

DOCUMENT RESUME

ED 473 275

RC 023 929

AUTHOR Manson, Spero M.
TITLE Focus on Research Methods.
PUB DATE 2002-04-00
NOTE 11p.; In: Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM), Symposium on Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities; see RC 023 923.
AVAILABLE FROM For full text of entire monograph: <http://www4.nau.edu/ihd/airrtc/pdfs/monograph.pdf>.
PUB TYPE Opinion Papers (120) -- Speeches/Meeting Papers (150)
EDRS PRICE EDRS Price MF01/PC01 Plus Postage.
DESCRIPTORS Action Research; *American Indians; Confidentiality; *Cultural Awareness; Cultural Differences; Indigenous Personnel; Intellectual Property; Participatory Research; *Research Methodology; *Research Problems; Sampling; Spirituality; *Tribal Sovereignty
IDENTIFIERS *Research Ethics; *Researcher Subject Relationship

ABSTRACT

A brief review of the papers presented at the Symposium on Research and Evaluation Methodology highlights some of the major issues of research in Indian Country. There is a need to translate research results into terms that are meaningful at the local level, yet the act of doing this reveals tensions between scientific objectivity and advocacy. Tribes have developed research ethics codes, but recognition of them by mainstream institutions has been slow. Sampling issues reveal a tension between generalizability and local specificity of findings, which have different kinds of constituents and different lessons attached to them. The imposition of national evaluation models also involves the tension between the general and the specific. The development of tribally operated and administered institutional review boards presents numerous challenges, not the least of which is how to fund them. There are issues involved with confidentiality. Sponsoring agencies often want all data made public, but tribes may insist on community confidentiality. Using Native persons for data collection is often assumed to enhance rapport between researchers and study participants, but there are disadvantages to be considered. Issues involved with informed consent include language barriers, cultural differences, and who is authorized to give informed consent. Spirituality is important to Native communities, yet measuring it is problematic, especially with Western scientific methods. The length of time involved in conducting culturally respectful participatory research presents its own barriers to young researchers whose success depends on publication. (TD)

Reproductions supplied by EDRS are the best that can be made
from the original document.

✓ This document has been reproduced as received from the person or organization originating it.

□ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Focus on Research Methods

Spero M. Manson, Ph.D.

ED 473 275

I've organized my remarks into two parts. First, I have a series of general reactions to each of the individual papers, which I'll take in the order of their presentation. Second, in synthesizing the lessons learned that you've shared in your respective contributions and considering them in the context of my own experiences, I have noted a variety of challenges and opportunities that are reflected in this work. I'll attempt to summarize them succinctly, as a platform for further discussion. By no means is this meant to be an exhaustive set of comments; rather, I've chosen to highlight a few points and to seek clarification on others.

Beginning with *A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities*—it's a really nice piece, Jamie. It provides the general historical context that any reader—investigator, sponsor, or consumer—in this particular area needs as the basis for understanding the challenges before us and the backdrop to those challenges.

Early on in your paper, Jamie, you note the importance of translating the results from our work as investigators, or from the scientific research process, into terms that are meaningful at the local level, to the key stakeholders (to borrow Walter's term). This is critically important for several reasons. One is that most of us, based upon the nature of our training, are not adequately prepared to speak in terms that are easily and appropriately consumed by this set of constituents. This poses a major problem for us; I know that it does, in my experience. In the context of tribal review, we prepare scientific manuscripts for which we're seeking the tribe's comments; we also provide community summaries of no more than two pages double-spaced. Nothing drives home the challenge in this translation process more than something as mundane as

using the Microsoft Word grammar-level function to figure out the grammar level we've used and the language complexity we're employing. We always exceed the 12th grade level in the first try, and work very hard to simplify it to 8th and 9th grade level. I don't say this pejoratively, implying that our constituents are simple or that their language abilities are limited. The challenge is to render it understandable to most people! I use my parents as the model, because my parents understand both the content and the import of this work. If I can explain it to them, then I'm likely to reach most audiences. This is no easy task; it's one we're not typically trained to do, but it is critically important.

Jamie, the other issue that you've introduced to us—and I'll return to it in my general remarks—is the tension that's at work here. One of the other papers talked about it in terms of the subjective-objective relationship, that we as investigators working in this particular field find ourselves asking, "Where does science end and advocacy begin?" Jamie, you talk about the importance of translating the results of this kind of work into appropriate and meaningful local applications. I agree entirely with you. But I also submit that our training does not equip us to undertake this particular set of tasks.

So how do we go about doing this? Gatherings such as this are an important part of the process. They establish role models. Virtually all of us do this kind of translation. But we have to be able to demonstrate it for our younger colleagues, to illustrate how it's appropriately done. We have to be able to share with them the angst, the trials, and the rewards that accompany this struggle. So this is a particularly important message that you conveyed, Jamie.

As you reviewed the historical backdrop, although his name doesn't appear, his voice

023929

certainly does: Vine Deloria. All of us need to remember Vine Deloria's important work from the early '60s through *Red Earth, White Lies* in 1995, in which he talks about the way local knowledge in our respective Native communities has been judged inferior to the assumed eminence of western science. This is one of your messages: colonization takes a variety of different forms and its effects last many decades.

Jamie, as well, the last portion of this particular manuscript talks about best practices. You provide the readership a very nice overview in regard to the different types of research ethics codes that are emerging in Indian Country, and that are even now finding their way into such taxonomies as the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000). As a psychologist, you are particularly interested in the latter; it's probably one of the reasons you chose it as an example. But this example illustrates the ways in which some doors are opening even in the most conservative institutions—psychiatry among them. And, Jamie, I encourage you to review *Culture, Medicine and Psychiatry*, beginning with Candace Fleming's article (1996) that helped establish the case studies series in this publication. Three of us have published case studies in this forum, all involving American Indians, using the DSM-IV diagnostic formulation for cultural outline. Candace, Terry O'Neil, and I employed American Indian cases to illustrate how this kind of a cultural formulation moves us well beyond the typical gains of business as usual.

So, a very nice piece. Thank you.

Regarding *Research in Indian Country: Challenges and Changes*, Walter, always a delight to read your work. It's very important that you have called our attention to these three roles—sponsors, consumers, and stakeholders—and critically important for us, as scientists working through such partnerships, to translate the outcomes of these efforts into meaningful terms across all three

categories. This tripartite distinction is really at the heart of what may be our first step: a critical analysis of the ways in which these kinds of relationships should unfold and what kind of work we can best apply ourselves to.

Walter, you made a very nice point in regard to the role and responsibility of federal agencies' sponsorship of research in Indian Country. We really do owe a great deal to the Clinton Administration with respect to its support of and advocacy for government-government relationships and consultations. We're beginning to see this come to fruition in various agencies, but not as aggressively nor as comprehensively as such consultation should be. The extent to which this is seriously addressed will take us much further in terms of these sponsors understanding the kinds of issues that are before us. Let me give an example. One of the new, major initiatives that the National Institutes of Health (NIH) is required to address has to do with public access to data generated by its grants. Now, this poses a very particular set of concerns that are thorny for us working in Indian Country, as we consider the full ramifications of such demands. This requirement poses often competing demands when we work with our tribal and community-based partners.

Walter, you hit the nail on the head in your manuscript when you wrote about the major scientific challenges that face us with respect to sampling: the "denominator problem," whether it be with the census or with the community-based work that we must do to capture the data needed to address broader issues. In our work, epidemiologically, etc., sampling is an enormous challenge for us. And it brings us back to an issue that I'll return to in my more general remarks: the tension between generalizability and local specificity of research findings, which have different kinds of constituents and different lessons attached to them.

Walter, you also talk about there being an increasing number of institutional review boards (IRBs) in Indian and Native

communities. Through a fairly systematic survey I'm aware, right now, of nine formally chartered IRBs in Indian Country, three or four of which are very active. However, it's not my sense that at present many IRBs are tribally operated and administered. For the most part, many tribes look to the Indian Health Service and its area offices to serve that function for them. I'll return to this point. It's a big issue for our communities, for us, and for sponsors. How does one promote, support, and encourage the development of tribal-level IRBs? There are a number of challenges for everybody; not the least is how they'll be financially supported, which is not clear—and often not even the case. Our investigative team has discovered several solutions, but until our sponsors recognize that part of their responsibility is to help finance such review structures, we will be frustrated by the speed with which we see tribal IRBs working in our respective communities.

Walter, you raise several interesting tensions having to do with the issue of confidentiality. I'm always amazed at the extent to which non-Native colleagues are surprised by the emphasis on community confidentiality in reporting research findings. They understand and respect the importance of confidentiality regarding the individual, but are puzzled by why many communities would want this respect extended to their entire communities. I refer them to an article published some years ago that led to the establishment of the Navajo Nation Health Research Review Board. For that article, CDC investigators, in collaboration with the Navajo Health Authority, had agreed to present their manuscript on the epidemiology of the Hanta Virus during the initial peak of concern. The Navajo Nation approved it, asking that the 20 communities not be identified but named in a way that wouldn't diminish the scientific basis of the findings, thereby avoiding local stigmatization. The CDC agreed—but when the article appeared the Navajo communities *were* named, abrogating their agreement. Early in that investigation, a newspaper in Denver

carried a front page headline, a half-page picture of a hogan, and a caption that spoke of the "Navajo flu" and dirty living conditions, implying that traditional lifestyle contributed to the risk of that particular disease. This was right on the heels of that particular publication by the CDC—underscoring the stigma and the rightful concerns of the Navajo Nation.

Walter, you talk about how the quality of the data collected is often improved by enhanced communication, better rapport between researchers and study participants. Then you qualify this as you talk about the costs and benefits of trying to accomplish this match between the people who collect data and the people who give it as a gift. It's a very important point. For the most part, those who are inexperienced or less experienced with these issues assume that it's a ready-made solution: if a Native person is part of your data collection team, you will be immediately catapulted over such problems. You provided several excellent examples to the contrary, illustrating how it's not necessarily the solution, the panacea, one might assume.

In a recently completed two-stage epidemiological study of alcohol use and dependence in a Northern Plains community, the first stage involved administering sensitive questions to community members. The reported rates of alcohol abuse and dependence were quite low in the data generated by that phase. But in the second phase, a clinical reinterview of a large subsample of the same study participants, we observed rates of alcohol abuse and dependence several times greater than estimates based on the first stage. In debriefing our team we found, in fact, that we had inadvertently staffed one of our field offices largely with recovering alcoholics—so the community members whom they interviewed in the first stage felt less disposed to disclose their true personal histories of alcoholism. This reminds us that there are trade-offs. The message you've conveyed is that we need to be critically thoughtful about the advantages and disadvantages in hiring Native persons

from a given community to assist with data collection in that community.

Walter, you also talk about the issue of individual informed consent. There are two excellent examples of the challenges that we face in Native communities as we approach this issue. Joseph Carrese, an associate editor of the *Journal of General Internal Medicine* at Johns Hopkins, published an article about six years ago (Carrese, 1995) that demonstrates so powerfully the challenges that we face in appropriately informing study participants, and the role that culture plays in this regard. The example he gives is that among the Navajo it is believed that giving voice to bad things, negative things, increases the probability that those things will occur.

What do we do in an informed consent form? We present a long litany of possible risks. We characterize all the possible adverse events that might occur through participation in this study—hence violating at the very outset the Navajo view that giving voice to such things increases the likelihood of their occurrence. How do we address such issues in the informed consent process? And that's beyond all of the other potential barriers, such as language comprehension, etc.

There's another issue with respect to informed consent that we experienced (Norton & Manson, 1996); it has to do with who is appropriate to give informed consent. In this particular study we worked in five different tribal culture areas; one was in the southwest, involving several pueblos. In visiting the tribal council, we reviewed the research protocol, indicating that individual informed consent would be required. The council refused. They said, in effect, "We as the Tribal Council are responsible for providing consent for all of our tribal members." It was an expression of the manner in which that tribe is organized socially, in terms of its collective responsibility for members.

This proved to be an extremely thorny issue with our institutional review board (IRB) here at the University of Colorado Health Sciences

Center. Ultimately, a compromise was reached. But this example underscores how even the notions that guide the informed consent process and that are embodied within our IRB processes reflect particular cultural assumptions about responsibility, authority, and individuality. Walter, those strike me as two useful examples that you might use to emphasize this point.

Regarding *Cultural Competence Approaches to Evaluation in Tribal Communities*, Paulette, delightful; a pleasure to read your paper. You've nicely captured an issue that Catherine and her colleagues note in their manuscript as well: the importance of attending to the local construction of the phenomena, the experiences, that our research seeks to understand, describe, and explain. Your example, Paulette, relates to the concept of disability. You mention it in the context of the Global Assessment of Functioning (GAF) (American Psychiatric Association, 2000) and of various tribal grantees' attempts to operationalize this construct in locally meaningful terms. This is a key struggle for us, and for sponsors as well, to recognize. This is an instructive lesson, Paulette, and there are other examples in the literature which you might consider referencing here. Especially when coupled with the manuscript by Catherine and her colleagues, your paper exhorts us to be more reflective, more systematic, in our search for locally meaningful constructs of this nature.

A current example, not reflected in these manuscripts but certainly anticipated by them, is "spirituality." Paulette, your manuscript touches a little bit on spirituality; our Circles of Care initiative is centrally concerned with this concept. How do we measure spirituality? How do we build it in to our evaluation strategies? Into our research approaches? We were driven to do this in our work. I was reluctant, as a scientist, because it seemed to threaten polluting the sacred with the profane. By that I mean, why should we assume that western scientific methods lend themselves to measuring such a sensitive construct as

spirituality—or that it would even be appropriate to do so? Frankly, it was our Navajo colleagues who challenged me on this. They said, “We want to. To the extent that it can be measured, we believe it will prove critically important to understanding risk and protection among our people, as well as broadening the theories and models available to us from the general literature.” So that is a lovely point.

The converse, which you also talk about, is the frequent observation that “wraparound services” is a familiar notion in Indian communities, one we’ve adopted for a long time. It’s probably no accident that John VanDenBerg (VanDenBerg & Minton, 1987), one of the earliest advocates of wraparound services, did his first work in Alaska. Much of his work in the Alaska Youth Initiative involved Native villages, wherein life emulates many of the basic tenets of the wraparound model. So another important observation is not just that it’s important to adapt these kinds of things for application in Native communities, but that there are lessons to be learned from doing so, and that the greater world of science can benefit from careful attention to these matters.

Now I’m going to take you to task a little bit. I can do so, being a little more privy than most to some of the tensions that emerged with respect to the Systems of Care initiative through my participation at meetings that brought the Indian and Native grantees together with ORC Macro to debate the adequacy and the felt imposition of the national evaluation model on the formers’ communities. You persuasively characterized the way in which the Indian and Native grantees challenged ORC Macro to develop new constructs or to adapt the national evaluation plan’s existing constructs. But what’s lost in your discussion, Paulette, and is important for the audience to share in, is the tensions that were at issue, not just that they were resolved.

That will return us later to more general remarks regarding tension between the general

and the specific. Meanwhile, though, it would be helpful if you elaborated and shared the tensions and the demands on Macro. They had a responsibility to develop a national evaluation plan, and did so in good spirit and with good intention based upon a particular set of scientific tenets about the notion of comparability, reinforced by a scientific advisory board—a board that I happen to be on. Yet, at the same time, Macro was pressured by Congress and by the Center for Mental Health Services (CMHS) to produce evidence as to the effectiveness of this particular initiative that cuts across the grantees. Grantees sought to be responsive to these demands, recognizing their contractual obligations. But, at the same time, they suffered from the imposition of an external view of process and outcomes. At the same time, the grantees did not understand the organizational constraints on Macro that limit its ability to respond. So, it would be helpful to the audience if you bring to the fore a bit more the human fabric that underlies some of these tensions. One of the lessons here is demonstrating or chronicling these lessons, enabling other agencies, other sponsors, and other grantees to acquire a better sense of what issues to anticipate and the paths to their solution. Of course, they’re not yet solved at this point, but well on their way to appropriate solutions. A lot of this is, as you know, process. This is the piece missing here: conveying to the audience the process by which these important milestones were achieved.

Okay, Paulette, now I’ll let you off the hook; it’s a nice piece of work.

Catherine, I was very pleased to see that *Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work*, more than any other paper here, takes head-on the issue that “culture counts”—a phrase borrowed from the *APA Monitor* summary (Daw, 2001), as cited in your paper. In fact, there’s a whole chapter on culture that appears in the 2001 supplement to the Surgeon General’s 1999 report on the *Mental Health of the Nation* (U.S. Department

of Health and Human Services, 1999). It was a major battle to get the various agencies to actually adopt this language—that “culture counts.” Your paper, more than any other here, underscores the issue, and reminds the audience that this is not just a matter of American Indians or Alaska Natives vis-à-vis some broader societal group, but a matter of culture, involving process, dynamic, meaning. So this is critically important.

This manuscript is also the only one that talks about urban issues, which are vitally important. You speak about the strengths and weaknesses of your community assessment approach, which was pencil-and-paper originally, and your subsequent adaptation of the method. You did this in Denver and Texas, if memory serves, and subsequently in Minneapolis. It’s a nice example of how to carry forward a set of methods, adapting to the voices in our respective communities.

In this portion of your work you’re drawing upon your own experience, but there’s another example that may be useful to reference, having been used both in reservations as well as urban settings: the Community Readiness Model developed by Colorado State University (Jumper-Thurman, Beauvais, Plested, Edwards, Helm, & Oetting, 2001). It serves a similar kind of purpose. We all would benefit by looking more closely at both kinds of approaches. Each represents thoughtful, systematic ways of giving voice to the stakeholders, in Walter’s terms, who are represented in these communities.

This manuscript goes to great lengths about the importance of key collaborators. I fully agree with the underscoring of the importance of the key collaborators. But let me note that the people who choose to collaborate with us are not devoid of their own agendas. They have their particular views. They have their particular priorities. It’s important for us to be critical, analytic, about who chooses to collaborate, what may be at stake for them, and what they see as the issues, benefits, and costs. Collaboration is critical. Identifying key

stakeholders to participate in these partnerships is critical. But another important part of the process is to retain a self-reflexive perspective, to understand who has agreed to collaborate with us and whom we have collaborated with. We all know that in working in our communities, joining with one person often precludes our ability to work with others. And what does that have to say about the particular views to which we are privy? About the tasks we have chosen to undertake? About the outcomes desired and thought possible?

Learning from and Working with Yup’ik Professionals is a lovely work. As you noted, Jennifer, it is different from the others in terms of initial orientation and focus. But it’s an extremely valuable contribution. You’ve taken the Ages and Stages modules and demonstrated the use of certain organizational techniques to build teams with certain kinds of outcomes. You’ve taken us more deeply into the processes often at work at the more abstract level. You’ve done it within a systematic framework that allows us to examine how those processes unfold in similar or different ways among Yup’ik and non-Native northwest professionals. Although I encourage you to explore this even more deeply, you were able to talk about some of the apparent “disconnect” between the Yup’ik approach and how their cultural values of respectful listening and patience seemed at some points to run counter to the process. In debriefing Yup’ik participants, you asked what they might like to change in a reiteration. They suggested more structured settings that would allow them to comfortably adopt the particular values assumed in the Ages and Stages approach, thereby enabling them to engage in a dialogue, in a narrative, in discussions that would otherwise be more difficult. But this is really more than a case study, Jennifer. Quantitative and qualitative investigative techniques have been integrated and then applied to a process that may be generalizable beyond these particular groups. Let’s face it, issues of organizational culture are among the

biggest challenges for us to address as we navigate the various partnerships that emerge in our work.

Now, let me try to characterize for you more broadly what I believe to be the challenges as well as the opportunities that your papers anticipate for us, and that my modest experience suggests to me, as well.

First, the tensions anticipated in my earlier comments. There is a general tension between science and advocacy that we need to address openly. It goes to the heart of the manner in which we're trained and how most people construe the appropriate role of science and scientist. Only recently have sponsors such as NIH begun to talk about the importance of the translation process. They're even talking about "translational science"—about how to systematically translate research findings, whether in the lab or more controlled experimental settings, into meaningful, real-world applications. We're not trained to do this; we're not well equipped to make such translations. These efforts also typically are not funded by our sponsors, so that it falls to us to expend the extra time and energy to accomplish them. The translation process also engenders a fair bit of discomfort for us; we're extending ourselves into areas that are less familiar than other areas. But this is an important undertaking; our communities demand this of us, that we engage in advocacy and in this translation process.

There are other tensions mentioned earlier, and that Walter touched upon in his discussion of sampling: generalizability and local specificity. Paulette, it surfaces among the evaluation issues that you and Brigitte face with respect to Macro. How does one deal, scientifically, with the notion of comparability in a way that is locally meaningful and that speaks to the integrity of the initiative you're a part of? How do we generate outcomes or results that can speak to the general effort, but that are at the same time locally meaningful? Not easy tasks.

Yet a different tension springs from the mandate to compare—namely, the assumption that uniformity somehow brings with it, as a natural consequence, comparability. Not true—but it's part of the challenge that we face as scientists, in educating our fellow colleagues as well as in working in our respective communities, to find points of compromise.

There are other tensions as well, between academic freedom and tribal sovereignty. Working recently with a colleague, I became distressed at how much more work we have yet to do and progress yet to accomplish. The individual in question had conducted work in a community with which we had agreed to present all presentations and publications for prior review and approval. Despite being Native, despite being aware of our agreement, this colleague, wishing to present a paper at a forthcoming conference, but absent tribal approval, asserted the primacy of academic freedom over tribal sovereignty, couching the issue in terms of censorship. There may be some merit to her argument, rooted in the history of how we've been trained to do science and the expectations of the institutions in which we work. But it was appalling to me that this argument issued from a young, Native colleague, underscoring the work still before us.

Shifting from these tensions to other challenges, I mentioned earlier the issue of supporting—not just in principle, but financially—local tribal review processes. This is not a straightforward matter. Our experience over the last four years of working directly with tribal IRBs reveals an enormous amount of variability among them in terms of their organization, the speed at which they move, the kinds of information they request, their decision-making processes. And not minimal by any means is the issue of how that entire endeavor is financed at the local level. If we're serious as sponsors, consumers, and stakeholders about promoting tribal review, we have to become serious about funding it.

Discussions with the National Institute of Mental Health (NIMH) in recent months have yielded their agreement to include in grants subcontracts to our tribal partners to fund this process. Yet, several other institutes have rejected this approach out of hand. There is considerable variability among the institutes at NIH, but this foothold gives me greater optimism for addressing this important need.

I've also suggested to several of these tribal review boards, each dramatically underfunded, that they charge for the review process, which also makes it easier to build such costs into research funding mechanisms. In Colorado (and this is true in many other universities), the Colorado Multiple Institutional Review Board charges \$1,200 to review applications not submitted by members of our institution. Well, why can't tribal IRBs adopt a similar private enterprise model for those investigators wishing to work in their communities? There are solutions out there. We just have to become more aggressive in seeking them.

One issue that arises as a natural segue with respect to this issue of local review has to do with ownership of data. I confess to being caught in the middle of interesting struggles about the ownership of data. NIH, the sponsor of most of our work, asserts that we, as principal investigators, own the data. My institution has a particular view on that as well. Several of the tribes with which we work also assert that they own the data. So what does ownership mean? Is there multiple ownership of data? Are there different but complementary applications of the data? How does one pursue this notion of multiplicity of ownership? How does one negotiate the respective responsibilities and areas of mutual responsibility?

NIH has instituted a major policy regarding public access to data to ensure that data is shared, that it doesn't just sit in some investigator's computer unused for decades, that the investment the American public has made in sponsoring such work actually sees

the light of day. How does one think about meeting the spirit of this intent when working with entities that also claim ownership of the data? And we all have very appropriate concerns about what is subsequently done with data.

Walter, you pointed out that the greatest area of contention right now is in terms of the ethical, social, and legal implications of genetic research, particularly in American Indian and Alaska Native communities. That particularly volatile issue involves commercialization and the subsequent profit that may derive from gene banks, etc. These recent concerns heighten the debate, and tend to polarize views on the research process. How do we navigate these shoals, remaining open to reason and reasonable arguments?

What's the threshold for seeking permission to disseminate findings? Is it simply naming our tribal partners in the products of this dissemination? Paulette, your paper raises interesting challenges for us in this regard. You solicited feedback from the tribal grantees, the Indian grantees, in your paper. What constitutes permission? Did they all send back something formal that you can document as having given their permission to name them in your particular manuscript? Jill, you know our struggle in preparing the *Promising Practices Monograph* for Circles of Care (Burns & Goldman, 1999). What standards should we adhere to? What are realistic expectations, especially in the face of the demands and the lack of resources among our community partners to act on these kinds of requests in some cases? Who represents the community? Is it always the tribal council? Is it the health and human services committee? It's often the case that it's *not clear* who represents the community.

Community-based participatory research requires an enormous amount of time and effort. I'm almost frightened to calculate how much time is spent engaging our community partners, throughout the research process. The tribal review of our manuscripts alone, for

example, adds at least seven to nine months, in most cases, to submission of a manuscript to a journal for review, and if the peer review requires substantive modifications, tribal re-review is necessary—a process that adds at least 12, maybe as much as 18 months of capital investment of time and energy. It presents a major problem for our younger colleagues.

For those of us in the academy, with many younger Native colleagues trying to break through the sometimes not-so-transparent ceiling in terms of successful promotion and tenure in medical schools or colleges of liberal arts and sciences, the currency of success is grantsmanship and publications. The longer it takes, the less likely we are to succeed. There are only 11 American Indians and Alaska Natives who are associate professors or above in medical schools in the entire country. When one looks at the rate of success, one finds that the vast majority never make it from assistant professor to associate professor—and that's in large part because we're Native. We are assigned a disproportionate amount of responsibility for various committees in our respective universities. We're asked to teach more. The kind of work we do takes two to three times longer if we're committed to doing it in the way suggested by these papers and in which we all believe. So there are many challenges before us. One is to ensure that people become educated about such issues, about possible solutions. And it may have to do with modifying routes by which one rises through the academy.

Just two other things to comment on. I've been struck by the experiences of two of the tribes with which we've been working most closely in recent years. Indian Health Service (IHS) area IRBs previously performed the review process on their behalf. Recently, both tribes have rescinded this relationship, concerned about tribal sovereignty and delegation of that decision-making process to the IHS. This action has raised some interesting dilemmas for us as we've moved forward in the research.

One of the dilemmas has to do with contracting relationships with the IHS where IHS contracts with a given tribe for the tribe to provide some of their own health services. The IHS asserts—Dr. Bill Freeman, former Director of Research for the IHS, was an eloquent spokesman in this regard—that if a particular facility or group of resources, be they people or records, are funded through contract dollars, the IHS IRB has jurisdiction. However, if the research at issue involves a facility or resources funded through a Public Law 93-638 contract (Indian Self-Determination and Education Assistance Act, 1975), many tribes believe that it's their responsibility, and falls under their jurisdiction, not the IHS's. So there's a major conflict. Compacting, where tribes choose to manage all health service resources, presents an entirely different set of circumstances. The Indian Health Service readily recognizes that the tribes have direct, immediate, and primary responsibility for reviewing research that involves compacted personnel and facilities.

The point I'd like to end on, and the biggest issue facing us, is this: *Our discussion is not new.* Beginning in the late '60s, many, many conferences and symposia have been organized around the very same issues and concerns voiced here today. Travel forward in time to the early '80s—one sees a new series of conferences, symposia, and initiatives on exactly this same topic. Here we are again, 12 to 15 years later. What do we need to do to carry forward the momentum that these efforts began? To weave these conversations together, establishing a sense of continuity and ongoing immediacy to the discussion? What does it take to move this dialogue further along than we've been able to do on past occasions? I don't have an answer, but it needs to be one of the critical questions we must pose to ourselves if we are to have greater impact than history suggests we otherwise are likely to have.

These are my thoughts, then. Thank you very much for the opportunity to read your respective manuscripts. I look forward to future discussion.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed. text revision [DSM-IV-TR]). Washington, DC.
- Burns, B.J., & Goldman, S.K. (1999). Promising practices in wraparound for children with serious emotional disturbance and their families. *Systems of care: Promising practices in children's mental health* (1998 series, IV).
- Carrese, J.A., & Rhodes, L.A. (1995). Western bioethics on the Navajo reservation: Benefit or harm? *Journal of the American Medical Association*, 274, 826-829.
- Daw, J. (2001). Culture counts in mental health services. *APA Monitor*, 32(11), 16-17.
- Deloria, V., Jr. (1995) *Red earth, white lies: Native Americans and the myth of scientific fact*. New York: Scribner.
- Fleming, C.M. (1996). Cultural formulation of psychiatric diagnosis. *Culture, Medicine and Psychiatry*, 20, 145-154
- Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, 25 USCS §§ 450. 88 Stat. 2203 *et seq.* (2002).
- Jumper-Thurman, P., Plested, B.A., Edwards, R.W., Helm, H.M., & Oetting, E.R. (2001). *Using the community readiness model in Native communities in health promotion and substance abuse prevention among American Indians and Alaska Native communities: Issues in cultural competence*. Rockville, MD: Substance Abuse and Mental Health Services Administration (DHHS/PHS), Center for Mental Health Services. (BBB31380); Special Education Programs (ED/OSERS), Washington, DC. (ERIC Document Reproduction Service no. 429422).
- Norton, I. M., & Manson, S.M. (1996). Research in American Indian and Alaska Native communities: Navigating the universe of values and process. *Journal of Consulting & Clinical Psychology*, 64, 856-860.
- U.S. Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity. A supplement to Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, U.S. Public Health Service.
- VanDenBerg, J., & Minton, B. (1987, September/October). Alaska Native youth: A new approach to serving emotionally disturbed children and youth. *Children Today*, 15-18.



U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)



NOTICE

Reproduction Basis

- This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.
- This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").