

# Building Partnerships Between Indigenous Communities and Universities: Lessons Learned in HIV/AIDS and Substance Abuse Prevention Research

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Many HIV/AIDS and substance abuse prevention studies in American Indian and Alaska Native communities have been directed by academic researchers with little community input.

We examined the challenges in conducting HIV/AIDS-related research in American Indian and Alaska Native communities and the benefits of changing the research paradigm to a community-based participatory model. The lessons we learned illustrate that the research process should be a cyclical one with continual involvement by community members. Steps in the process include (1) building and sustaining collaborative relationships, (2) planning the program together, (3) implementing and evaluating the program in culturally acceptable ways, and (4) disseminating research findings from a tribal perspective.

These steps can enhance the long-term capacity of the community to conduct HIV/AIDS and substance abuse prevention research. (*Am J Public Health*. 2009;99:S77–S82. doi:10.2105/AJPH.2008.134585)

## THE NORTH AMERICAN

Indians of the 21st century are a diverse and complex group whose demographic patterns and cultural multiplicity result from 5 centuries of conflict between the indigenous population of North America and the Europeans who colonized the continent. When Europeans first arrived in North America, there were many culturally, politically, and geographically dispersed groups of indigenous people. Estimates of the indigenous population at the beginning of the European invasion of North America vary between 7 and 18 million.<sup>1</sup> Today, only 4.1 million Americans (1.5% of the US population) report their race as American Indian or Alaska Native (AIAN).<sup>2</sup> This number includes 2.5 million persons who report being American Indian or Alaska Native alone and 1.6 million persons who report being American Indian or Alaska Native in combination with another race.

Although the AIAN population is a diverse group of more than 560 federally recognized tribes (as well as tribes recognized at the state level and other tribes seeking recognition), the AIAN population as a whole has experienced a long history of oppression and alienation. For some tribes and individuals, this history is believed to have led to unresolved grief and negative health outcomes.<sup>3–6</sup> Among the people of one tribe, evidence has been found of a “historical trauma response,” including depression, survivor guilt,

excesses in cardiovascular disease and mortality, and violent deaths.<sup>7</sup> Furthermore, the general health of American Indians and Alaska Natives continues to lag behind that of the general US population; American Indians and Alaska Natives experience high rates of illness and early death from injuries and disease.<sup>8,9</sup> In addition, HIV/AIDS is a growing concern in AIAN communities. Thus, our focus is to present the challenges of conducting HIV/AIDS-related research in AIAN communities and the benefits of using a community-based participatory model.

## HIV/AIDS IN AMERICAN INDIANS AND ALASKA NATIVES

According to data from the National HIV/AIDS Surveillance System<sup>10</sup> through December 2005, the cumulative total of 4266 reported AIDS or HIV cases among AIAN persons is less than 1% of the total number of persons with HIV/AIDS but must be considered in the context of a much smaller AIAN total population.<sup>11</sup> Furthermore, recent studies point to substantial underestimates of HIV/AIDS prevalence and incidence rates because of racial misclassification of AIAN persons in surveillance data.<sup>12,13</sup>

American Indians rank third when one examines rates of AIDS cases among all races: 54.1 per 100 000 in the non-Hispanic Black population, 18.0 in the Hispanic population, 7.4 in the AIAN

population, 5.9 in the non-Hispanic White population, and 3.6 in the Asian/Pacific Islander population.<sup>10</sup> AIAN persons with AIDS are likely to be younger than non-AIAN persons with AIDS and are more likely to be residents of rural areas. The percentage of AIAN persons with AIDS whose mode of exposure was through heterosexual contact has increased over time.<sup>14</sup> Several interconnected cofactors are believed to enhance the vulnerability of Native people to HIV/AIDS.<sup>15</sup> These factors may include historical trauma, oppression, prejudice, racism, poverty, high rates of sexually transmitted infections, substance abuse, violence, stigma, denial, and concerns about confidentiality.<sup>16</sup>

## COFACTORS IN THE SPREAD OF HIV/AIDS

Almost one third of the AIAN population lives below the poverty level, compared with 13% for all other races in the United States.<sup>17</sup> Despite the federal trust responsibility to the tribes, the US government spends less per person on AIAN health care than on that of any other group, including veterans and military personnel.<sup>18</sup> Geographic isolation characterizes many AIAN communities, limiting access to health care and many other programs and services available to other Americans. Although more than one half of the Native population lives in cities; many urban Natives migrate back and forth to rural areas for work,

ceremonies, and family visits.<sup>14</sup> Migratory patterns may increase HIV risk in rural populations.<sup>19</sup> Poverty and unemployment can also play significant roles in substance use, including injection drug use and alcoholism, which are, in turn, associated with increased risk of violence and transmission of HIV and sexually transmitted diseases.<sup>20</sup> Thus, HIV/AIDS in Native communities is “situated within a complex web of historical, social, cultural, economic, and health cofactors.”<sup>14(p18)</sup>

For prevention and treatment programs to be effective, this multifaceted context must be carefully considered, and the strength and resilience of AIAN peoples and communities must also be emphasized.<sup>21</sup> Furthermore, health research and intervention studies must embrace a participatory research approach to engage the *emic* (insider’s) perspective, rather than just the *etic* (outsider’s) view, as has historically been the case with research in indigenous communities.<sup>22</sup> Community-based participatory research holds great promise as a particularly valuable approach in indigenous communities where distrust of research has historically been high. As cited by Burhansstipanov et al., community-based participatory research refers to a “partnership approach to research that equitably involves community members, organization representatives, and researchers in all aspects of the research process.”<sup>23(p70)</sup>

### CHALLENGES IN BUILDING COLLABORATIVE PARTNERSHIPS

In 1977, Joseph Trimble<sup>24</sup> provided a thorough discussion of the many barriers to building collaborative relationships between

researchers and tribal or Native communities. Since then, several others have contributed to this discussion.<sup>23,25</sup> Native people may be resistant to participating in traditional research methods for several reasons.

First, there has been little, if any, community or tribal participation in anything other than the data collection process.<sup>24</sup> Much previous research in Native communities prominently directed by outside researchers, and community members were expected to play a passive role. As Beauvais<sup>26</sup> pointed out,

a major difficulty with this approach is that problems are often poorly defined, since they do not consider the real conditions of the community and are consequently of little help to the community. Unless the community context, including the cultural context is understood, research is likely to arrive at incomplete, if not erroneous, conclusions.<sup>26(p124)</sup>

Members of AIAN communities need to be involved in all aspects of the research process: from conceptualization of the research issue, to refinement of the methodologic approach, to data collection, to analysis and interpretation of results, to dissemination of those results.<sup>27,28</sup>

Second, research findings have been stigmatizing and have contributed to controversy.<sup>24</sup> Much of what has been published about American Indians and Alaska Natives has proved to be a liability rather than an asset. In some cases, previous data and findings were misrepresented or misinterpreted by researchers, which resulted in extreme shame and controversy for Indian communities. Because many research programs with AIAN populations explore “problem areas,” it is necessary to proceed carefully; otherwise, it is possible to perpetuate negative stereotypes.

Third, tribal members often do not trust researchers and feel that research is an intrusion into their culture.<sup>24</sup> Many Native communities feel that they “have been researched to death.”<sup>23(p71)</sup> The collective tribal history with researchers has contributed to a general distrust of outsiders who come to study, ask questions, and publish their findings.<sup>29</sup> Past and even more recent abuses (such as the case in the Southwest where researchers used tribal blood samples in ways for which research participants had not given consent)<sup>30</sup> have led to tribes establishing and enforcing restrictions on further research. In some cases, the problem has become sufficiently severe that the community has imposed a complete ban on research.<sup>24,31</sup> The researcher must be aware of and sensitive to these feelings and the history of relationships before a community is approached.

A fourth reason is a previous lack of tribal policies regarding research endeavors.<sup>24</sup> With the growing emphasis on self-determination, is it not surprising that some tribal governments are establishing formal processes to protect themselves from the abuse of research. Several Indian communities in North America have now established guidelines intended to regulate the research process. Usually, researchers must present a proposal before a tribal or community governing body that describes the purpose, nature, risks, and benefits of the project. According to Burhansstipanov et al., steps in the process often include the following:

- (1) time on the agenda of the Indian Health Board, Indian Tribal Health Council, and/or Tribal council for overall approval of the project; (2) tribal resolution of support from the Tribal Health Board and/or

- Council; (3) letter(s) of support from the Tribal Health Director, Tribal Health Board, and/or Tribal Council Chair; (4) HIPAA-approval protocols and compliance documentation; (5) local tribal IRB approval; (6) Indian Health Service IRB approval; (7) National Indian Health Service IRB approval; and (8) academic IRB approval.<sup>23(p73)</sup>

This approval process must be built into the timeline of the project.

Fifth, few studies have contributed to program development or have directly benefited tribal communities.<sup>24</sup> It is critical that communities get something of value from the study that can be utilized for program development. Although most prevention programs in Indian country have an evaluation (research) component, it is surprising how little use is made of the results.<sup>27</sup> In many cases, neither the community participants nor the tribal nations receive summaries of findings from studies implemented in their communities.<sup>23</sup>

The final reason we discuss is that research findings have been viewed in non-Native theoretical frameworks.<sup>24</sup> The explanations of and solutions to health problems among AIAN populations call for innovative strategies for preventive intervention. These approaches must take into account the impact of both the traditional and the modern cultures upon the individual. Community members are an invaluable resource because they can identify the differences in values between the Native and Western worlds.<sup>32</sup> Thus, input from the community is imperative in framing, testing, and interpreting theoretical perspectives. Crazy Bull<sup>29</sup> described these values in her advice to researchers who come into Indian country:

We, as tribal people, want research and scholarship that

preserves, maintains, and restores our traditions and cultural practices. We want to restore our homelands; revitalize our traditional religious practices; regain our health; and cultivate our economic, social, and governing systems. Our research can help us maintain our sovereignty and preserve our nationhood.<sup>29(p17)</sup>

In addition to these general challenges in conducting research with AIAN populations, specific challenges are inherent in conducting HIV/AIDS prevention research. For example, Native people strongly believe in the power of the spoken word and may fear discussing diseases because of concerns that this will lead to self-fulfilling prophecies. Many perceive themselves to be at relatively low risk of acquiring HIV and other sexually transmitted diseases, and therefore prevention may be a low priority. Taboos may also exist surrounding the discussion of sex and drug-related behaviors, as shown in one study by the reported lack of communication across sexes and between adolescents and adults on topics dealing with sexual activity, pregnancy contraception, and sexually transmitted disease.<sup>33</sup> Finally, the level of traditionalism varies from community to community, and this has implications for determining how prevention efforts should be structured.<sup>14</sup>

## PARTNERING WITH INDIGENOUS COMMUNITIES

To involve indigenous communities as active partners in designing and conducting HIV/AIDS, alcohol, and drug abuse prevention research projects, we advocate using a cyclical model (as described previously).<sup>27,33</sup> This model entails continual leadership, input, and feedback from community members.

The processes involved in each of these steps (with more recent examples) are summarized below.

### Build and Sustain Collaborative Relationships

*Foster dialogue and develop trust.* The first step of any partnership is to develop a sense of trust and to foster an ongoing dialogue between all parties. A researcher must know and use appropriate channels to enter into a relationship with a Native community. Outside researchers should plan on spending a considerable amount of time first getting to know the community before they approach individuals, groups, or organizations about ideas for research partnerships. Researchers must also recognize the multiple voices and perspectives in the community. A focus on encouraging equitable participation and open communication, establishing norms for working together, selecting and prioritizing goals and objectives, and identifying community strengths and concerns are all particularly relevant at this stage.

*Establish a community advisory board.* An advisory committee or board comprising community residents and leaders can play an extremely important role in continually monitoring the progress of the project and providing guidance to the project team. In an effort to identify appropriate tribal community partners, tribal health board directors can play an important role in recommending key people with whom the researcher should work. It is critical to have 1 or more tribal elder as a member of the team.<sup>23</sup> A traditional healer may also be an essential member to provide spiritual guidance throughout the project. The tribal community also needs to identify the appropriate researchers for the partnership team.<sup>23</sup>

*Partner with change agents within the community and hire indigenous staff.* It would be inappropriate to expect community members to serve in volunteer roles when academic researchers receive salaries to conduct studies. Beauvais stated,

It is well accepted in the field of community development that the strongest and most lasting changes in community life are generated from within the community and not by outsiders who may not have lasting investment in the welfare of the community.<sup>26(p17)</sup>

Several of our projects have been fortunate to have been able to recruit local community members to serve in key roles: administrative assistants, school health coordinators, interventionists, curriculum development consultants, and evaluators. This is a critical component of any community-based participatory research project in Indian country.

### Plan and Design the Program Together

*Use focus groups and qualitative methods to obtain local insight.* For several projects in which we have been involved, focus groups were the principal means of obtaining community input in the early stages of development of the curricula and assessment tools. Focus group questions can elicit information on styles of local discourse, communication patterns, normative beliefs about the topic, and feelings of confidence in engaging in specific preventive behaviors.<sup>33</sup> Focus groups can also help to create a necessary sense of partnership by providing the beginnings of important, ongoing dialogue among various groups of the community and university.<sup>34</sup>

*Adapt theoretical perspectives to incorporate the local culture.* The relevance of social cognitive theory approaches for HIV and

alcohol and drug abuse preventive interventions with AIAN communities offers much promise.<sup>35,36</sup> We have also found that social action theory,<sup>37</sup> which is based on an integration of scientific theories of behavior change, is compatible with AIAN indigenous holistic health belief systems.<sup>33</sup> However, it is important to adapt models to fit the local context. According to the Native Communities HIV/STD Prevention Guidelines Task Force, "Today, many rural and urban Native communities continue to use traditional forms of healing."<sup>14(p32)</sup> At the core of traditionalism and Native sacredness is a world view of understanding and respect for the circle of life. In this world view, people, earth, air, water, and animals are connected, and there is acknowledgment of the need for all beings to maintain balance in the world. To ensure cultural fit and selection of appropriate intervention and assessment approaches, we need to work closely with members of the local communities. Each community will have a way of communicating about sensitive topics such as HIV/AIDS, sexual intercourse, and alcohol and drug abuse. Understanding of the diversity of language must also take into consideration the language of different subgroups in the populations.<sup>14</sup> Finally, in many tribal communities, strategies for dealing with sickness and wellness are not viewed as just an individual concern but as a community concern, and thus must be addressed at the community or family level.

### Implement and Evaluate the Program

*Deliver intervention and provide training and support activities.* When members of the target audience serve as intervention deliverers, they are more likely to

develop a sense of ownership toward the study. Elders, cultural leaders, spiritual advisors, teachers, parents, and youth leaders can all be potential prevention resources and interventionists for HIV/AIDS prevention programs. Native persons who are HIV positive and their family members can also offer to serve as natural spokespersons. Prevention messages need to be tailored to be salient to the culture, age, and gender of the target population. The Native Communities HIV/STD Prevention Guidelines Task Force stated that, "The use of visual materials that reflect specific tribal images is preferred; local music, images, and values may increase the community's identification with the materials."<sup>14(p32)</sup> The use of tribal legends and stories is also a common prevention strategy.<sup>14</sup>

Training is another critical component of a community-based participatory research project. However, training occurs from both sides: the university researchers can learn as much (if not more) from the cultural experts as the community staff learns from the university researchers. Our training workshops have focused on describing the intervention rationale and intervention materials, providing a session-by-session analysis of interventions, and providing time for rehearsal of skills for delivery of the intervention.<sup>27</sup> Ongoing training is often needed to support effective prevention skills and will ultimately enable staff members to address sensitive topics.

*Monitor the intervention during the implementation phase.* During all phases of research (but especially the implementation phase), it is critical to monitor the research project and become personally involved at the field site.<sup>24</sup> Researchers can learn a tremendous amount by actively immersing themselves

in the culture. Demonstrating a genuine interest and willingness to participate in community-based social and cultural events (e.g., powwows and traditional ceremonies when invited) that may not be directly related to the project's research agenda are also important ways of showing respect and showing a commitment to the wellness of the community.

*Explore alternative methods of evaluation.* Although outcome-based evaluation is essential in prevention research, experimental designs are often difficult to carry out and may be discouraged for ethical and practical reasons. As noted by others,<sup>38</sup> it is difficult to randomly assign adults or children into a treatment or control group in small AIAN communities. We have found quasi-experimental designs to be more accepted, because there is no control group from which an intervention is withheld. We have also found qualitative evaluation (including repeated focus groups and periodic spot surveys and interviews with key informants) to be particularly effective. Alternative forms of evaluation might include video-taking and critical reflection, community forums for public evaluation, and gaining group consensus. It is essential to have the right balance between scientific goals and the targeted community's input.

*Analyze data and disseminate findings.* Data analysis and report writing have previously been viewed as technical tasks that are assigned to the data analyst and co-directors of the project, who then present the results to the program staff and other local groups. As we have discussed here, however, community partners need to be involved in every aspect of the research, including data analysis and dissemination of results. In addition to

Native staff members participating directly in data entry and analysis, we have found community advisory board members to be an invaluable resource in the early stages of data analysis and interpretation. Similar to Legaspi and Orr,<sup>39</sup> we have developed an iterative process of working with advisory board members and community consultants to develop, reflect on, and refine presentations to be disseminated locally. Although dissemination of information should eventually occur at the national level (to inform both research and lay audiences), we believe that it must first start "at home." Locally, dissemination options might include a summary in a local tribal newspaper, a public service announcement on the radio, public community presentations (such as to the school or health board), and regional conference presentations with council or tribal institutional review board approval. For presentations at a regional or national level, we encourage joint presentations with both tribal partners and academic researchers. The research team should also identify publication sites and develop publications collaboratively. Many tribal institutional review boards also now require development of a dissemination plan and approval of abstracts for presentation or of draft manuscripts before submission to peer-reviewed journals.

*Enhance long-term capacity of community to conduct research.* Several issues are relevant to the empowerment of the community and its ownership of the program and its outcomes. Pentz<sup>40</sup> summarized key indicators that the capacity of the community has been enhanced to conduct prevention research. These include

changes in community acceptance of the initial problem and

social norms for the target health behavior; increased centrality of community leader and inter-agency communications and cooperation; increased community leader and resident perceptions of empowerment and capacity to empower other leaders and agencies for long-term health initiatives through policy change; and institutionalization of prevention programs in the community.<sup>40(p87)</sup>

In our community-based participatory research projects, we have found that norms change in discussing the taboo topics of sexual intercourse and HIV/AIDS when community leaders mobilize to talk openly about these issues. In one project, a tribal AIDS office was formed as a result of greater community awareness and concern about HIV/AIDS and its potential impact on the tribe.<sup>34</sup> In addition, schools found ways to institutionalize components of a HIV/AIDS prevention program into the curriculum for the school district and permanently hired community staff who had participated in the project. Tangible products such as curricula, posters, videotapes, and reports summarizing results of the study were also developed with community input and were used by schools and community-based agencies.<sup>34</sup>

The best way to ensure effective HIV/AIDS and substance abuse prevention efforts in AIAN communities is to have the communities guide and participate in all aspects of the research process.<sup>14</sup> Prevention programs that include a leadership component not only build skills in a community, but also support community members in developing the research, action, and advocacy skills needed to change policies. More funding should be directed toward the training and education of AIAN students, scholars, and community members in HIV/AIDS and mental

health research endeavors. Programs should also be made relevant to local norms, values, and conditions through culturally sensitive adaptations. Finally, researchers need to embrace and demonstrate a commitment to “cultural humility,” defined by Tervalon and Murray-Garcia<sup>41</sup> as “a lifelong commitment to self-evaluation and self-critique” to “develop and maintain mutually respectful and dynamic partnerships with communities.”<sup>41(p118)</sup> ■

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Contributors

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## Building Infrastructure for HIV/AIDS and Mental Health Research at Institutions Serving Minorities

The National Institutes of Health and other funding agencies have initiated various programs aimed at enhancing diversity in the workforces for health care delivery and biomedical research. These programs have resulted in improvements in research infrastructure and moderate successes in increasing, retaining, and strengthening the pool of underrepresented minority students and junior faculty at resource-poor institutions serving minorities.

We discuss some of the barriers and obstacles confronting such institutions, and the enablers and facilitators that may ameliorate or overcome such barriers. Although our analysis is drawn from lessons learned at an institution serving a largely Asian and Pacific Islander population, analogous situations may be found for other institutions serving minorities. (*Am J Public Health.* 2009;99:S82–S86. doi:10.2105/AJPH.2008.136903)

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**THE UNIVERSITY OF HAWAII AT** Manoa, the westernmost grantee of the National Center for Research Resources' Research Centers in Minority Institutions (RCMI) program, serves mostly Asians and Pacific Islanders. It is also the sole US institution of higher education designated by the Carnegie Institute as actively engaged in biomedical and biobehavioral research and training in the Pacific Basin region. Because of the distance separating the university from research-intensive universities on the US mainland, it faces unique challenges. At the same time, Hawaii's comparatively small size, its ethnically diverse population, and limited out-migration provide unparalleled opportunities for conducting prospective, population-based, longitudinal-cohort, and clinical and translational studies on a wide array of ethnic and racial disparities in health.

Historically, low numbers of minority students in medical schools and bioscience graduate programs, insufficient awareness of research career opportunities, lack of culturally appropriate mentors, and a paucity of successful role models

have contributed to the underrepresentation of ethnic minorities in medical research faculties.<sup>1</sup> In an effort to expand the capacity for biomedical and biobehavioral research at institutions serving minorities and to enhance the diversity of the health professions' workforce, the National Institutes of Health (NIH) and other funding agencies (such as the Robert Wood Johnson Foundation and the Howard Hughes Medical Institute) have initiated programs aimed at increasing, retaining, and strengthening the pool of underrepresented minority students and supporting junior faculty. These programs have also provided general counseling and curricula that enhance premedical students' chances of being admitted to medical school, as well as funds to improve the research infrastructure.<sup>2</sup>

Here, we discuss some of the barriers and obstacles confronting institutions serving minorities and the various enablers and facilitators that may ameliorate and overcome such barriers. We place primary emphasis on factors relating to the institution, faculty, mentoring, training, local community, and local economy. Although

our analysis is drawn from lessons learned at the University of Hawaii, many of these insights may be pertinent to other institutions serving minorities.

### A CHANGING UNITED STATES DEMOGRAPHY

As the fastest-growing racial/ethnic group in the United States, Asian Americans and Pacific Islanders (AAPIs) are expected to grow from 5.1% to 9.2% of the US population (from 15.5 million to 40.6 million) by 2050.<sup>3</sup> Because AAPIs have diverse backgrounds and national origins and because some, as recent immigrants to the United States, have a poor command of English, they experience significant health disparities, barriers to health care, and poor access to mental health services. In addition, their rank in terms of higher education and incomes varies considerably (Table 1).<sup>4</sup> While AAPIs represent less than 1% of all HIV/AIDS cases in the United States, they have the highest estimated annual percentage increase in HIV/AIDS diagnosis rates of all races/ethnicities (8.1% for males, 14.3% for females)