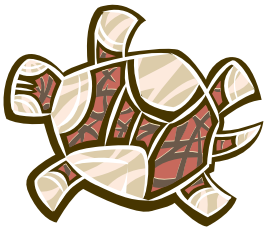
Methamphetamine and Other Drugs (MOD) in American Indian and Alaska Native Communities (CTN-0033*)

Preliminary Report on the Process of MOD Research Partnerships between Community and Institutionally Based Researchers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Introduction

The Methamphetamine and Other Drugs (MOD) in American Indian and Alaska Native communities (AIAN) project grew from NIDA's commitment to reducing health disparities with a specific emphasis on a better understanding of the epidemiology and treatment of drug abuse, and its health consequences in minority populations in general, and AIAN communities in particular. Because few data exist on methamphetamine and other drug use in AIAN communities, NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN) funded several exploratory and developmental projects in order to develop collaborative research partnerships with AIAN communities. The original overall goal of these partnerships is to gain knowledge on the use and abuse of these drugs, through mutually beneficial relationships between scientific investigators and the AIAN communities. As noted below, this goal was expanded at the request of our AIAN partners to include documentation of the strengths and resources already existing in these communities.

Seven points are noteworthy in the MOD projects. First, although NIDA expressed specific interest in focusing on methamphetamines in AIAN communities, our preliminary discussions with potential participating communities indicated that, although methamphetamine was still somewhat of a problem, there was an alarming increase in the abuse of prescription pain medications and related negative consequences; also, alcohol continues to be the primary substance of concern.

Second, as linked but separate MOD projects, the five Nodes had originally planned to develop and implement a national protocol to collect comparable information using similar methodologies. However, as we developed our research partnerships based on the principles and approach of community-based participatory research it became clear that the uniqueness of each AIAN community/organization required that we develop similar but distinct research protocols across the nodes, even though some issues would be the same or similar across AIAN communities,.

Third, researchers historically have focused on substance use problems that might exist in Native communities with a tendency to pathologize both individuals and communities. Our Native research partners indicated that they want to have the strengths and resources that exist in their communities identified and documented and to collaborate on research regarding cultural practices that are effective in prevention and treatment.

Fourth, the processes for developing collaborative and trusting research partnerships with Tribal entities as Sovereign Nations and subsequently obtaining authority and approval for specific research activities are very complex and often require a great deal of time and negotiations. It is necessary to obtain Tribal Council resolutions (or authority via the mechanism as required by the Tribe or Native agency), Memoranda of Understanding, and multiple IRB approvals. Most or all of these require review and approval by both the community and the university or other research institution and all of them require substantially more time than conventional research protocols. Tribal Council memberships change over time as do clinical and program staff so developing understanding, trust, and support for the MOD projects was an ongoing process. It is also important to point out that "one size does not fit all" and that each Tribe or AIAN agency may have a unique process for if and how research is conducted with their community. It is the responsibility of the researcher to learn, understand, and follow Tribal processes as well as those required of their own academic institutions.

Fifth, many of the Native communities with whom we partner are in geographically diverse locations. Many are in rural areas and may be in isolated, remote locations which results in challenges with regards to travel; developing and implementing research protocols can be greatly affected by weather and other conditions "out of our control," e.g. power outages, road closures, etc. These logistical issues contribute to making community-based research in the field considerably more challenging and time consuming than is true of other types of research conducted within the NIDA CTN.

Sixth, while Native communities are grateful for those non-Native investigators who are allies and trusted partners, many still state that they are most comfortable when Native investigators are part of or leading the research teams and trust is often more easily established.

Seventh, spiritual ceremonies of various tribal groups must be considered in the research processes. For example, some tribal groups conduct major ceremonies during the summer months, such as the Sun Dance ceremonies held on many of the reservations in the northern plains area during the months of June, July and August. Another example is the annual Tribal Journey held in July and August among Tribes in the coastal regions of Oregon, Washington, British Columbia, and southeast Alaska. Therefore, data collection may not be possible during these ceremonial times. Nevertheless, analyses of already-collected data could go on during these times to keep the research process moving.

Furthermore, our AIAN research partners frequently refer to the fact that research with AIAN communities has historically not been conducted using ethical, effective, and collaborative approaches but rather has been typified in an approach described as as "helicopter research". Helicopter research is an approach in which outside researchers come in with pre-determined research questions and protocols, collect data, and leave the community without ever reporting back any results – "never to be heard from again". Tribal communities believe that such research rarely results in any benefit to them and, in fact often results in harm to the community. The history of these abusive research practices have led to reluctance, and sometimes outright refusal, on the part of AIAN communities to agree to participate in research protocols. However, as AIAN communities become increasingly sophisticated partners in, and consumers of, research, two research approaches have emerged as being effective, ethical, and culturally appropriate; Community Based Participatory Research and Tribal Participatory Research. There is an increasing literature about the use of these approaches for health research in collaborative efforts between AIAN communities and university based research (see Appendix A for a brief reference guide). The MOD project committed to following CBPR/TPR approaches and in collaboration with our community partners deliberately crafted a list of principles to guide the research process (see Appendix B). Even with this commitment, the academically based research teams required training and time to acquire new skills needed to successfully adhere to these principles.

At the present time, all of the MOD research partnerships are in the process of gathering data. All research activities have IRB approval from the respective university IRB's. In addition, each community partner either has IRB approval from a Tribal or IHS IRB or they have obtained a Federalwide Assurance and delegated IRB authority to a university or other IRB.

As described below and throughout this brief report, each participating Node has specific processes in place for reporting and disseminating research findings that require Tribal approval from its respective research partners. Therefore, findings from these projects will be presented in future publications and at professional meetings -- in full partnership with our community research partners. The purpose of this brief report is to describe the ***process*** followed by each of the Nodes as they have developed their research partnerships with AIAN communities; lessons learned and recommendations for others interested in ethical research with AIAN communities are also presented. This introduction provides a brief who, what, when, where, why, and how of the overall MOD project and is followed by brief process reports from each of the participating nodes. Please note that our AIAN community research partners have participated in writing and/or reviewing this report.

WHO Five Nodes of the NIDA Clinical Trials Network are participating in the MOD project: Pacific Northwest, Oregon/Hawaii, Southwest, Ohio Valley, and California/Arizona. Each of these nodes is partnering with AIAN communities in their regions, including Tribes (reservation and urban), treatment agencies, health consortiums, and/or urban health centers. Staff from the five Nodes and representatives from their affiliated partners participate in monthly conference calls to insure that we are working collaboratively and ethically.

WHAT The Methamphetamine and Other Drug project (CTN-0033) is an exploratory and developmental project that is being developed and implemented in partnership with AIAN Tribal and community entities in order to better understand and document issues and strengths experienced by AIAN communities with respect to methamphetamines and other drugs.

WHEN The MOD projects were funded through supplements to the Nodes' parent CTN grants in September 2007 and will end in February 2010. As described in the individual Node reports below, each of the projects is on a similar but unique timeline to be respectful of the resources and readiness of the partnered communities, as well as that of researchers new to conducting CBPR/TPR in collaboration with AIAN communities. Data collection, analyses, interpretation, and reporting back to the AIAN partners will be completed by February 2010.

WHERE Each of the five CTN Nodes is collaborating with AIAN communities, treatment agencies, health consortiums, and/or urban health centers that are in their respective geographic region. In addition, the Oregon/Hawaii Node is also partnering with sites in Oklahoma and the Ohio Valley Node is partnering with Tribes in the IHS Aberdeen Area.

WHY To develop effective, ethical research partnerships with AIAN communities as the essential first step to better understand and document the issues related to prevention and treatment needs of AIAN communities with regards to methamphetamines and other drugs, as well as to better understand and document the strengths and resources that exist in the communities that support effective prevention and treatment strategies and programs. There is a lack of current, accurate literature and information with regard to methamphetamine and other drugs in AIAN communities and very little documentation of community based and culturally grounded prevention and treatment strategies and programs that are working in Native communities. Furthermore, it is hoped that the research partnerships and current findings will lead to future epidemiological studies and clinical research that is rigorous, community based, and culturally appropriate.

HOW The specific ways in which each project was developed and implemented varied from node to node. However, several initial processes took place for each of the nodes:

- Each node committed to partner with willing AIAN communities and organizations in its region.
- The 5 nodes participated in bi-weekly conference calls to collaborate, share experiences and resources, and provide updates. These calls later convened on a monthly basis as the research activities in the communities began to mature.
- Potential and actual community research partners were identified and also participated in the MOD conference calls.
- Approval to proceed with the research partnership was obtained as required by each of the participating AIAN communities and organizations.
- Tribal Council and/or or other Tribal leadership approval was also obtained for all research activities, inclusive of MOU's that document roles, privileges, responsibilities, and guidelines for all aspects of the data. It is important to point out that Tribal Council memberships change over time as do clinical and program staff so developing understanding, trust, and support for the MOD projects was an ongoing process
- A set of principles by which the MOD project would operate was crafted; these principles outline CBPR and TPR steps to insure that our research partnerships were ethical and respectful of the unique status of our AIAN partners as sovereign entities.
- Community Advisory Boards comprised of key stakeholders were identified and constituted to guide the MOD projects in many of the partnering communities.
- A national MOD protocol was drafted; the initial plan was that each node would implement the common protocol in their respective sites.
- It was agreed that both qualitative and quantitative data would be important, particularly at this early stage of the research. Depending on the needs of each site, focus groups and key stakeholder interviews are being held with participating communities.
- Most sites agreed to collect data using the Addiction Severity Index. The CA/AZ Node decided with their AIAN partners that this would not be appropriate at this stage in their collaboration. The PNW Node determined that this would not be appropriate for their community partners due to the small size of the participating communities and clinics.
- IRB approval by the university and, as appropriate, Tribal and/or IHS IRBs were obtained.
- As needed, AIAN communities and agencies obtained their own Federalwide Assurances in order to regulate the research activities via delegating IRB authority as deemed appropriate by them.
- A Certificate of Confidentiality was obtained in order to further protect research participants and communities.

In addition to the steps listed above, each node developed and implemented research protocols specific to and in collaboration with their community research partners. The

processes by which these steps were taken are described in the four CTN MOD Process reports below.

All of the teams that are working on these projects are honored to have the privilege and opportunity to work collaboratively with our Native research partners. We are committed to this work and see these projects as developmental and an essential foundation for a long term process that requires a great deal of time and effort in order to develop trust, understanding, knowledge, and true partnerships that will guide research that is rigorous as well as ethical, effective, and culturally appropriate. Critical to the success of these partnerships is the willingness of the academic researchers to *go to* the communities, *spend time* in the communities, be *present* in the communities, and *listen*. We are grateful to NIDA for understanding the importance of this long term commitment and we are especially grateful to the Native communities for welcoming us and allowing us to partner with them.

California-Arizona Node – Process Report

CA-AZ Node Project

The California-Arizona CTN Node is working with an American Indian tribe in Arizona and an urban AIAN urban treatment program in the San Francisco Bay Area. When initially approached about conducting research, neither the American Indian tribe in Arizona nor the urban AIAN treatment program was willing to conduct research, and thus our project focused on building and strengthening working relationships. In particular, we have established relationships with key contact persons in each AIAN community.

Through a variety of activities, including discussion groups, workshops, and a one-day conference, staff of the CA-AZ Node met with frontline clinicians at AIAN programs, developed cultural competence, and gained familiarity with the psychosocial problems and health care needs of American Indians in urban and rural areas. In turn, staff of the node's AIAN treatment programs have become more familiar with the goals and research infrastructure of the CTN, past and current clinical trials conducted by the CTN, and resources available to the American Indian programs and tribes through their affiliation with the CA-AZ Node.

Accomplishments and Lessons Learned

The first collaborative activity was a group discussion with clinicians at the urban AIAN treatment program. In this initial meeting, we found that many staff members were skeptical of research because of past exploitation of American Indians by researchers. In addition, staff argued that many evidence-based substance abuse treatments were not developed with American Indians and may not address cultural competence. They noted that in many ways the movement to develop evidence-based practices progressed in parallel to the cultural competence movement.

Regarding the development of evidenced-based treatments for American Indians, two strategies could be taken, and the viability of these strategies at the treatment program was discussed. First, a culturally competent treatment developed in the American Indian community could be tested empirically, or second, an existing evidence-based treatment could be adapted and studied in the American Indian community. Both approaches were greeted with skepticism. For example, American Indians may not appreciate the role of random assignment in testing an evidence-based treatment and research procedures such as writing treatment manuals of American Indian spiritual/religious practices and developing measures of therapist adherence and competence. Due to the initial reluctance to participate in NIDA clinical trials, we decided to find common ground and collaborate on a mutual goal with the staff at the urban AIAN treatment program. It was suggested that we explore the influence of historical trauma on American Indian communities.

In response to this request, we organized a conference on historical trauma, informed by a theory developed by Dr. Maria Yellow Horse Brave Heart of Columbia University. The conference brought together both American Indian researchers and clinicians. The conference was held in San Francisco on July 1, 2008 and titled "Historical Trauma: Healing Approaches in Native American Communities." The conference allowed the node to reach a wide audience of clinicians in the AIAN community. Over 200 participants attended; 42% were American Indians representing over 30 tribes. Speakers included Drs. Maria Yellow Horse Brave Heart of Columbia University, Karina L. Walters

of the University of Washington, and Joseph P. Gone of the University of Michigan, as well as Theda New Breast, consultant and member of the Blackfeet Tribe. Staff from the urban AIAN treatment program also spoke. The presenters focused on Native American wellness, mental health, and substance abuse. An article about the conference was published in the Fall/Winter American Psychological Association Division 50 Newsletter (Shopshire & Paschke, 2008), and a DVD of the conference was produced, which was distributed and is available upon request. In addition, video files of the conference are viewable and downloadable on the CTN Dissemination Library website.

In a second collaborative activity with the AIAN treatment program, staff of the node participated in a workshop on the conduct of community-based participatory research in American Indian communities. Dr. Candace Fleming, a clinical psychologist at the University of Colorado Denver School of Medicine and a member of the Kickapoo-Oneida-Cherokee tribes, facilitated the workshop. Themes that emerged from the workshop included: 1) the limited resources available to address the health care needs of urban American Indian communities; 2) the role of American Indian spirituality in positive change; 3) the inappropriateness of developing manual-guided interventions of American Indian cultural and spiritual practices; 4) the identification of evidence-based practices that might be modified and suitable for adoption by American Indian communities; 5) the possibility of writing a grant proposal in which a current evidence-based substance abuse treatment is adapted for American Indian communities (e.g., Seeking Safety); 6) past abuses and exploitation of American Indians in research and how researchers must address these concerns when forming future research collaborations; 7) the role of staff of an AIAN treatment program in all aspects of the research process (i.e., data safety and ownership, who is involved in interpreting the results and disseminating research findings); and 8) the advantages and obstacles of participating in CTN clinical trials.

The node also built a collaborative relationship with a tribe in rural Arizona. Node staff met with administrators and clinicians at the substance abuse treatment program that treated members of the tribe on the reservation. Training needs for staff working with substance using populations were identified, and the goals of the CTN were discussed. The possibility of conducting research was discussed, but at the present time it is unlikely that the Tribal Council will approve of research studies . The staff of the treatment program expressed interest in receiving training on the NIDA/SAMHSA Blending Product, “Promoting Awareness of Motivational Incentives,” This training was provided to the substance abuse treatment staff and staff of the diabetes prevention program. In addition, to ensure that the CA-AZ Node has an ongoing relationship with the tribe, colleagues at the clinical psychology program at the University of Arizona provided regular training to clinical staff on family therapy.

As with other nodes, the CA-AZ Node has learned that it was difficult to establish rapid communication with substance abuse clinicians who work on a reservation. Not only are staff members busy working with clients who have a multitude of problems, but they have to cope with stress and trauma that they experience in their own families and communities. Thus, patience was essential to maintain ongoing communication with the key contacts at the tribe. Having a regularly scheduled training event with University of Arizona faculty facilitated a line of communication with the treatment providers at the tribe. Despite an initial reluctance to participate in research, time spent with frontline clinicians and program administrators at the rural tribe and the AIAN urban treatment program has allowed node staff to building stronger working relationships, which have

increased the likelihood that these AIAN communities may participate in future research collaborations.

Ohio Valley Node Process Report

The Ohio Valley Node (OVN) has been working with Northern Plains American Indians within the states of Iowa, South Dakota, North Dakota and Nebraska since 2007 to explore the possibilities of collaborating in clinical research. During this period, staff from the OVN Regional Research and Training Center (RRTC) have developed close relationships with the Aberdeen Area Indian Health Service Department of Behavioral Health, with members of the Aberdeen Area Tribal Chairmen's Health Board (AATCHB), with the South Dakota Division of Alcohol and Drug Abuse Agency, with health centers serving Native American populations in urban areas and with Dr. Duane Mackey of the Prairielands Addiction Transfer Technology Center (PATTC). The AATCHB, a non-profit organization, was created in 1986 by the Tribal Councils of the 18 American Indian Reservations[1] in the Indian Health Service Aberdeen Area (North Dakota, South Dakota, Nebraska, and Iowa) and serves over 200,000 American Indians. AATCHB was established in order to provide the Indian people of the Aberdeen Area with a formal representative Board as a means of communicating and participating with the Aberdeen Area Indian Health Service and other health agencies and organizations on health matters. Dr. Mackey, a consultant to the OVN, is the South Dakota Coordinator for the PATTC and on faculty at the University of South Dakota. In addition, Dr. Mackey is an enrolled member of a Northern Plains tribe.

Throughout this relationship-building process, Dr. Mackey and OVN staff have had the opportunity to meet with a number of substance abuse treatment providers in both tribal, urban Indian Health, and non-tribal programs, as well as with representatives from South Dakota state agencies, to discuss areas of concern including substance abuse trends and barriers to treatment in Indian Country. Part of this process has included attending and presenting at several quarterly meetings of the Aberdeen Area Alcohol Program Directors Association (AAAPDA) to learn about current issues being faced in the reservation-based treatment programs and to provide updates on the progress of the activities resulting from the relationships being developed. While numerous difficulties are faced by the tribal treatment providers, the issues below were raised repeatedly as significant barriers:

- There is often a disconnect between state agencies and tribal treatment programs that impedes the funding of tribal programs and the sharing of resources. A number of factors have created this; the most notable being 1) that the system used for electronic collection of patient data required by the state is currently incompatible with the system used by the tribes, which creates barriers for the tribes in accessing state block grant funding, and 2) that the state certification process for programs and counselors did not initially recognize the certification process used by the tribes, which inhibited coordination of services between state and tribal facilities. Both of these factors have been the subject of ongoing negotiations for a number of years. No resolution is in sight for the electronic data issue, but as of July 2009, the state of South Dakota has implemented a mechanism for recognizing tribal certification for programs.
- The geography of the Northern Plains contributes to the trafficking of illegal substances in the area. Non-native drug traffickers from other regions enter the

[1] The Trenton Indian Service Area in western North Dakota and eastern Montana is not a Reservation; it consists of BIA trust lands allotted to members of the Turtle Mountain Band of Chippewa; it has a tribal council, chairman, and an Indian Health Service Health Center. This Service Area is counted as a Reservation in this application in order to simplify the text.

reservation to distribute illegal drugs and/or run illegal methamphetamine labs, hiding in the remoteness of the reservations. Although the tribal police forces are vigilant, the vast distances involved on many of the reservations makes it difficult for law enforcement to apprehend these traffickers; by the time officers learn of their presence on the reservation and travel to where the traffickers are located, they have completed their business and moved back off the reservation.

- American Indians in the Northern Plains struggle with extreme poverty and high unemployment level. These, along with a history of traumas such as being subjected to massacre and forced assimilation, provide a backdrop to the significantly high rates of suicide, drug abuse, and alcohol abuse found among the Northern Plains tribes.
- The Aberdeen Area Indian Health Service's Department of Behavioral Health, which works with tribal substance abuse programs through a contract process, reports being underfunded to meet all of these needs. Consequently, tribal substance abuse programs also report that they do not have enough funding to meet the demands for substance abuse services on the various reservations.
- Many of the tribes reported that they do not have the funding and/or facilities to provide detoxification services at the present time.
- The tribal alcohol programs do not have enough residential treatment beds to provide substance abuse services. Therefore, many tribal members in need of substance abuse treatment services are sent off to non-tribal treatment programs in the region.

It is important to note that despite these significant barriers, the Aberdeen Area tribes have maintained a commitment to providing quality treatment and prevention to the extent feasible. The network of treatment providers represented in the AAAPDA work together to problem-solve, disseminate information, and advocate for their people. Further, many tribes have developed Methamphetamine Task Force groups to address the influx of methamphetamine on the reservations and are open to identifying ways to prevent and/or treat substance use disorders more effectively within their tribes.

A tribal-based participatory research approach was used to design, develop, and implement the NIDA study: CTN-0033-Ot-4: *An Exploration of Methamphetamine and Other Drug Use and Treatment Options Among Urban and Rural Northern Plains American Indians.* In addition to the Ohio Valley Node, Dr. Mackey, and the AATCHB, collaborators for this study include the City County Alcohol and Drug Program (Rapid City, SD) and a Community Advisory Board with representatives from three Northern Plains tribes. Starting in March 2008, weekly teleconferences were held to begin initial design of the study. Potential Community Advisory Board members were identified and approached in May, and a face-to-face protocol development meeting was convened in June 2008 with OVN representatives participating by teleconference. Note that elements of this event typified some of the constraints inherent in developing research partner ships such as these: the OVN staff was scheduled to meet with the CAB face-to-face but ended up meeting via teleconference due to the cancellation of their airline flight. A final version of the general protocol was approved by the Advisory Board later that month, and weekly calls continued as the team moved toward implementing the procedures associated with the urban, non-tribal treatment site. Following the necessary regulatory protocol, the urban procedures initiated in October 2008; study procedures at that site are completed as of 7/31/09. In November 2008, the study team and the Community Advisory Board began working on study procedures that would be implemented within

the individual tribes. As each tribe differs in needs and structure, individual ancillary protocols were developed for each tribe. As with the treatment process, geographical issues have affected the research process as well. Regulatory procedures for these tribe-specific protocols began in January 2009, but because of long-lasting severe winter weather in the region, tribal regulatory entities were unable to respond until April 2009. Since April, the process has taken several additional months to pass through the multiple levels of approval necessary; coordinating and communicating with all the involved parties has required ongoing effort. At present, the ancillary protocols respective to each of the three participating tribes have been approved by each tribe's review board, legal counsel, and/or Health Committee, and have been approved by each Tribal Council as well. The Aberdeen Indian Health Service has also reviewed each proposal and has given provisional approval awaiting final approval from the tribal councils. Now that those approvals have been received, the study team is awaiting final approval from the IHS IRB and then will submit for approval through the University of Cincinnati.

Lessons learned from this process include:

- The Northern Plains Tribes are open to conducting research on the reservation with equal participation as partners in the research process
- Urban Indian Health programs are also open to participating in meaningful research projects.
- Regulatory issues with the tribes are complex and require extra time to pass through the multiple layers of authority
- Additional factors, such as weather, geographic distance, changes in tribal procedures and personnel, and seasonal cultural activities (such as Sun Dance) must be taken into consideration when planning for study approval and implementation
- Maintaining an ongoing relationship between researchers and tribal communities throughout the life of the research project, including the involvement of a Community Advisory Board, is critical for the success of the project.

As a result of the relationships developed during this process, OVN staff and collaborators from the AATCHB and their associated tribal substance-abuse treatment programs have participated in two major meetings aimed at exploring research efforts with American Indian communities. Four members of the study Executive Committee (including the Advisory Board) were presenters at the NIDA-sponsored workshop "Conducting Research with American Indian/Alaska Native Communities in the CTN" held in October 2008. In June 2009, Dr. Nora Volkow, Director of NIDA and Dr. Betty Tai, Director of NIDA's Center for the Clinical Trials Network, participated in a joint meeting with representatives from the AATCHB, tribal substance-abuse treatment providers, tribal college health program representatives, urban treatment programs serving American Indians, the state of South Dakota, the Indian Health Service, and the OVN to discuss the current state of substance abuse and other behavioral health concerns among Northern Plains Tribes, and to identify potential areas for intervention and research.

Oregon- Hawaii Node – Process Report

The Oregon-Hawaii Node (OR-HI) partnered with the Northwest Portland Area Indian Health Board (NPAIHB) to assess drug use patterns among American Indians and Alaska Natives (AI/AN) admitted to reservation-based and health clinic-based addiction treatment centers. The NPAIHB, established in 1972 and funded by the Indian Health Service and the Centers for Disease Control and Prevention, provides technical assistance to the 43 federally recognized tribes of Oregon, Washington, and Idaho. In 1996, the NPAIHB established the Northwest Tribal Epidemiology Center to conduct research on health care delivery and prevention of chronic disease. Health services researchers and epidemiologists from Oregon Health & Science University work in close collaboration with the NPHIHB and its EpiCenter. Most research projects are community-based and participatory, and the Executive Committee of the NPAIHB and delegates from member tribes serve the role of community oversight, along with project specific community advisory committees. All research protocols are reviewed and monitored by the Institutional Review Board of the Portland Area Indian Health Service.

By consensus resolution, the 43 tribal delegates of the NPHIHB identified methamphetamine use prevention and treatment as a "Key Indian Health Issue" (http://www.npaihb.org/health_issues/issue_methamphetamine/). Anecdotal accounts suggest that Indian reservations are often targeted for distribution of methamphetamine produced in Mexico. Methamphetamine remains a large public health burden on the tribal communities in which it is prevalent, challenging public health, health care and treatment, law enforcement, and criminal justice systems.

The OR-HI Node is working with two large reservation communities: one community of 4,000 is located central Oregon, and the other of 10,000 members is located in central Washington State. Additionally, data are collected at a regional alcohol and drug treatment center in Portland that provides both outpatient and residential treatment to AIANs. Combined, the two rural community sites and the urban site provide a sample of drug use among AIANs seeking treatment in the Northwest US.

The study characterizes treatment needs and assesses impacts of methamphetamine and other drug addictions on individuals, families, and communities. The two specific aims are:

1. Conduct interviews using a standardized questionnaire routinely used in treatment clinics: the Addiction Severity Index, or "ASI".

2. Conduct focus groups (talking circles) with leaders, treatment providers, patients, and families to assess methamphetamine use, treatment services, and the health, legal, financial, and social impacts on tribal communities.

A secondary aim is the pilot-test of the anonymous respondent-driven sampling method to assess addiction severity in methamphetamine users who are not in treatment. During 2008-2009, Tribal Councils, Health & Welfare Committees and the administration of the urban clinic reviewed and approved the study protocol. In turn, Institutional Review Boards for the Portland Area Indian Health Service and Oregon Health & Science University also reviewed and approved study procedures. Training on interviewing methods and the ASI was conducted in Spring 2009 and 15 counselors, all of whom are AI/AN, received ASI interview training. Data collection at reservation and

community sites began in April 2009, and to date, over 50 interviews have been completed with a goal of reaching 75 interviews. Focus group scripts have been completed and the focus groups with providers, patients in treatment, and affected families will be conducted in September and October 2009.

The OR-HI node also received supplemental funding to include a southeastern tribe in this effort. Because this tribe had already developed a number of initiatives to combat methamphetamine abuse, many of which were based on consultation and planning in tribal communities, the focus group component of the study seemed duplicative. Accordingly, we focused efforts here on identifying existing data on methamphetamine and articulating a plan to get that data into analyzable form to prepare reports for the tribe and for the MOD project of the CTN. The tribal behavioral health director devoted 10% of a calendar year on the project through a formal subcontract with OHSU.

Initial consultations with tribal health administrators and relevant program directors identified unanalyzed ASI data from one of the tribal residential treatment centers as an important, but underutilized, source of existing information, so the project prioritized the entry of these paper copies. A student volunteer entered this data for the tribal treatment program, and de-identified data was released to OHSU investigators following approval from the tribal IRB. This work underscored a keen interest in developing sustainable data systems for the tribal treatment programs and the identified a need for surveillance systems to better shape prevention efforts.

<u>Lessons Learned</u>

- Even with a long-established record of research collaboration between the NPAIHB and OHSU, the review and approval of a research protocol by the IHS and university IRBs takes time to complete.
- The tribes of Oregon, Washington, and Idaho regard methamphetamine and other drug abuse as leading public health issues.
- The counseling staff and administrators of tribal substance abuse treatment programs are highly interested in participating in research and building their professional skills and treatment program capacities.
- Administrators of tribal treatment centers are appreciative of descriptive data collection but are more interested in participating in intervention research.
- The Addiction Severity Index (Native American Version) appears to be practical to use as a data collection instrument with counselors at tribal treatment centers, but its use needs to be balanced against other data collection demands on programs, including those driven by other grant-funded activity.

Pacific Northwest Node – Process Report

PNW Study

The Pacific Northwest CTN Node is working with several American Indian/Alaska Native (AIAN) communities in Washington State and Alaska. Our overall study plan is to gather qualitative information through semi-structured focus groups and individual interviews from a variety of community key stakeholders about their perspectives regarding the current substances of concern (including methamphetamine) and the challenges, difficulties, and needs that these present for the community. Equally important, key stakeholders are also being asked for their perspectives regarding existing community strengths and resources around substance use/abuse prevention and treatment, in particular what might already be working in their communities. We are committed to collaboration with our community partners at every step of the research process and utilize a CBPR/TPR approach in our work. Our team of three includes a doctoral level Native investigator (Tlingit) who has ongoing relationships with many of the participating communities.

For all of the communities with which we have partnered, we first invited each to participate and then requested approval and permission to proceed with developing the research partnership and research protocols. We sought to build trusting relationships and research partnerships through conversations, meetings, time spent in communities, and participation in community events; this is an ongoing and important process in CBPR/TPR. In each community, there are key contact persons who have helped to coordinate each of the needed steps. Although each community has different research procedures, these steps have usually included presenting the study to and discussing it with Tribal governments (e.g., Tribal Council or Tribal Senate), health and wellness teams or boards, and Community Advisory Boards. In addition, documented approvals have been obtained as required by specific community protocols and in accordance with our MOD research partnership principles, including Tribal Council Resolutions and Memoranda of Understanding.

Communities are currently at various stages of the study process which reflects their willingness, readiness, resources, and community procedures for engaging in research. In some communities, Community Advisory Boards (CAB) have been convened and have collaborated with UW researchers to develop study plans that are specific to each community's needs; other communities are still in the early stage of identifying and developing CABs. Communities have also varied in their choice of Institutional Review Board, with some choosing to utilize a University of Washington IRB committee, and others choosing tribal review by an Indian Health Services IRB. In some cases, it has been necessary for communities to obtain a Federalwide Assurance and to sign an IRB Authorization Agreement in order for them to use the IRB of their choice. Data collection in these communities will begin as soon as IRB approvals are received.

True to CBPR/TPR principles, communities have partnered with us to shape their own study plans; therefore the final protocols differ somewhat in each community. For example, communities are deciding to hold a range of focus groups and interviews, with some communities choosing to hold 2 and others as many as12 focus groups; similarly, we will conduct anywhere from 5 to 20 key stakeholder interviews in each community or village. Some communities have chosen to focus on community key stakeholder and health/wellness service provider perspectives about the community, and others have decided to include current substance abuse / chemical dependency treatment clients

and persons in recovery. Finally, most communities have adopted (with some modifications) a core group of questions about: 1) the existence or occurrence of substance use and abuse within the community (i.e., prevalence); 2) effects of substance use/abuse on the community (i.e., impact); 3) community actions to prevent substance abuse, including community strengths and resources (i.e., prevention); 4) the availability and effectiveness of substance abuse treatment in the community (i.e., treatment availability and effectiveness); and 5) tribal and local cultural influences on prevention or treatment (i.e., culture). In addition, questions will be asked of current treatment clients and persons in recovery in some of the partnered communities which may also elicit information about what facilitated or served as barriers to their entry into treatment, what is/was most and least helpful for them during or after treatment, and whether there was a turning point before or during treatment that facilitated the path to wellness/recovery. In addition to the research activities described above, we have begun to collect similar data through telephone interviews with Washington State tribal health directors or their designees, such as chemical dependency treatment program managers. Finally, our overall study includes the analysis of a subset of existing substance abuse treatment data contained within the Washington State Division of Alcohol and Substance Abuse's (DASA) Treatment and Report Generation Tool (TARGET) database with those communities who have given us permission to do so. These data will be analyzed to assess possible trends in primary substances upon treatment admissions and other treatment trends.

Accomplishments and Lessons Learned

Some members of the PNW MOD team have had a great deal of experience working with AIAN communities using CBPR/TPR approaches and others have had the opportunity to gain these skills along with our community partners. It has been a pleasure and an honor to become acquainted with and to learn from our partnering communities over time. We are committed to building long-term relationships, and it takes time to lay the foundation for trust and equitable partnering. In particular, the importance of university based research staff being willing and able to spend time in the community is critical. We have consistently heard that the communities appreciate seeing the researchers at community events and activities in addition to research related meetings. It can sometimes be challenging to schedule this time, but when we do it is one of the most enjoyable parts of our work.

This process is also a learning experience for communities and for university departments, such as the grants and contracts office and the human subjects division. Many opportunities have arisen in which education and "training" of our own institution has been needed. For instance, we need to recognize that data gathered are ultimately the property of the communities, and we also need to allow them to make decisions about how to best protect the privacy and confidentiality of their community members who participate in research. The researchers have learned the importance of timelines and clear communication about necessary procedures such as IRB review and university approval of project documents such as MOU's that may require negotiation between a sovereign Tribe and a university. Coordinating these materials between community review and approval and university review and approval usually takes additional time, sometimes months, which must be built into project plans and timelines.

Along with the joys and satisfying collaboration of this work, there have also been challenges and we continue to learn from each other. We are accustomed to a western/institutional timeline with rapid communication back and forth; however, this sort

of pressured schedule sometimes does not work well with AIAN communities. It may not take into account the realities of the demands faced by our community partners in light of their commitment to providing the best possible services to their communities while partnering on research projects with little immediate or apparent benefit. This is partly due to our having different priorities, resources, traditions, experiences, and expectations than our Native research partners. Researchers need to be mindful of community priorities, some of which vary at times during the year for reasons such as subsistence and cultural activities. Although research might be a priority in our minds and schedules, this is not always the case in communities and it requires the valuable and scarce resources of staff time, effort, and money in order to coordinate and move the study forward. We have learned that it is necessary to fund staff time for community based partners so that study collaboration does not detract from existing needs or services provided within the communities. Furthermore, many of our partnering communities are located in geographically isolated areas and thus struggle with meeting their community members' everyday needs; being at a distance from our research offices requires time and resources for us to travel to the communities. Because building trust and true collaboration means that university based staff who may be accustomed to working from their offices will need to spend a great deal of time in the community, it will be necessary to build additional time and resources into future studies. In addition, we, as university based researchers, must understand that much of the time we devote to our research partnerships is a gift of our time rather than a portion of our work day.

Southwest Node – Process Report
2009-8-28

NNR-08.241; The Navajo Nation Human Research Review Board has reviewed and given approval for this section only

Methamphetamine in Native American Communities in New Mexico:

There is a perception that methamphetamine use is prevalent in American Indian communities, yet limited data are available. In the reports we came across that pertained to our geographic location in the Southwest, there was some evidence that methamphetamine did seem to be a serious problem for American Indians. For example, Indian Health Service (IHS) reported that methamphetamine use among Native Americans is three times higher than that of the general population and that 30% of Native American youth have tried methamphetamine. The Youth Risk Behavioral Survey (2004) reported that 15% of the high school students in or near the Navajo Nation reported lifetime methamphetamine use.

To further investigate this research question of the nature and extent of methamphetamine use, we set out to develop collaborations with tribes and Native American treatment programs in order to explore the epidemiology of methamphetamine use and co-occurring problems and disorders in diverse Native American communities in and around New Mexico. Our goal was to have a better understanding of the severity of methamphetamine use in Native American communities, to identify particular strengths and protections provided by tribal affiliation, and apply our findings to future efforts in prevention, treatment research.

We began by talking with clinical directors in tribal treatment programs to learn more about their perspectives regarding problematic use of methamphetamine in their communities as well as resources for substance abuse prevention and treatment. Questions we were curious about were:

- *The amount of methamphetamine use in Native American populations*
- *Problems related to methamphetamine use (e.g., injury, trauma, infectious disease, mental health)*
- *Protective factors against methamphetamine use (e.g., spirituality, social networks, community involvement)*
- *The availability and helpfulness of treatment and other forms of help for methamphetamine use*
- *Ideas about what is needed to address methamphetamine use more effectively*

Reconciling Different Approaches, Questions, and Goals

"We'd like to work with you on a study of methamphetamine use in your community…"

As we began approaching sites throughout rural and urban New Mexico and had initial discussions related to this project, one of the very first things that came up was the providers' opinions that methamphetamine was not the big problem in the population they served. The providers felt that alcohol and other drug use (e.g., heroin, cocaine and prescription drug use) continued to be the primary substances people were struggling with. We therefore had our first encounter with "creative tension" (a term used by one of our tribal collaborators) between the research agenda we had and the needs

of the tribal communities. The providers felt that this research didn't interest them because methamphetamine wasn't a problem they found to be highly prevalent in the community. This was one of our first "aha" moments as we began to work within the community-based participatory research approach. We discovered that our own curiosities and questions weren't necessarily the same questions held by our community partners and that we needed to back-track to begin with asking the question of "what questions do need to be answered in your community?" Questions our tribal community partners had were:

- *What drugs are people using most in our communities?*
- *What's working in the communities to keep people from using drugs?*
- *Where are the drugs coming from?*
- *How effective are our current programs in helping people with drug problems?*
- *How would this research this benefit our community?*
- *How does this research help us provide better treatment?*
- *What are the risks?*
- *Will trainings/educational materials about drug use be provided?*
- *How will our community members be protected?*

We found that by broadening the initial questions about a specific drug (methamphetamine) to drug use in general, and by learning about the drug use not only from the perspective of the people seeking treatment, but also through the inclusion of providers and the community members, that these revisions created questions the tribal programs were excited about in working with us to better understand. Together with the communities, we decided that it would be helpful to have three types of data collection: focus groups with providers, patients and community members; phone surveys with people working in schools, treatment agencies, and law enforcement; and Addiction Severity Index (ASI) self-reported substance use for people presenting for treatment.

In some ways, it's what we have known all along about helping relationships: offering people options that fit with their own needs, wants, and desires resulted in increased readiness and willingness to work together on a research agenda. We had attempted to come in with our own identification of the problem, and the community leaders gently reoriented our approach from the prescriptive "we have what you need…" to the evocative "what ideas do you have? How can we help you answer those?"

"…This is a one-year supplement"

Implementing research in a tribal community is a lengthy process. It was important to have detailed discussions and receive feedback and input from the tribal collaborators working directly with us as investigators and the larger group of agency staff. For some agencies, we assumed that a "sounds good!" response from the clinical director meant that if we had the director's approval to do the study the clinicians working for him or her would be in agreement. During the early stages, we underestimated the impact of the larger treatment provider community and assumed the Western top-down chain of command. We found, however, that for many agencies the clinical staff as a whole needed to hear the proposal, discuss the pros and cons, and made a collective decision as a group.

We then needed the larger community's support, so we attended chapter house meetings and tribal councils during monthly meetings to discuss the research in more

detail. These chapter house meetings take place each Sunday throughout every chapter of the Navajo Nation. The chapter house meetings include a panel of chapter officials and members of that chapter community. Community issues and developments are addressed, and often various decisions impacting the communities are made. Prior to applying for approval from the Navajo Nation to conduct the MOD project, we were asked to seek support from at least two Navajo chapter houses. We sought support from the three chapter houses in the areas which we planned to partner with community treatment agencies. Having the support of the local chapters, we were able to seek further support from the local agencies. Once we had the agency and tribal support and detailed aims of the study, we moved forward with university IRB approval and then with Navajo Nation IRB approval. The Navajo Nation IRB process requires that all applications (as well as any revisions) be submitted to the agenda one month prior to the board meeting. The PI and other core research staff are encouraged to then attend the meeting (held in Window Rock, Arizona) one month later. We then hear feedback and if any revisions or changes are suggested we complete the same process of submitting for the agenda and then attending a meeting two months after the initial meeting.

One issue that required lots of steps and was particularly time-consuming was the issue of data ownership. In NIH funded studies, it is typically the case that the University and NIDA (for example) own the data and researchers are obligated to publish the findings of their study. When we completed the IRB application for the Navajo Nation, one of the agreements we signed was that the Navajo Nation would be the sole owner of all data collected and retained a right to review all publications and presentations resulting from our study. Therefore, we had to amend the Data Sharing Agreement we had with NIDA and work with our University Counsel and NIDA to give sole ownership to the Navajo Nation. Some of these steps are still ongoing and the variable stages of research efforts with different treatment agencies seem to reflect the degree of interest in this research study and the degree of familiarity with research.

"See attachment and provide feedback…thanks!"

We quickly realized that email was not the preferred method of contact. After drafting initial versions of the protocol and IRB documents, we would send it to our tribal partners and not hear anything back. The value of routine in-person contact was a stark contrast to our Western approach of email and other forms of rapid communication as the primary sources of communication. Instead, we began having weekly conference calls and making weekly visits to one of the programs in Gallup, New Mexico (approximately 2 hours away) as the method for developing the protocol and working on the Navajo Nation IRB application. We also began having more frequent contact with two other sites in Farmington (approximately 3 hours away).

We have a MOD "squad" of three university-based investigators working on this protocol in different capacities as well as our community partners and several individuals working as support staff. The treatment programs have made it clear that they want to be able to put faces with names, and prefer that anyone mentioned anywhere in the research protocol or who is involved directly or indirectly with the project should be present during meetings. Thus, we have attempted to have face-to-face meetings as frequently as possible and have learned to quickly introduce any new members of our research staff who come on board. A significant challenge continues to be the struggle in trying to get work done remotely distance between UNM and sites and the time commitment required in scheduling meetings and accommodating the necessary travel time. Building these relationships, however, is the foundation for successful collaboration and there are clearly no shortcuts to these meaningful interactions.

"Our clinical director is no longer with this agency…"

Because of the length of this project, our study progress moved forward with the natural progression of clinical programs and we encountered significant staff turnover along the way. When a new staff member joins a program, we have learned to develop patience in orienting them to the study, addressing concerns, and working with them on changes if they deem them necessary.

Accomplishments

Some members of the Southwest Node's MOD group have a great deal of experience working with AIAN communities and have a more intimate understanding of the intricacies of community based participatory research. Most of us, however, have learned—and are continuing to learn and re-learn—these skills along the way. We have learned the importance of respect for communities and the necessity of communication, adding "how are we communicating?" along with other agenda items during our weekly conference calls. We have attempted to immerse ourselves as a means of familiarizing ourselves with cultural differences, such as the American Indian relaxed attitude toward time. We have learned to slow down, to accommodate the traditions of socializing, and to incorporate rituals such as food and prayer into our meetings. Out of respect for the communities that have graciously allowed us to learn with them, we view the community members with whom we work as collaborators in this process, and we are continuing to work on this research *with* these communities rather than *on* these communities.

Brief Reference Resource for CBPR/TPR
Methamphetamine and Other Drugs

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The Methamphetamine and Other Drug Research Group
Ethical Principles

Each of the participating nodes and partnering communities from the NIDA Clinical Trials Network will ask at least one community stakeholder to join the project conference calls and local discussions with those implementing the MOD project. Embracing Community-Based Participatory Research and Tribal Participatory approaches, the team working on this project is committed to community-based decisions and solutions that reflect each tribe's ability to identify and address its community concerns. Thus, the stakeholders are asked to engage in our discussions and review our materials and methods to ensure that:

1. Any research project conducted will have the goal of improving the quality of life of American Indian/Alaska Native people;
2. Our work is responsive to tribal community needs and desires;
3. There is ongoing, meaningful, and equal participation and collaboration from tribal community members;
4. Tribal community members are full partners during the entire research process, from conception to dissemination;
5. Our work reflects and respects cultural knowledge;
6. Our work encourages and reflects indigenous ways of knowing;
7. Our work reflects and respects cultural values and community priorities in the generation of research questions and processes;
8. The project is built from culturally appropriate processes and oversight, clear communication, and appropriate terminology;
9. Appropriate attention is given to tribal research codes;
10. Critical documents and materials are obtained, such as Tribal Council resolutions that authorize the research, Memoranda of Understanding that clearly state the roles and responsibilities of the research partners, and Federalwide Assurances if indicated;
11. Data are jointly owned by the tribal community and the research institutions; (this statement applies to all study sites except the Southwest Node. The Navajo Nation retains full ownership of the data and the right to review all materials prior to publication or presentation);
12. The tribal community reserves the right to review and approve all proposed publications and presentations;
13. Continued attention is given to the validity, reliability, and utility of the project findings, from both academic and indigenous perspectives;
14. Collaboration exists around decisions about what research questions are analyzed, how findings are interpreted, and how research is disseminated.
15. Dissemination strategies to American Indian/Alaska Native communities will be in a language and manner of sharing research findings that is culturally appropriate.