

# BUILDING A COMMUNITY-BASED RESEARCH PARTNERSHIP: LESSONS FROM THE MOHAWK NATION OF AKWESASNE

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*The purpose of this article is to present a framework which describes the development of a community-based research partnership in a culturally distinct community. A research project, currently underway in collaboration with the Mohawk Nation of Akwesasne is described in which respect, equity, and empowerment (Akwesasne Task Force on the Environment, 1996), serve as guiding principles. Within this framework the dimensions of adapting styles of communication, gathering information, establishing a research agenda, gaining acceptance, sharing knowledge, negotiating roles, and resolving differences are discussed as essential components of the research process. © 1998 John Wiley & Sons, Inc.*

Conducting research in diverse community settings presents many formidable challenges to the novice and experienced researcher alike. Our educational training programs provide little guidance in conducting field research with diverse cultures and ethnic com-

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munities. Even less attention is given to examining how scientific methodologies may, or may not, fit with the norms, behaviors, and beliefs of such communities. Weinstein (1994) cogently stated that “. . .addressing cultural diversity . . . carries with it a *reconceptualization of our knowledge base as well as how we gain our understanding*, that is, our methods concerning human behavior within context” (p. 815).

It is also well recognized that integrating Western scientific approaches with the traditions of non-Western cultural and ethnic communities presents a challenge. Researchers may be well versed in experimental and sampling designs including statistical methods of analyses, but rarely do they have the knowledge base to reflect upon how, and in what context, the research is to be carried out, as well as the impact that the study results will have on a given community (Manson & Shore, 1981; Wronka, 1993).

Within the field of community psychology, Trickett, Watts, and Birman (1993) called for an ecological approach to working with communities in which research is conducted in a “cultural context.” Although not explicit in their theoretical formulations, one could argue that this cultural context should apply to every phase of the research process.

The purpose of this article is to describe such a process in our fieldwork with the Mohawk Nation of Akwesasne located along the St. Lawrence River between northern New York and Canada. A variety of issues that warranted careful consideration are presented. These issues cut across all aspects of a community-based research project currently underway, starting with the initial discussions concerning the needs of the community to the actual design and implementation of the study. A variety of issues were faced in the attempt to define and establish research methods and practices consistent with the values and beliefs of the Mohawk community. A conceptual framework that may be useful in conducting community research in diverse cultural settings is described. Before examining these issues, a brief history and description of the project is presented.

## **BACKGROUND OF THE RESEARCH STUDY**

Many American Indian reservations, rural areas, and major cities have been negatively impacted by toxic wastes in the environment. The exposure to toxic substances is especially problematic for the Mohawk community living at Akwesasne. The exposure to a variety of toxicants has affected their diet, economy, and way of life. Traditional forms of their economy such as fishing, hunting, and agriculture have been adversely affected as a result of soil, sediment, air, and water contamination.

During the 1950s the St. Lawrence Seaway and Moses–Saunders Power Dam were built to encourage rapid industrialization of the area. Subsequently, several plants were built, namely, General Motors Corporation–Central Foundry Division, Reynolds Metals, and the Aluminum Company of America. For nearly 25 years, these industrial plants released toxic substances that contaminated the surrounding land, air, and rivers [Akwesasne Task Force on the Environment (ATFE), in press]. The Mohawk Nation community of Akwesasne, located along the St. Lawrence River between northern New York and western and eastern Ontario, was contaminated by a variety of toxic substances such as fluorides, metals, cyanide, and phenols.

In recent years, polychlorinated biphenyls (PCBs) have been the target of investigation. During the late 1950s to 1974, PCBs, a fire-resistant manmade chemical, was used in die-casting machines by the General Motors Foundry Site. The wastewater treatment system generated PCB-contaminated sludge, which was directly disposed of at several sites near Akwesasne, including the St. Lawrence River. The discovery of high PCB lev-

els in the fish and wildlife, as well as finding detectable levels in locally grown produce, is a source of great concern to this population, given the potential harmful health effects of such exposure (Casey & Bush, 1995; Bush & Kadlec, 1995; Skinner & Jackling, 1989; Sloan, 1986; Sloan & Jock, 1990).

Moreover, a common cultural belief among many, if not most, indigenous populations is the importance of the natural world and their relationship to the land. Native Americans believe that their land is to be respected and preserved (ATFE, in press). Thus, environmental contamination can have a negative impact on Native American communities. Specifically, Curtis (1992) cogently stated that “hazardous or radiological materials can have adverse impacts when the access of a Native people to traditional lands, places and items that have been contaminated or damaged is restricted or eliminated” (p. 67). Curtis further speculated that the effects include a loss of tribal identity, destruction of religious (spiritual) values, and reduced quality of life. This is also the case at Akwesasne.

In response to concerns about the potential risks to humans, Ms. Katsi Cook, a traditional midwife and prominent community leader, requested an investigation into the level of exposure in nursing mothers and their infants. Between 1988 and 1992, a study was conducted to investigate levels of PCBs and other toxic substances in the milk of Mohawk women from Akwesasne [New York State Department of Health (NYSDOH), 1995]. Since then, the ongoing efforts of the Mohawk community to pursue environmental justice has resulted in expanding the research on investigating the effects of exposure to chemical contaminants in children, and adult men and women living on the reservation. It is evident that Ms. Cook’s concern for her community’s well-being was the turning point for all current and future research endeavors.

The National Institute of Environmental Health Services Basic Research Program recently funded a five-year (1995–2000) interdisciplinary research, training, and community outreach project to investigate the effects of PCBs and other known toxic substances on human health, and develop ways to clean up these hazardous wastes. The research team, consisting of scientists from a number of academic communities in such disciplines as anthropology, biology, chemistry, entomology, chemical engineering, medicine, epidemiology, and psychology, came together to establish this interdisciplinary, and comprehensive research program. Approximately 15 individual research projects and four core support projects make up this large program sponsored by the School of Public Health, University at Albany, State University of New York, in collaboration with the Akwesasne Task Force on the Environment.

The Akwesasne Task Force on the Environment (ATFE) is a community-based organization whose primary purpose is “. . .to conserve, preserve, protect, and restore the environment, natural and cultural resources within the territory of Akwesasne. The Task Force works to fulfill the responsibilities that we as *Onkwehón* [italics added]: . . . people have to the natural world to promote the health and survival of the sacred web of life for the next seven generations” (ATFE, 1996, p. 3). Members of this group hold formal academic degrees (i.e., AA, BS, BA, MS, PhD degrees), and have expertise in a variety of areas including wildlife biology, ecotoxicology, aquaculture, civil and environmental engineering, biology, and in traditional medicine, environmental and cultural knowledge. Through formal training, life experiences, and leadership roles, they are well respected in their community.

Our specific project, entitled, “The Biopsychosocial Well-Being of Akwesasne Residents” is one of three human health studies underway. The purpose of our study is to

examine the extent to which exposure to PCBs is affecting physical and psychological functioning. An important aspect of this study is to examine how this exposure has affected cultural identity and practices, and overall quality of life.

The framework for conducting this community-based research project represents a partnership that is guided by a set of principles developed by the Akwesasne Task Force on the Environment (ATFE, 1996). Several of these principles have helped guide the current research project, and are intrinsic to the proposed framework. Fundamentally, these principles are central to initiating, conducting, and carrying out all environmental scientific research at Akwesasne (ATFE, 1996).

### **COMMUNITY-BASED RESEARCH PARTNERSHIP: GUIDING PRINCIPLES**

This research project follows the guiding principles of *respect*, *equity*, and *empowerment*. The principles of respect, equity, and empowerment are a transformation of Mohawk beliefs that people must strive for peace (*Skennen*), a good mind (*Kariwiiio*), and strength (*Kasastensera*).<sup>1</sup> The principles of respect, equity, and empowerment were established by Mohawk community leaders to ensure that the people of Akwesasne would benefit from the research, and to offer direction in ways to effectively conduct the various research endeavors. Underlying these principles is the notion that investigators outside the community must establish a collaborative partnership with the Mohawk community in the process of conducting research studies.

Newbrough's (1989, 1992a, 1992b, 1995) perspective on a paradigm shift which redefines the notion of "community" is relevant here. He noted that the postmodern view of community centers on justice and fairness in which the emphasis is on "equality," "fraternity," and "liberty." Moreover, social interactions are grounded in the principles of "human ecology" and "balance." As such, this frame of reference may be more in keeping with Mohawk sociopolitical and historical backgrounds, as well as their cultural values.

The first guiding principle is respect. We learned that the community had a vast storehouse of valuable information to offer in forming a scientifically relevant research project. For example, we learned about the concern for their environment which had been unjustly contaminated. We listened to them explain how this could affect present and future generations of residents. The community wanted additional reliable data to address their concerns. Many hours were spent talking with community members before we began conceptualizing the research project. We respected the community members for their knowledge and guidance, and the community gained some understanding of our interest and commitment to the research.

The second principle is equity. In the context of our work with the people of Akwesasne, Carpenter (1995) noted that "Equity means that some of the support dollars from the grant go to the community, members of the community are supported on the grant, and others are trained through the program. Equity means that the design of the research protocol reflect the needs and concerns of the community and not limited only

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<sup>1</sup>*Skennen* is the Mohawk belief that individuals, communities, and nations should strive for peace based on spiritual, social, and political consciousness. *Kariwiiio* is the belief that people should have a good mind or good word. This means that people must eliminate beliefs about prejudice, privilege or superiority, and strive for equality. *Kasastensera*, strength, is an outcome of peace and a good mind. According to Mohawk beliefs, strength is achieved by preventing mistreatment of the environment and its people.

to what some . . . investigator thinks is a fundable project” (p. 130). The principle of equity is evident in the project’s design. First, the project was reviewed by a Mohawk community-based advisory board before it went to the funding agency. One of the purposes of this review was to ensure that there was a reasonable allocation of funds and resources to the community. Second, financial support was budgeted for community residents. For example, we hired residents to serve as our field staff which consisted of three interviewers and a project coordinator.

It is clear that the Akwesasne model is vastly different from the hierarchical structure that is inherent in many large-scale research projects in which the principle investigator controls the dollars and makes all the decisions. At the outset, research funds became a shared resource, and provided a means for both the community and the university-based researchers to benefit. Thus, both parties learned and profited from the equitable sharing of information and scientific data. The scientists have not only gained valuable data, but the Mohawk community has also gained information that can be used for the benefit of all its residents. In many respects, control over the research project including decision-making power has been a shared enterprise. In keeping with Tyler, Pargament, and Gatz’s (1983) “resource collaborator” model, it is through a cooperative spirit that both the university-based researchers and the Mohawk’s leadership continue to gain equity.

Empowerment is an important guiding principle that has provided direction in the research process. The ultimate goal for any community is to have the means to make changes in the lives of its members. Consistent with contemporary views of empowerment, this research partnership emphasizes knowledge as power in which both the individual and the community as a whole benefit (Newbrough, 1989, 1992). Furthermore, in describing psychological interventions with indigenous population, LaFromboise (1990) stressed that empowerment is the development of skills that enable individuals to create and mobilize support systems. For instance, the Mohawk field staff underwent extensive training in various aspects of conducting psychological research including methods on sample selection, administration of measures, and confidentiality of data collection. The comprehensive nature of the training allowed the field staff to receive college credit which was paid by the grant. Each person was eligible, as a “nonmatriculated status” student, to receive three credit hours at either the undergraduate or graduate level, depending on the level of coursework.

Through training, the field staff expanded their knowledge-base in methods of research design and implementation, and psychological test administration. We believe that providing this training empowered members of the community by helping them obtain the skills and knowledge to develop and evaluate projects of their own.

In the context of community development, the seminal work of Biddle and Biddle (1965) offers a conceptual framework in which the research design of a project is an integral part of a community development “process.” Process, as defined by Biddle and Biddle, is “. . . a progression of events that is planned by the participants to serve goals they progressively choose. The events point to changes in a group and in the individuals that can be termed growth in social sensitivity and competence” (p. 79).

In this context, we have chosen to use the phrase “research process” because we believe that the project underway—its design, methodology, and implementation is not a “fixed product,” but rather a dynamic and continuous activity in which the Mohawk community’s leadership and field staff are active participants. This dynamic process also involves resolving differences in how the research is conducted.

## FRAMEWORK FOR BUILDING A PARTNERSHIP

As illustrated in Figure 1, *adapting our style of communication* to facilitate dialogue is at the core of this partnership. We learned that effectively communicating with community members required a reevaluation of our skills, attitudes, and styles. This was the starting point in which community representative and researchers worked collaboratively to identify what was to be done and how it was to be carried out.

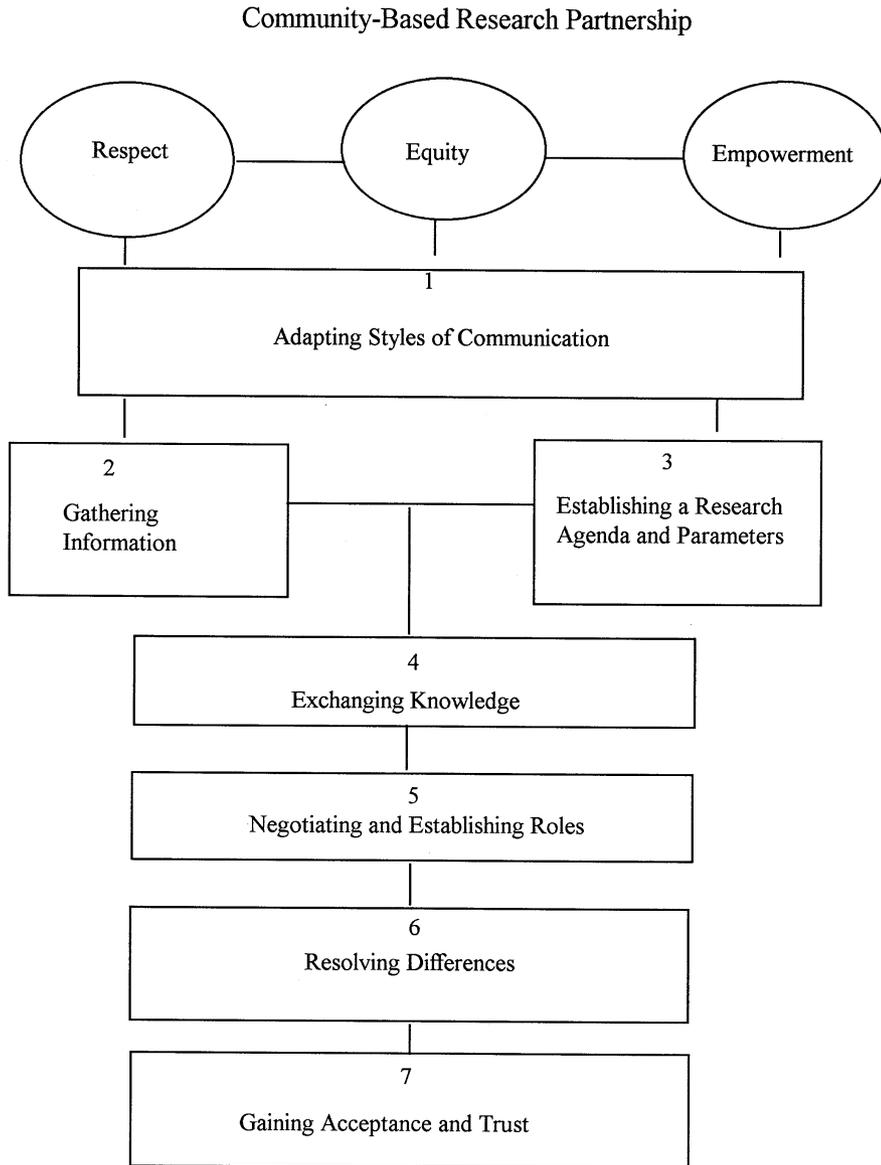
Montero (1994) coined the phrase that it is a "dialogue-oriented" approach in which people come together to talk about what is needed. As such, we spent a significant amount of time with various constituencies during the initial stages. Because we knew that their interests in the project would vary, it was important to obtain a broader understanding of the project's relevance.

In the context of critical theory, Forester (1980, 1982, 1983) claims that researchers should examine potential barriers that may influence communication. He eloquently states that "Critical theory seeks to show the practical, moral, and political significance of particular communicative actions, speech acts (Austin, 1961), and nonverbal communications more generally. It also investigates how a given social structure may itself be a structure of systematically distorted communicative actions that practically and subtly shape its members lives" (Forester, 1983, p. 235). Recognizing that communication can easily be distorted, we tried to maintain a cooperative interchange between us, the community's leadership, and the community at large.

Along this line of reasoning, one of the most difficult challenges we faced was how to effectively explain concepts or convey messages that would promote dialogue and understanding. Through dialogue and observation with the Mohawk community, we explored ways to convey "psychological" research that would be consistent with their beliefs about mental health.

Biddle and Biddle's (1983) model has also proven useful in describing the second dimension of *information gathering*. For instance, they described a stage called "exploration" in which the investigator seeks out information about the community and its members including events (past and present) that contribute to the problems or concerns. Our information gathering essentially involved two parts. First, during the early stages, we attended meetings in which a number of scientists and community representatives discussed preliminary findings regarding PCB-exposure levels in fish, wildlife, and residents in the area. At this gathering, several community members voiced concerns about how this contamination was affecting their children, health, culture, and way of life.

As we pursued these concerns, a number of questions emerged from community members that became vital in establishing a meaningful project. For instance, such questions as: (a) How will I and my family benefit from this study?; (b) What will I get out of this?; (c) How will my community benefit from this study?; and (d) What will you do with the study results? were asked. These questions and the discussions that followed took place in informal settings and community forums where the Mohawk leadership was present. For example, the community-based health service providers were more interested in knowing how we proposed to maintain confidentiality of individual participation in the study, whereas the environmental task force wanted assurances that we would follow a formal research review protocol that was developed by its members. Additionally, the elders were very concerned about how the environmental contamination was affecting their culture, and wanted confirmation that we would address this in the project. Such issues required careful thought and discussion among the university-based researchers,



**Figure 1.** Framework for an action-oriented approach to establishing a partnership with the Mohawk Nation at Akwesasne.

and the Mohawk community's leadership. As illustrated in the third dimension, these questions and discussions helped guide us in *establishing a research agenda and parameters*.

The initial stages of our work with the Mohawk community also involved conducting a small pilot study. There were primarily three reasons for taking this necessary step. First, we were cognizant of the criticisms in the psychological assessment literature regarding the use of measures that do not reflect culture specific values, customs, and behaviors, thus rendering inaccurate interventions (Dana, 1993). Although we carefully

selected measures that had been used with Native populations, it was necessary to determine the extent to which some of the psychosocial and neurological assessments were culturally appropriate for a Mohawk tribe while not jeopardizing their overall reliability and validity. Second [as Trimble (1990) suggested], we used the pilot study phase as an opportunity to learn and understand how mental health problems were defined and expressed. We also learned about the community's formal and informal systems in dealing with mental health concerns. Finally, the pilot study offered an opportunity for participants to provide us with their impressions on such matters as the wording of the recruitment letter and consent form, procedures used to administer the assessment tools, and specific items on the questionnaires. Thus, it enabled us to uncover potential mistakes.

Approximately 36 participants were recruited from the reservation by a member of the community. Those who volunteered were a cross-section of the community residents including members of the Akwesasne Task Force on the Environment, elders, and long-time residents. After completion of the measures and participating in the interview protocol, they were asked to provide feedback regarding the questionnaires, and to discuss the relevance of the study for them and the community.

In this process, not only did we gather important information, but also it became evident that we were invested in developing a research project that represented the concerns and issues of different community constituencies. One could argue that some of the participants were considered "opinion leaders," because to some extent, they were perceived as being influential figures (Rogers, 1983). For example, some of them identified individuals who they thought would be important to talk with such as the local mental health staff. We were also advised to seek out prominent elders. Thus, they offered invaluable ways to network with community members who were part of these various constituencies.

Subsumed in the third dimension are the issues of *data ownership* and the *report of research findings*. In a commentary regarding the legendary Barrow Alcohol Study of the Inuplaq people, Trimble (1989) cautioned researchers to follow ethical principles regarding data ownership and release of findings. The Mohawk community also had legitimate reasons to be suspicious of information-gathering methods, storage, and ownership of the study data. Thus, we were expected to address this matter in the initial stages of the project. Although these discussions continue, a number of concerns were resolved in order to move forward with the project. First, it was agreed that copies of both participant forms and all data would be stored on the reservation. This stems from the belief that the information derived from the data ultimately belongs to the community (Trimble, 1989). Second, research findings are to be presented to the Research Advisory Committee before their publication. The Research Advisory Committee was established by the community to ensure that all research endeavors are following the principles and guidelines set forth by the Akwesasne Task Force on the Environment. Furthermore, a community liaison was assigned to the project to enhance communication between university-based researchers and the community. Finally, authorship of any research findings to be published is to include the Akwesasne Task Force on the Environment or a designated member (ATFE, 1996).

A fourth dimension is trusting the community's knowledge and engaging in an *exchange of that knowledge*. A necessary first step involved our need to be educated in Mohawk cultural norms, beliefs, and customs including the history of the community. Their willingness to accommodate the researchers and share such knowledge was invaluable,

because it provided a context with which to build a reciprocal relationship. Kelly (1988) emphasized the importance of understanding a community's concerns by examining the strategies and methods used to address them. In this case, when working with a cultural or ethnic community, researchers should be aware of how history, traditions, beliefs, and customs influence decision-making processes and behaviors. Early on, we realized that if we were to build a trusting relationship, it was necessary to learn about their culture and take direction from them. Through this process, we gained invaluable insight into the methods of conducting research that are culturally appropriate.

A second step involved providing the community members with the tools in basic research design and methods that can be used for future projects. The goal has been to provide the community's leadership with sustainable knowledge. Ms. Katsi Cook, now the Director of the First Environment Communication Project at Akwesasne, reminds us that ". . .the message is quite clear: scientists working in our community must take direction from us. We respect scientific methodology, but the purposes of all studies must be guided by our own need to know what is happening to us—individually and as a community" (Cook, 1995, p. 64). Thus, the challenge for us was to find ways to bridge scientific methodologies with the community's cultural, sociopolitical, and historical knowledge.

A fifth dimension focuses on *negotiating* and *establishing roles*. Unlike most approaches in community research, considerable time was devoted to identifying and reaching a consensus on the roles and responsibilities of the field staff. The field staff, consisting of a project director and three interviewers, are Mohawk and reside on the reservation. The project director oversees the daily operation of all the human health studies, as well as supervises the field staff. These individuals are highly motivated and invested in making the project a success. Activities such as designing the participant consent form and developing a recruitment procedure were done in consultation with our field staff.

Similar to Latkin, Littman, Sunberg, and Hagan (1993), we negotiated mutually acceptable roles for the field staff which are likely to evolve as time goes on. Furthermore, their experience conducting field research and first-hand knowledge about their community provides leadership and direction in the research process. For instance, most of the field staff have been consultants or served as interviewers in an earlier human health study conducted on the reservation. These individuals also possess first-hand experience and formal training in the use of standardized interview protocols and medical procedures such as venous blood draw.

A sixth dimension of our conceptual framework involves the concept of resolution. Resolution is defined as the "act or process of resolving" (Merriam-Webster, 1989) issues that invariably come up during the research process. *Resolving differences* involves reaching an agreement on issues in which all parties are satisfied with the outcome. While this concept may seem to be a simple one, all too often, investigators enter communities with the goal of "getting the study done" with little regard given to the consultation and negotiation processes, especially when conflicts arise. When conducting research in communities that practice customs, mores, and norms different from those of the researcher's experience, this can be particularly challenging.

As researchers, we have been trained in academic environments that foster competition and individual achievement. These values may contrast with those indigenous communities that foster *cooperation for the good of the group*, rather than on individual achievement. Furthermore, Tyler, Cohen, and Clark (1982) stated that some indigenous communities may place great importance in being harmonious with nature rather than changing it for personal gain.

The Mohawks share this belief in that there is an interconnectedness with everything that surrounds them. Thus, understanding their spiritual attachment to the land and the impact of the environmental contamination is relevant here. The challenge for us, then, was to understand and appreciate those cultural values, beliefs, and customs that were unique to the Mohawks and how this was reflected in their way of approaching problems and reaching decisions. For instance, the Mohawk custom of resolving problems by consensus is an exhaustive process; however it is believed that everyone benefits from this approach (ATFE, 1996). As such, we encountered difficult situations along the way. An issue that arose creating conflict and a breakdown in communication involved the time-consuming nature of making decisions by consensus colliding with the time constraint of meeting research study deadlines set forth by the funding agency. As university-based researchers, we had to learn to adjust our working pace to accommodate the consensus process while the community members tried to meet the time demands of the study.

A mutually agreed upon strategy was to maintain constant communication between the investigators and the field staff. The travel distance between the reservation and the university is about 4½ hours which limits the frequency of communication. Thus, we needed to find ways to enhance communication between the field staff who live on the reservation and the university-based researchers. This was no trivial matter knowing that the Mohawk staff places great value on face-to-face contact, and reaching decisions by consensus. Recognizing that distance was an issue affecting all of us, we began meeting about once-a-month at a halfway point between the reservation and the university. We have learned that meeting with all members of the research team on a regular basis influences the effectiveness of reaching a resolution on matters regarding the study.

*Gaining acceptance* is the seventh and final dimension. We believe that acceptance of our project was enhanced by efforts to conduct a pilot study. As stated earlier, the purpose of taking this necessary first step was to test a number of measures for their appropriateness. Equally important, we found that the pilot project helped establish contact with a representative group of individuals who provided valuable suggestions on effective ways of conducting this kind of research. By conducting the pilot study, we were demonstrating a commitment, increasing our understanding of the unique experiences of the Mohawks at Akwesasne, as well as establishing some credibility. For example, the suggestions offered by those who participated were incorporated into the current research project's design including the revision of several measures. We also met with participants to review and discuss ways in which study results should be disseminated. Following Milburn, Gary, Booth, and Brown's (1991) lead in "negotiating entry" into an African American community, we found that it was necessary for us to identify individuals who could support the research project through their involvement with the pilot study.

## CONCLUSIONS

The intent of this article was to present our experiences working with a community whose unique culture and history guide the research efforts currently underway. Our work with the Mohawk Nation at Akwesasne exemplifies not only the complexities involved in designing and implementing a community-based research study, but also the importance of remaining alert and sensitive to potential cultural conflict in the process. We have emphasized the collaborative nature of our work that goes beyond merely understanding differences in word views. It involves working with a community in a historical and cultural context in which we are the learners, thus redefining our roles as re-

searchers. This perspective and the principles of respect, equity, and empowerment guide us in this journey.

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