only narrow changes taking place. Finally, the *collaborative paradigmatic* partnership involves the pursuit of mutual interests and consensus building, resulting in a collaboration that is citizen-centered, where power sharing becomes the norm and government recognizes the need to adapt (Sranko, 2011). Sranko's work suggests that different collaboration processes may result in different outcomes.

Several approaches can be used to foster community involvement (see Figure 2.1 and Table 2.1). Although several terms are presented for these approaches, including ***community based participatory research*** (CBPR), ***participatory research*** (PR), ***participatory action research*** (PAR), and ***community partner participatory research*** (CPPR), they all feature community involvement in the design and execution of a study. These approaches come from a long line of research starting with Kurt Lewin's discussion of action research in 1946 and building on the work of Paulo Freire (1982, 2000), both of which place a premium on the involvement of the community as active agents in the design and execution of research studies. ↳ p. 40

Figure 2.1



Level of Community Involvement Based on Study Design.

Table 2.1 Degree of Community Involvement in the Design and Execution of the Research Study by Stage of the Research Process

	Type of Community Research Approach				
Stages of the Research Process:	**Standard**	**Community-Engaged Research**	**Participatory Research/Participatory Action Research**	**Community Partner Participatory Research**	**Community-Based Participatory Research**
Designing the study question	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive
Developing the questionnaire	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive
Developing the sample design	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive
Developing the data analyses	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive
Executing the analyses	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive
Report writing	Low Intensive	Low thru More Intensive	More Intensive	More Intensive	More Intensive

Dissemination of findings	Researcher Driven	Low thru More Intensive	More Intensive	More Intensive	More Intensive

Sources: Community Engaged Research: Handley, M., Pasick, R., Potter, M., Oliva, G., Goldstein, E., & Nguyen, T. (2010), *Community-Engaged Research: A Quick-Start Guide for Researchers.* From the series *UCSF Clinical and Translational Science Institute (CTSI) Resource Manuals and Guides to Community-Engaged Research*, P. Fleisher, ed. Published by Clinical Translational Science Institute Community Engagement Program, University of California, San Francisco, available at http://ctsi.ucsf.edu/files/CE/guide_for_researchers.pdf. Participatory Research: Cornwall, A., & Jewkes, R. (1995), What is participatory research? *Social Science & Medicine, 41,* 1667–1676 10.1016/0277-9536(95)00127-S . Community Partner Participatory Research: Jones, L., & Wells, K. (2007), Strategies for academic and clinician engagement in community-partnered participatory research, *Journal of the American Medical Association, 297,* 407–410 10.1001/jama.297.4.407 . Community Based Participatory Research: Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998), Review of community-based research: Assessing partnership approaches to improve public health, *Annual Review of Public Health, 19,* 173–202 10.1146/annurev.publhealth.19.1.173 .

Community-involved designs such as those presented in Table 2.1 all pay attention to diversity—including, but not limited to, race, ethnicity, class, gender, and culture—issues in the research collaboration process. In particular, they are sensitive to the power dynamics of the research and the potential for vulnerable populations to be exploited in the research process. Transparency in the design and execution of the study, communication regarding the project planning and decision-making strategies, and the sharing of information and resources are used by these designs to share power and to minimize the researchers' exploitation of the target population.

The vignette presented at the beginning of this chapter focused on the CBPR framework to design and validate a consumer assessment of mental health providers' cultural competency. While the content in the case scenario summarizes the empirical side of the development of the tool, the discussion understates the collaboration process that was critical to the successful development and sustaining of the partnership. As noted above, the partnership was based on a group of 22 African American, Asian American, and Latino mental health consumers and administrators who originally met in 1997 to develop a consumer-based mental health service satisfaction tool. This led to the development of an autonomous nongovernmental advisory group that spent four years building their partnership and exploring the concepts that were related to cultural competency before requesting empirical support in designing a tool to assess cultural competency. Close to 40% of the group members were ↳

↳ consumers. Another 50% of the group members were mental health professionals and administrators. The remaining 10% of the group members were researchers. The presentations within the group, in conferences, and within the public mental health agencies that served these consumers included many direct and frank presentations regarding the lived and felt experiences of stigma and marginalization, how the system overlooked the needs of consumers, and what was needed to solve this problem. The research conversations that took place included discussing the importance of matching the development processes that have taken place with the processes of questionnaire design and analyses. This was a fluid process where the decisions regarding each step of the collaboration process were determined by the Cultural Competency Advisory Group, not the survey methodologist (Arthur et al., 2005; Cornelius et al., 2004).

This process created a venue that assisted consumers in using their experiences related to being under-served and stigmatized by the mental health delivery system to create a tool that can be used to evaluate an aspect of the mental health delivery process. This example highlights the importance of the use of a transactional process to develop a survey instrument. In this case, by "transactional process," we mean that the process was more than just conducting a literature review to identify and develop survey questions, or conducting a factor analysis on behalf of a client. Instead, it involved having intensive sessions with the community about how these measures would and would not meet their priorities for social change, while using standard empirical processes for developing survey questions.

It should be noted that, although this collaboration resulted in the publication of survey findings, it may be more important to choose not to publish findings from a survey in order to maintain the trust that you have developed with a community. In one such example, one of the coauthors was involved in working with the Piscataway Conoy Tribe in developing a community-based survey that examined barriers of access to medical care. The Piscataway Conoy people are the indigenous people of the region we call Maryland today (Sturtevant & Trigger, 1978). Their presence in this region goes back over 11,000 years, yet the Piscataway only recently (2012) received state recognition as a tribe (Rodricks, 2012). The Piscataway Indians face many of the obstacles to participation in American life encountered by other American Indians. Some of the challenges include a lack of access to employment, educational services, and ↳ health care; however, foremost among their challenges was the lack of tribal recognition. In discussing the systematic historical subjugation, exploitation, and domination of American Indians, Ward Churchill indicates that the ability of naming one's destiny is foremost among the priorities of American Indians. "Peoples hold a legal right to decide for themselves the nature of their destiny, such as the larger nations into which they would be arbitrarily lumped if they were relegated to the status of ethnic or racial minority populations" (Churchill, 1994, p. 328). Placed in the context of other tribes in North America, the continued lack of official recognition of the Piscataway left the tribal members with a lack of trust in many of the formal systems and structures in American society.

It was this lack of trust of formal systems or structures that set the stage for community skepticism regarding our intentions as academic researchers in a CPBR project that focused on working with the Piscataway Coney Tribe to design and administer a health needs assessment to identify barriers to cancer screening and other health services. Data on factors related to cancer screening practices were obtained from a purposive sample of 194 adult members of the Maryland Piscataway Conoy tribe. We used comparable measures from two surveys, the Behavioral Risk Factor Surveillance System and the 1994 Commonwealth Fund Minority Health Study (Hogue, Hargraves, & Collins, 2000), which enabled us to see how the respondents from the Maryland Piscataway Conoy tribe fared in relation to other Maryland residents and other Americans on measures of barriers to the receipt of medical services. Throughout the three-year collaboration process, we talked extensively in the monthly tribal council meetings about the right of the Piscataway to determine their own destiny in the collaboration process. This included their right to receive and use the survey data for their own purposes and the right to decide if or when the academic researchers could publish the findings. Although members of the tribal council and the academic researchers presented the findings at two meetings, the findings were not subsequently submitted to peer review journals.

Sampling Overview

Thus far we have focused on the importance of having conceptually driven social justice research as well as how to design surveys that can answer ↳ questions that are relevant to social work research. We have also focused on the notion of CBPR as a way to provide equal decision-making power in the survey design process. Another activity that is integral to the survey development process is the process of sampling respondents for the survey. This section provides an overview of the sampling process. A full discussion of issues related to sampling is beyond the scope of this book, so we focus on sampling issues as they relate to social justice issues and provide references to additional resources on sampling at the end of this chapter.

Rationale for Using Samples

In the best of all possible worlds, it would be preferable to collect data from all persons in an agency or a ***population***. However, cost and time constraints often limit our ability to survey all persons in a population. To accommodate these constraints, we typically ***sample*** a subset of the population. Given that we collect data from a subset of the population, the ideal goal of the sampling process is to collect data in a manner that allows one to generalize the findings to the larger group from which the sample is drawn. Our ability to generalize findings from this sample is based both on the type of sampling strategies used and on the size of the sample.

There are two key types of sampling strategy. One strategy is called a ***probability sampling*** design, in which each person has a known chance (e.g., an equal probability) of being selected into the sample. The second strategy is called a ***non-probability sampling*** design (e.g., a convenience sample) in which some may have a greater chance than expected of being selected into the sample.

There are some situations where one can make the argument that it may be better to collect data from a sample than from the whole population. A good example of this is the problem of the census undercount. In the 1990, 2000, and 2010 censuses, the Census Bureau faced challenges in trying to reach all segments of the U.S. population. The Census Bureau (2012a) estimates that there were 16 million omissions in the 2010 census count. This includes persons who could not be reached or persons who did not complete all of the core census demographic questions. Renters, African Americans, Latinos, Native Americans, and men of all races between the ages of 18 and 49 were more likely to be undercounted than other groups. ↳

Probability Sample Designs

There are several core types of probability designs: simple random sampling, systematic sampling, stratified sampling, and cluster sampling. These designs are summarized below.

Simple Random Sampling (SRS)

According to Huff (1982, p. 21), “The test of the random sample is this: does every name or thing in the whole group have an equal chance to be in the sample?” The ***simple random sample*** is the most basic of the group of probability samples. In this case, all units or individuals have an equal chance of being selected into the sample. Once each person in the ***sampling frame*** has been assigned a number, one uses a table of random numbers to select persons for the sample for the study. Most statistical packages (e.g., Statistical Package for the Social Sciences [SPSS], Statistical Analysis Software [SAS], and Statistics and Data [STATA]) include a module for the generation of random numbers (see also http://www.random.org/integers/to generate a chart of random numbers, or Levy and Lemeshow [1999] Table A.1, for an example of a random numbers table). Thus, for example, if one wishes to conduct a study of NASW members, one would first obtain the membership list of the National Association of Social Workers (NASW, ***the sampling frame***) representing the “universe” (or population) of all persons in the organization. Everyone in the list is assigned a unique numerical identifier, and then a table of random numbers could be used to select the sample. Alternatively, everyone in the list is entered into a database or spreadsheet that has a random sampling feature, such as EXCEL or SPSS.

Systematic Sample with a Random Start

Here one uses a table of random numbers to randomly pick where to start on the list, and then continues to collect every *n*th element in the list. For example, to select a 10% sample, the *n*th in this case could be 1 out of every 10 persons; if the random start number is 7, then the 7th, 17th, 27th, 37th, 47th (etc.) individuals on the list would be selected for the sample. In this example, the sampling ratio would be 1/10 (one out of ten). Thus, as in the case above, you would just use the table of random numbers to determine the starting point for the sample. This would be followed by ↳ drawing every 10th case that followed. This approach can be useful if you only have a paper list of the members of the population; however, if you have a computerized list, it is likely to be easier to use a spreadsheet or statistics package to select a simple random sample as discussed above.

Stratified Sampling

Before drawing the sample, you sort the sample into the subgroups you wish to stratify by (e.g., gender, age, race, or ethnicity); these subgroups are called strata. Once this is done, you draw the sample independently within each stratification group (stratum) to create a ***stratified sample***. This ensures that you have an adequate sample size from the subpopulations you stratified. In this case, one would ask that the NASW membership list first be sorted by the strata (e.g., gender), and then one would pull the sample from members within each stratum. Any of the software packages mentioned above can select samples based on strata. It is important to note that if sampling from the stratum is not equal, then weighted data analysis procedures need to be used (weighted data analysis is beyond the scope of this book, but we provide a resource for further information on it at the end of this chapter).

Cluster Sampling

Cluster sampling may be employed when it becomes difficult to draw a list of all the members of a population. Thus, for example, if you do not have access to the membership list for all of NASW members but have access to a list of members living in all the cities on the Eastern U.S. Seaboard, you would take a sample of the cities on the Eastern Seaboard and then sample the NASW members within those cities. Within these clusters, you can use simple random sampling, stratified sampling, or systematic sampling.

Multistage Cluster Sampling Stratification

The process of sampling for this type of study requires a discussion of an expansion of the sampling unit concept. In a simple random sample or a systematic sample, there is only one stage of sample selection (e.g., persons, families, organizations, etc.). However, the multistage cluster ↳ sample requires drawing the sample in several stages. In this case, you may choose to sample cities along the Eastern Seaboard, and then sample ZIP Codes within those cities, and then NASW members within those ZIP Codes. The cities along the Eastern Seaboard that are sampled are called the "primary sampling units" (PSUs), as they represent the first stage of the selection process. The ZIP Codes in the sample are called the "stratum" (or strata, if more than one stratum is sampled per PSU). The NASW members sampled within these ZIP Codes are called the "enumeration units," or "listing units." Using the above example, one may choose to sort out the cities on the Eastern Seaboard (PSU) and then select the sample from certain ZIP Codes within each city selected in the sample (strata). It is important to be able to identify and distinguish between the PSU and strata in the sample selection process, as one will need to organize the data by these characteristics in order to use the statistical software that adjusts for the sampling strategy in both weighing the data and computing the statistical analyses (e.g., Survey Data Analysis [SUDAAN], STATA, SPSS).

Probability in Proportion to Size (PPS) Sampling

One of the underlying assumptions in multistage cluster sampling is that each NASW member has the same chance of being selected. However, some cities have more NASW members than others. What PPS does is sample the NASW members based on the size of the city. As indicated by Babbie (1979), the PPS comprises three parts:

1. The probability of a cluster being selected is equal to its proportional share of all the elements in the population *times* the number of clusters to be selected.
2. The probability of an element being selected within a cluster is equal to the number to be selected within each cluster, divided by the number of elements contained within that particular cluster.
3. The overall probability of an element being selects equals (1) times (2). (pp. 188–189)

Suppose a city has five ZIP Codes (where each ZIP Code equals a cluster), and 1,000 NASW members across all ZIP Codes (elements in the population), and you want 200 NASW members in the sample. Under the rule of equal chance of selection, this would mean that each member in p. 48 ↳ that city should have a 200/1000 or a 20% chance of selection. However, in adjusting for proportional size of ZIP Code, one has to account for the fact that some ZIP Codes have more members than others. Thus if ZIP Code 1 in this city has 60 members selected for the sample, the probability of selection in this ZIP Code would be 30%: the number of clusters (5) times the proportional share of the number of members of the population in that cluster (60/1,000) = 30%. If ZIP Code 2 has 140 members selected for the sample, then the probability of selection in the second ZIP Code would be 5 × 140/1,000 = 70%. By default, the probability of selection for the other three ZIP Codes would be 0, because all 200 members for the sample were selected from ZIP Codes 1 and 2.

Types of Non-Probability Sampling Designs

The underlying assumption of non-probability sampling is that you do not have access to the population or universe and therefore it is possible (or likely) that some respondents may have a greater chance than others of being selected into the study.

Quota Sampling

In quota sampling, you would develop a matrix that describes a population. For example, you have a report from an agency where they provide a statistical summary of their client population by age, gender, sexual orientation, and so on. The data regarding the breakdown of the population would allow you to compute the proportion within each group (e.g., males vs. females). You would use these proportions to weight the data for that group under the notion that the weighted data will provide a reasonable representation of that population. One of the weaknesses of this approach is that the data themselves may be skewed. For example, you may have more persons with clinical depression in your study because you drew the clinic sample on the day for the weekly depression treatment program.

Convenience Sampling

In this case, you select the sample based on who is available at the time. This process may be biased based on the time and location of the study as well as on program characteristics. ↳ p. 49

Snowball Sampling

In this case, the persons you sampled are asked to refer another person or persons to you. This approach may be biased because the referring person and their referral may have some things in common in a way that is related to the treatment, intervention, or program.

Although random sampling may be an ideal approach, there are cases where purposive sampling may be a viable alternative. The main caveat here is that, even though you may be able to collect a large amount of data, it is possible that the resulting sample is biased based on how the participants were selected. Given the possible biases that may come from using a non-probability sampling design, the choice regarding the use of non-probability sampling techniques may need to be grounded by considerations that are based on the literature, external experts, and community needs. The plan to use a non-probability design should also include a strategy for comparing the findings from your study with other published data from a comparable population to detect biases that may be due to differences in key sample characteristics (this process is called ***benchmarking***, as you are comparing your data against an external benchmark).

An example of using community considerations to justify the use of a non-probability design focuses on a study of immigrant populations conducted by Drbohlav and Dzurova (2007). Drbohlav and Dzurova found incidents in France, the United Kingdom, Germany, the Netherlands, and the United States where tensions and violence between majority populations and immigrant populations led to a lack of integration of those immigrants into the larger society, disparities in employment and educational opportunities, residential segregation, and substandard quality housing. Based on these observations, Drbohlav and Dzurova used a snowball sampling strategy to conduct a study of Ukrainians, Vietnamese, and Armenians living in Prague, Czech Republic. They believed that it would be difficult to draw a random sample of this population (due to an expected low response rate), yet it was important from a substantive point of view to collect data on the issues facing these immigrants. Based on this rationale, Ukrainian, Vietnamese, and Armenian immigrants living in Prague were targeted using individual contacts and ethnic community associations, and by focusing on areas where a high concentration of these groups worked or lived. They used a purposive sampling strategy, and they engaged the community in the research effort to enhance the relevance of the issue studied. ↳ p. 50

Concluding Thoughts

In this chapter, it is implied that being a social justice researcher is not a static process. One way to think about it is that every day you get a new opportunity to see whether you are in fact engaging in the principles of social justice, irrespective of whether you are developing a survey or not. In these discussions, we suggested that it would be advantageous to be sensitive to the notion of the lived experiences of the persons we are collecting data from in order to align the survey with their needs and priorities. Although community-based research strategies were offered as a means for achieving this goal, we do not see this as the only way to connect with the lived experiences of others. One of the issues we underemphasized is the potential for research conducted using this approach to be underappreciated or unsupported. In the first case, it is possible that, in spite of the commitment to designing a high-quality study and using validated measures, the findings may not receive the affirmation they deserve. In other cases, such as the work of Rachel Carson, your work may receive both intense praise and opposition all at the same time. Finally, given the processes that are required to build strong community partnerships, it may be a while before you are able to collect the data you need to tell the story about the inequities facing a population. All these factors require some thought and consideration as you begin or continue the journey as a social justice researcher.

Resources to Continue the Lifelong Process of Being a Social Justice Researcher

The aforementioned presentation should be seen as an introduction to a well-developed and established field of social justice research. Several resources are recommended to support both the continued process of becoming a social justice researcher as well as approaches that can be used to foster community-driven research collaboration efforts. In addition to the resources listed below, Heeringa, West, and Berglund (2010) provide a good introduction to weighted data analysis for complex survey designs.

Resources to Consider in Becoming a Social Justice Researcher

Earlier in this chapter, the work of Paulo Freire was introduced as a tool for becoming a reflective researcher. His body of work has been used by community advocates to shift the power dynamics from us as "experts" to the community. Two books are recommended as a means to continue to reflect on the processes that can support this transition to becoming a reflective researcher. *Pedagogy of the Oppressed* (Freire, 2000) and *Teachers as Cultural Workers: Letters to Those Who Dare Teach* (Freire, 1998).

Resources to Consider in Developing Collaborative Research Processes

As in the case of the discussion of the processes of becoming a reflective researcher, we present a variety of frameworks that have been used to foster community partnerships in the research process. There is an extensively documented literature regarding both the challenges in using these frameworks and the merits of these approaches. Several resources provide a good starting point for this process: Green and Kreuter (1999); Israel, Eng, Schulz, Parker, and Satcher (2005); Minkler and Wallerstein (2008); and Viswanathan et al. (2004).

Resources for Research Ethics

In December of 2013, The *American Journal of Public Health* published a special issue on the ethics of human subjects research with minority populations (Volume 103, Issue 12). Guest editors for the issue were Sandra Crouse Quinn, Stephen B. Thomas, and Nancy E. Kass. This issue focused on the importance of community participation in research, the impact of including minorities in research studies, and the need to understand the diversity of minority populations. At the same time it would be informative to review the Belmont Report (1979), which is available at http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html. Furthermore, the U.S. Department of Health and Human Services provides extensive information on human research protections at http://www.hhs.gov/ohrp/index.html, and specific information on obtaining informed consent can be found at http://www.hhs.gov/ohrp/policy/consent/index.html.

Notes

1 Sources for the second vignette: Arthur, Reeves, Cornelius, Booker, Morgan, Brathwaite,...Donato (2005), and Cornelius, Booker, Arthur, Reeves, and Morgan (2004).

2 As of this writing, the MHA is in the process of merging mental health and substance abuse into a Behavioral Health Administration (http://dhmh.maryland.gov/bhd/SitePages/integrationefforts.aspx).

3 In this context, "they" refers to the oppressors who only shift their point of view once they come to see the world through the lens of the oppressed.

4 The concept of "communities" discussed here includes groups, neighborhoods, Internet-based communities, geographically defined communities, and culturally defined communities.