Steps for Conducting Research and Evaluation in Native Communities

Introduction

Research and evaluation studies in Native communities have been characterized by mistrust and misrepresentation. Most of these missteps are the result of actions by researchers with little or no experience working with Native governments, Native communities, or Native American people. Research has been described as "probably one of the dirtiest words in the indigenous world's vocabulary" [1] and researchers have been called "…mosquitoes [who] suck your blood and leave." [2] In contrast, some program evaluations have been described as positive by both the Native entities and researchers involved.

This paper briefly explores the lessons and challenges of research and evaluation in Native communities, as well as the type of evaluations required by Federal funding sources to determine program effectiveness. It further identifies steps in conducting research and evaluation in these communities and concludes with personal stories of successful evaluation experiences.

Research Requirements

Native communities have received Federal, state, and private funding for decades. While the requirements of outcome evaluations have recently become more rigorous, they are not new. For example, in the mid-1980s, the Substance Abuse and Mental Health Services Administration (SAMHSA), Office for Substance Abuse Prevention, now known as the Center for Substance Abuse Prevention (CSAP), awarded a number of grants to Native governments and organizations that required that a program evaluation be conducted by independent evaluators according to a prescribed methodology. Subsequent CSAP grants and many other funding sources have had similar program evaluation requirements. In response, Native entities, which frequently include Native colleges, have developed working partnerships with evaluators, who may themselves be Native American.

Problems in Conducting Research in Native communities

American Indians and Alaskan Natives recognize the need for program evaluations to reduce the very substantial health and behavioral health problems that their communities face. The implementation of research and evaluation in Native communities has created concern, however. For example:

- In a fairly recent and notorious case, researchers collected blood samples over many years from members of the Havasupai tribe in Arizona, ostensibly to investigate the genetics of diabetes, as specified by signed informed consents. These blood samples were allegedly then used for other purposes, including an investigation of the genetics of schizophrenia, during the course of which the blood samples were distributed nationally. [2]

- In Canada, blood drawn from the Nuu-chah-nulth people for the stated purpose of health research was then used to investigate their ancestry. [2]

- A health department inadvertently stigmatized a Native community by publishing the results of a survey on venereal disease in a local newspaper in a way in which the tribe could be identified. [3]

- The results of the Barrow Alcohol Study in Alaska were revealed in the context of a press conference that was held far from the Native village, and without the presence, much less the knowledge or consent, of any community member who might have been able to present any context concerning the socioeconomic conditions of the village. Study results suggested that nearly all adults in the community were alcoholics. In addition to the shame felt by community members, the town's Standard and Poor bond rating suffered as a result, which in turn decreased the tribe's ability to secure funding for much needed projects. [4, 5]

Literature clearly suggests that some research and evaluations in Native communities have betrayed Native members' trust by failing to conduct research in a collaborative and respectful manner: exploiting Native members' stories to advance research careers; failing to understand and thus misrepresent Native culture; identifying and then stereotyping, stigmatizing, and otherwise damaging the reputation of Native communities; and giving little or nothing back to the Native community to contribute to Native health and well-being. [6, 2, 7, 8] Evaluators have been described as rigid, hierarchical, condescending, and disrespectful of Native culture and norms. [9] Their research has been described as a manifestation of colonization. [10, 3] Many evaluators have focused evaluation outcomes on reducing a Native community's deficits and problem behaviors, and in so doing have emphasized the community's negative characteristics instead of recognizing and increasing its strengths. [11, 12, 2] Consequently, many American

Indians and Alaska Natives distrust research that has been conducted "on" rather than "in" or "with" their Native community. [13]

Steps to Conduct Research and Evaluation in Native Communities

1 – Establish Relationships

Evaluators typically approach, or are perceived as approaching, Native communities as "experts" with job titles and degrees earned. From the outset, the relationship between evaluator and community may be characterized by inequality rather than a collaboration in which the Native community serves as a full partner, with as much of an investment as the evaluator in the successful conduct of the research. [9, 12, 8, 7, 3] The evaluation process in Native communities requires the development of both personal as well as professional relationships between the evaluator and Native community. Building rapport and credibility should start well before the development, much less the implementation, of research protocols. [6, 14] If the tribe has invited the evaluator as a part of a grant or proposal, the relationship should begin with the program director who can direct the evaluator to the right people in the community. Evaluators should attend Native meetings, ceremonies, and other social and cultural events to develop relationships so that they come to understand the Native community and are understood by it. [13, 7]

2 – Appreciate History and Culture

The evaluator should develop an appreciation of the tribe's history and culture. This should include an awareness of any historical trauma experienced by the tribe, as well as the personal histories of the individuals who are most likely to be involved in the study. A full understanding of any previous research conducted within the context of the community, and its effects on the community, is essential. It is also important to understand the history of the relationship between the community and the evaluator's institution, which may be considered elitist. [15] Establishing a relationship with an elder or spiritual leader of the Native community, who can serve as a mentor, guide, and facilitator, [13, 16, 14, 7] may be particularly useful as a key informant concerning the tribe's power structure. An elder may not be someone who is aged, but rather someone who has a trusting relationship with tribal people and predominates in keeping the culture alive. An elder or spiritual leader can ensure that the evaluator consults with all pertinent gatekeepers who could potentially derail the evaluation if not consulted. [4] The elder or spiritual leader can also help the evaluator choose community-based partners with whom to collaborate, since the Native community may have collaborated in the past with multiple entities with sometimes very different perspectives on how research studies should be developed and implemented. The community may speak with multiple voices that are sometimes in conflict with one another, and researchers who rely on a single member to represent the entire community may delude themselves into thinking this effort to ensure participation is sufficient. [17] In general, identifying and cultivating relationships with key gatekeepers and decision

makers early in the process is very helpful, although the achievement of consensus on the conduct of the study may remain challenging. [13, 4] It is most important to listen to as many voices in the tribal community as possible.

3 – Demonstrate Respect

The evaluator should be careful to demonstrate tangible respect for the community and its indigenous expertise. This respect can take a number of forms, including the development of a Memorandum of Understanding (MOU) that includes a clear statement of the Native norms and values that are to guide the collaboration. In addition, paid consulting agreements can be offered to community members to assist in various components of the research to be conducted, such as program implementation and data collection. [8] As another manifestation of respect, the community can be invited to collaborate with the evaluator in specifying a research agenda and developing plans to ensure that study findings can be used to improve the community's quality of life. [11, 12] In preliminary planning meetings, it is particularly important that the evaluator take the time necessary to elicit opinions from Native members. Some of these may be unwilling to express an opinion until everyone else has spoken, sometimes by the use of a minute or two of mindful silence. Silence should not be interpreted as agreement, just that the words have been heard. This approach to process is particularly important if the tribe has a tradition of making decisions by consensus and of not moving forward until all participants in a meeting have had the opportunity to voice an opinion. [4, 8]

4 – Proceed in Community Time

The evaluator should understand that study schedules and deadlines may be substantially at variance with the community's priorities, and that Native and Western time may well diverge. Securing approvals for study protocols may be subject to unforeseen delays, as may program implementation and research protocols. Participation in Native ceremonies and other events that may be scheduled on short notice (such as family gatherings) may take precedence over study schedules. [14] Some tribes will stop most tribal business if there is a death in the community in order to observe their tribal rituals. Clearly, research and evaluation in Native communities is both time-consuming and labor intensive, and require considerable patience if they are to be implemented effectively. Issues pertaining to the potential for slippage in study schedules should thus be discussed in advance with funders. [9, 7, 18]

5 – Embrace a Strengths Perspective

The process by which the evaluator gets to know the community should include a systematic effort to appreciate its assets as well as its challenges. Where possible, the program to be evaluated should respond to community needs by capitalizing on recognized assets. The process of engaging community partners and securing support for the evaluation will be greatest when

the program to be implemented is perceived as a potential solution to a recognized problem and builds on the community's strengths. [9, 18] The evaluator should specify clearly how the study and its data would be of direct benefit to the community. This can best be accomplished by engaging tribal members who can communicate the benefits of the project and why the evalution is necessary.

The evaluator may also serve the community by employing community members, training them in research skills such as data collection, and developing mentoring programs. These measures not only build the capacity of the community to conduct its own research studies, but also recognize and value the time and contributions of community members. Similarly, the evaluator can also give preference to community-based organizations when various tasks require a subcontract, thus contributing to the local economy. In addition, the evaluator may prepare educational materials of potential use to the community and provide training and technical assistance to respond to a range of needs. Lastly, throughout the research process, the evaluator may serve as an advocate for the community and develop an infrastructure that facilitates future research opportunities. [13, 9, 16, 11, 19, 12, 2, 14, 8,18]

6 – Be Aware of Community Readiness

The evaluator should be aware that the program to be evaluated may need to undergo a careful and potentially time-consuming process of adaptation, in partnership with key community members, to ensure it integrates traditional practices and is congruent with the tribe's culture, language, and values. [8] This may generate challenges for evaluation designs that involve multiple intervention communities with distinct cultures, as formal evaluations tend to require that the intervention studied should be administered with consistency across sites. Conversely, evaluators who fail to implement programs to this process of cultural tailoring risk offending the community's cultural sensibility and attenuating the program's desired outcomes, [6] thus setting the evaluation up for failure. In addition, full program adoption and implementation may require multiple years, and failure to schedule sufficient start-up time will also result in the evaluation of a program that is poorly or incompletely implemented. [6]

7 – Be Transparent

Evaluators should be candid about all of their initial assumptions and expectations concerning how the research study will be conducted. Evaluators should spend the time required to ensure an understanding among key decision makers of the requirements and constraints of "scientific" research and anticipate and discuss issues, needs, and values that have the potential to generate conflict with the community. Of particular importance in this regard are the evaluator's assumptions about the need for objectivity in reporting results, relative to the community's potential desire to be presented in a positive light. The evaluator should engage community members in the development of study questions and the research strategies that will address

them, even if changes to initial research plans require negotiations with the funder. It is important to be clear at this early stage about how study results will be presented to the community and to the public, and what roles community members will be invited to play in developing and reviewing reports and publications. [13, 9, 14, 7]

8 – Be Respectful of Research Protocol

Many tribes, such as the Navajo and Cherokee Nations [9], have established Institutional Review Boards (IRBs) or similar Native bodies that have the authority to approve research protocols and then oversee study activities. In the absence of such a group, the evaluator should consider establishing an advisory board that comprises elders and tribal leaders or members who represent key constituencies in the community. Review boards may require a letter of support from responsible authorities in the communities where the study will be administered. Such boards may review closely all data collection protocols to ensure that the language of consent forms is simple and straightforward, which may create challenges for researchers whose own institution's IRB may require the inclusion of content that is opaque or simply irrelevant to the community. [20] Native review boards may also carefully consider questions concerning sensitive behaviors and ensure that extraneous questions are not asked. Advisory boards may commit the evaluator to limit the use of study data to the purposes specified, and even specify require that the community be given ownership of the data [12, 4], albeit presumably de-identified to protect the confidentiality of study participants. The board may also expect a full presentation and discussion of how the proposed research may harm as well as benefit the community, including the various venues in which findings will be reported. Indeed, the board may require a review of all publications that are generated from the study, particularly to ensure that they are presented in language that community members will understand and do not present the community negatively [13, 9, 12]. It has even been suggested that IRBs should be empowered to deny the evaluator the opportunity to publish study results in a scientific journal. [12] Native IRBs may also reserve the right to cancel research studies should they come to believe that the evaluator is reneging on commitments or failing to keep them sufficiently informed of the study's progress and problems in a timely manner. [9, 4, 5]

These constraints may constitute a particular challenge, as the evaluator and the funder may perceive them as a threat to the objectivity and impartiality of the study. However, the evaluator should see the review process as a valuable opportunity for clarification and transparency and to address any errors or misunderstandings.

9 – Respect Privacy

Culturally competent evaluations of Native programs should be focused inward on the particular contexts in which they are administered. Not only are Native communities primarily interested in

their own growth and development, but such comparisons across Native communities can also be invidious, if they suggest that one community may be superior to another [7].

10 – Employ Blended Research Methods

The evaluator should also be sensitive to the need to employ culturally-grounded qualitative methods in data collection protocols that include "indigenous ways of knowing," as valuable approaches to scientific enquiry. [2,14,10] These include individual oral histories and interviews with program participants and key informants. Some evaluators have utilized focus groups and talking circles as means to engage in a reflective dialog with program participants. One evaluation has utilized photographs taken by participants as a way to document their involvement in program activities. Personal stories of program participants, and their perspective on how they and others changed through program participation, can carry great meaning. [9,16,11,20] The evaluator needs to also be sensitive to community members who may believe they should be paid for the information they provide. [15]

As mentioned earlier, survey questions should be limited to those that bear directly on the evaluation of the program outcomes targeted; evaluators should resist the temptation to add extraneous questions that may support the development of tangential publications. [9]

Data sources, measures, and collection should be fully discussed with appropriate Native representatives. Evaluators of drug prevention programs typically seek to administer measures of substance use, while Native members may find such an assessment at best of secondary importance, particularly if the program seeks to instill an appreciation of Native culture, morals, values, spirituality, and respect for the wisdom of elders. A careful consideration of these issues is likely to yield an evaluation that has meaning to the community as well as the evaluator and funder. [4]

Measures that were developed for majority populations and that have not been used in Native communities may have very different meanings to Native populations [14], and should be subjected to the same scrutiny by indigenous mentors as the programs evaluated, to ensure their cultural appropriateness and relevance. Scales developed to assess psychosocial constructs may be particularly challenging in this regard. [4] Measures of some research questions may simply be infeasible. For example, Native youth may consider it a betrayal to report the beliefs, attitudes, and behaviors of peers and family members. [14] Community-wide data sources should be strongly considered, as opposed to data collected from individuals exposed to specific programs, since the program and its evaluation should be of benefit to the entire community. [11]

11 – Conduct "Reality" Checks

One of the most frequent complaints leveled at researchers in Native communities is that they have failed to adequately communicate their research findings. [7] The evaluator should thus

keep the community fully informed as the study progresses, by posting fliers or holding brief meetings that summarize study progress and accomplishments and that recognize and validate the contributions of community members. Some evaluators have taken and distributed pictures, a task that may be greatly expedited by the creation of a website. Others have used newsletters, radio stations, and local cable access television for this purpose and have encouraged study participants to spread news about study progress and findings by word-of-mouth through the "moccasin telegraph." [7, 2] Evaluators should capitalize on meetings and social gatherings to make brief presentations that include a summary of study data and how they are being used to benefit the community. Evaluators should also solicit ideas about ways in which study data may be constructively utilized in the future. Particular sensitivity is required to alleviate concerns about how the data may be misused, either to portray the community in a negative manner or to reveal private and sometimes sacred Native information. [13, 9, 8]

Study findings should be carefully discussed with, and interpreted by, community members. This strategy will increase the degree to which findings are presented in a valid and culturally grounded manner and will decrease opportunities that incorrect or incomplete interpretations will damage the community. [19, 12,4]

12 – Be Aware of Intellectual and Cultural Property Rights

The evaluator should consult the Native communities in all phases of reporting and in any oral presentations that present study results. The evaluator should be sensitive to community' rights to control the dissemination of their tribe's intellectual and cultural property, and the community deserves (at the very least) acknowledgement and credit for the scientific knowledge that results from the study. [2] The evaluator should consider engaging key community members as co-authors who participate in the writing of reports and publications and not simply thank them in the acknowledgement section. This strategy will ensure that the community's voice is heard and its perspective communicated, thus enhancing its ownership of the publication and responsibility for any subsequent positive or adverse effects on the community. As mentioned earlier, this strategy also requires the evaluator to relinquish exclusive, or even primary, control over the publication, and may induce the evaluator to omit content that does not reflect well on the community. The evaluator may also give authorship to community members who have contributed to the conceptualization, development, or implementation of the study but who are uncomfortable with the written word. In some cases, it may be appropriate for the evaluator to entirely forgo the dissemination of research findings. [13, 9, 2, 4]

13 – Plan for Sustainability

Many Native communities have experienced programs that come and go with grant cycles, lasting no more than 5 years, of which the first or second may be spent in development. The programs thus end at about the time they are fully implemented and community members

understand how the programs operate and what they are seeking to accomplish. Some communities have reported that it is worse for programs to be implemented for only a brief period than to have never begun them. Researchers should thus work closely with the community in either institutionalizing programs within current community structures or in actively seeking out and applying for funds to sustain them. In this regard, it is imperative to collect and present study data in a way that will support the community's efforts to secure continued program support. [13, 9]

Personal Stories

The following personal stories demonstrate the successful paths of evaluators in working with Native communities. The first story is provided by Eva Petoskey. Eva is a member of the Grand Traverse Band of Ottawa and Chippewa Indians and currently serves on the Inter-Tribal Council of Michigan as Lead Evaluator and as an Expert Panel member for the Native American Center for Excellence.

"Successful evaluation experiences can include a wide range of approaches. The success of an approach will vary depending on the purpose of the evaluation. For process evaluation using qualitative approaches, I have experienced great success using a talking circle or Native-oriented focus group. If an evaluator wants to provide a meaningful process for engaging community members in conceptualize emerging needs or developing and refining prevention strategies; a focus group can be a great tool. For the sake of brevity, I will use the term 'Native-oriented focus group' to describe what I am talking about since talking circles can have varied meanings within Native communities.

The Native-oriented focus group begins with a simple ceremonial opening, a smudge, or a prayer. I usually prepare a list of no more than four open-ended questions depending on the purpose of the evaluation. The process is usually conducted in a circle. The facilitator opens the process with the smudge/prayer and then each person has the opportunity to speak about the subject or question at hand. Prior to beginning an overview of the purpose, the process can be presented and consent forms can be signed, if necessary, informing participants about how the information discussed will be used by the project and how their privacy will be protected. The process works best if there is a team approach with one person facilitating while the other is taking notes. We have experienced great success using a tape recorder if people are agreeable and if there are resources available for transcription.

Once the process is completed, the information can be analyzed using qualitative data analysis techniques. A brief report can be prepared that includes a summary of the broad categories of ideas generated along with direct quotes from participants. I have found this approach to have the two-fold benefit of engaging people in a process that involves what I call 'learning from the inside out' and then taking individual ideas and joining them together into a collective thought process. Done well, this can be a powerful and useful tool for process evaluation; it also is a wonderful way to facilitate ongoing engagement of indigenous people in defining appropriate interventions within their communities. Participants find this process empowering and it helps to develop group decision-making and problem-solving skills.

Another successful qualitative approach I have used is to ask community members to tell their own success stories. Using a camera, program participants can make photo essays with brief written comments or stories. We have been able to collect extraordinarily moving narratives of life changing events through the use of this approach. If a project has resources to fully develop display boards with photos and real community stories, this can be a powerful evaluation and education tool.

Successfully using quantitative approaches to evaluation are always more challenging in Native communities. However, I have also experienced great success in this area by engaging people in the process. If a utilization-focused approach can be emphasized from the beginning, Native community leaders, program staff , and participants are more likely to actively and successfully engage in overcoming some of the challenges commonly found with quantitative evaluation. Many people find quantitative approaches more challenging because they are not holistic. Qualitative approaches are more palatable in most Native communities because they are more heart-centered or at least offer a balance between the heart and the head. Quantitative approaches are, by nature, much more left-brain and reductionist oriented. Reducing something into its parts is frustrating for many people unless they have experienced how the parts can be put back together into something that is useful. I have been involved in several successful large-scale quantitative data collection initiatives implemented by reservation communities. The key characteristics of these successful efforts include a high level of trust between the evaluators and the community facilitators, a clear connection between the data being collected and some direct community benefit, a commitment to training and learning, and a willingness to acknowledge and openly discuss the cultural dissonance issues that arise in the process."

The following second personal story comes from Dr. Susan Carter who provides us with an anecdote from Drs. Gladys and Arie Pilz. Dr. Carter is an educator and program evaluator for agencies and tribal communities in New Mexico and other states.

" During our first meeting in 1990 with a Native American Superintendent in a Native American school district, we requested permission to administer a substance abuse survey to students. The Superintendent's first response was, 'Absolutely not...you will NEVER get into our schools to administer this survey!' This was followed by a lecture about how Native people have been sabotaged and mistreated by Western scientists (we certainly could not argue with that). As the program progressed and got better and better 'press' in the community, we were invited to a School Board meeting where we were given blanket permission to conduct all evaluation activities. To us, this is a wonderful illustration of how the assumptions and timeline for non-Native/mainstream evaluation paradigms do not fit with Native assumptions. One has to prove oneself trustworthy and become known throughout the community.

We have also learned that even researchers with experience working in Native communities often find it convenient to oversimplify the decision-making process within tribes. A careful researcher should understand that the formal Native governing bodies are not always the most influential groups. In many tribes, elders, medicine people, traditional chiefs, and chapter houses must be part of research design preparation. Researchers need to understand what is and

is not appropriate, the community's history with 'outsiders,' and make plans for stakeholder feedback over the life of the research. This is both a matter of respect and research validity."

Conclusion

This paper explores issues and challenges related to what researchers and evaluators should and should not do in Native communities. The great majority of the accommodations and adjustments that evaluators are invited to make will mitigate the likelihood that the researcher will be seen as exploiting, demeaning, or stereotyping the study's community. The quality of the evaluation is likely to be greatly enhanced if the community participates in the development of the study's protocols, is kept informed of its progress, and participates in the interpretation of its results.

However, participatory research as described in this paper is not without costs to the evaluator's time and resources. Participatory research runs the risk that disagreements with the community can lead to the disruption of study protocols. [12] Advisory boards may become mired in conflict, and may be unable to address or resolve it in a satisfactory manner [22], although the decision-making process can be expedited if the board operates by majority vote. [6] The use of data collectors who are based in the study community may also generate a perceived risk that commitments to confidentiality may be compromised [8], which constitutes a major concern to Native participants in research studies. [15] Some reseachers have instead utilized Native data collectors from outside the community. [14] The capacity of Native partners to serve as co-researchers may be limited. [22] The deliberations of Native institutional review boards may be lengthy and iterative, and result in substantial alterations to study protocols. [6]

Further, some of the steps identified in this paper may appear to threaten the study's objectivity and the conclusions it yields. Funding agencies may be reluctant to provide grants to evaluators who state in proposals that they will share control with Native members and thus cannot guarantee that the activities they specify in their proposals will unfold as promised. Further, emphasis on qualitative methods and particularly on telling the stories of participants' encounters with the program studied, and the effects it has had on them, may be at odds with current standards of scientific evidence. [11] The sources we have consulted suggest that evaluators should approach program evaluation as a non-linear, iterative process that embraces interactivity and collaboration and seeks ongoing program improvement. Researchers are instructed to greatly reduce the professional detachment that separates them from the community in which the program is implemented and evaluated. Furthermore, the advice presented here encourages flexibility and evolution in both the program under study and the methods used to study it. Community participation in evaluative research is even seen as a desirable end in itself, as a means of promoting community empowerment, addressing historical trauma, and promoting social justice and transformation. [19,23,12,2,18,24]

Must researchers entering Native communities abandon the methodological techniques and strategies that remain the gold standard in the field of evaluation? If they do, how will their studies satisfy the criteria that continue to be specified by various national registries of effective prevention programs? Are we to the point of suggesting that there be two sets of standards for program evaluations, one that applies to Native communities and the other to studies conducted elsewhere? If so, who will develop standards for evaluations conducted in Native communities that will successfully discriminate between methodologically rigorous and superficial evaluations? Whose task will it be to ensure that these standards are accepted by national registries and funders? If program evaluations conducted in Native communities are designed to be formative and participatory, if their primary purpose is to benefit the unique needs of the community in which the program is set, and if the evaluator shares authority to control the presentation and dissemination of study findings, will the utility of the study be limited to the community in which it is conducted?

> Engaging in community-based participatory research does not mean leaving one's own scientific standards and knowledge base at the door but rather sharing one's own 'unique gifts,' including one's skills as a research methodologist, while accepting the gifts of others through a genuinely reciprocal learning process. (pages 692-693) [25]

In the final analysis, what may be most important is the attitude of evaluators as they approach the Native communities that will serve as the context for their research. That attitude should not only be based on cultural humility, but should also approach the relationship with the community as a "spiritual covenant," characterized by the core human values of trust, harmony, sensitivity, reciprocity, respect, mutual participation, and collective benefit. [8,5] Many researchers have attended meetings in Native communities that have involved prayers and ceremonies to mark their beginning and end that have been offered by spiritual leaders. Such ceremonies can serve as periodic reminders of the sacred nature of the covenant between the evaluator and the community and of the journey they take together. [26]

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