

AMERICAN INDIAN/ALASKA NATIVE HEALTH RESEARCH ADVISORY COUNCIL (HRAC)



RESEARCH ACTIVITIES

FISCAL YEAR 2009

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INTRODUCTION

The *First Annual Health Research Report* represents a compilation of findings related to important health research topics in American Indian and Alaska Native (AI/AN) communities. The American Indian and Alaska Native Health Research Advisory Council (HRAC) produced this report as a resource to share research findings with Tribes. It includes relevant submissions from various Department of Health and Human Services (HHS) operating and staff divisions, as well as HHS grantees.

HRAC BACKGROUND

The HRAC was established to provide HHS a vehicle for consulting with Tribes about health research priorities and needs in AI/AN communities, and collaborative approaches in addressing these issues and needs. The HRAC is comprised of elected Tribal officials, one delegate and one alternate from each of the 12 Indian Health Service (IHS) areas, and four Washington-based Tribal organizations. Federal partners participate in Council activities by providing input and support, and linkages with HHS' operating and staff divisions. These Federal partners include: Agency for Healthcare Research and Quality (AHRQ), Office of the Assistant Secretary for Planning and Evaluation (ASPE), Centers for Disease Control and Prevention (CDC), Intergovernmental Affairs (IGA), Indian Health Service (IHS), the National Institutes of Health (NIH) and the Office of Minority Health (OMH).

The HRAC serves three primary functions:

- Obtaining input from Tribal leaders on health research priorities and needs for their communities.
- Providing a forum through which HHS operating and staff divisions can better communicate and coordinate AI/AN health research activities.
- Providing a conduit for disseminating information to Tribes about research findings from studies focusing on the health of AI/AN populations.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

As one of 12 agencies within HHS, AHRQ supports health services research initiatives that seek to improve the quality of health care in America. AHRQ's mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. The Agency works to fulfill this mission by conducting and supporting health services research, both within AHRQ as well as in leading academic institutions, hospitals, physicians' offices, health care systems, and many other settings across the country. The Agency has a broad research portfolio that touches on nearly every aspect of health care. AHRQ-supported researchers are working to answer questions about:

- Clinical practice.
- Outcomes of care and effectiveness.
- Evidence-based medicine.
- Primary care and care for priority populations.
- Health care quality.
- Patient safety/medical errors.
- Organization and delivery of care and use of health care resources.

- Health care costs and financing.
- Health care system and public health preparedness.
- Health information technology.

The ultimate goal is to disseminate AHRQ's research findings to produce healthier, more productive individuals and an enhanced return on the Nation's substantial investment in health care. The articles and projects cited below are those issued/ongoing since the last update of AHRQ's AI/AN Program Brief which can be found on the Internet at <http://www.ahrq.gov/research/amindbrf.htm>.

Robeson County Primary Care Research Network Studies Prevalence of Diabetes in Local American Indians

The Robeson County project brought together 54 providers, 21 of which were American Indian, with the goal of creating a research network of primary care providers who largely serve American Indian patients in Robeson County, North Carolina—a rural county that is home to most of the state's more than 50,000 members of the Lumbee Tribe. In addition to creating the network of primary care practices where disease and Tribe-specific data can be collected, researchers estimated diabetes prevalence in adults and children and collected pilot data on diabetes care processes. The creation of the network, measurement of prevalence, and results of the pilot study will be used to direct further work for improving the identification of and care for diabetes in the community.

Principal Investigator: Bonnie Yankaskas, University of North Carolina at Chapel Hill
Grant HS15989, 08/01/06-07/31/08

Collaboration Creates Community Health Information Exchange Network

This project included a collaborative partnership among 12 agencies, including a rural acute care hospital, a large American Indian Tribal entity, an IHS hospital, a community health center, a health department, and a community consortium. The total patient population was 250,000 in 14 counties in rural northeastern Oklahoma.

The project included three components for improving quality of care. The first, Healthfinder, is an electronic and telephone resource to assist consumers in locating health providers and social services. It also assists providers in meeting community needs. Healthfinder (<http://www.okhealthfinder.com>) includes a special section to assist Native Americans in finding Tribal and Indian Health Service resources. The second component implemented an integrated community health information exchange network to facilitate provider coordination and transfer of critical patient information. The network is using Hastings Indian Medical Center, an IHS facility, and the Cherokee Tribe, the second largest Tribe in the country, as initial connections with the goal of allowing all IHS and Native American Tribes to connect quickly and inexpensively through the network. The last component explored areas for the most cost effective prevention strategies and adopts common objectives for prevention interventions and outcome measurement. This project built on an earlier 1-year planning grant (HS15364) by the same investigator.

Principal Investigator: Mark Jones, Tahlequah City Hospital
Grant HS16131, 9/30/05-9/29/08

Project Focuses on Healthy Weight and Cancer Outcomes for Women

This continuation grant builds upon its earlier capacity-building success during which the Montana-Wyoming Tribal Leaders Council developed a shared data resource and research infrastructure for participatory research among a majority of the 10 Tribes it serves. The continuation project will further build capacity for health care research on the priority health issues identified by the Tribes and continue to support culturally appropriate health programs. Three new research studies are planned: evaluation of interventions to promote healthy weight among women, examination of factors that contribute to breast and cervical cancer outcomes, and design and implementation of a “healthy reservations” model program for system-wide health improvement on reservations.

Principal Investigator: Gordon Belcourt, Montana-Wyoming Tribal Leaders Council
Grant HS14034, 9/30/06-9/29/11

Planned Care Cooperative

AHRQ transferred funds to IHS to support improvement in the delivery of preventive services through the IHS Chronic Care Initiative. Resources will be used to support the development of a systematic approach to communication and coordination between the clinical care community arms of the care team with a focus on improving primary and secondary prevention services to American Indians. In addition, resources will support the development of a culturally informed and tested training curriculum for clinical and public health staff providing self-management support services.

Family Health History Project with the Indian Health Service

AHRQ transferred funds to IHS and worked with IHS to help develop an electronic health record capable of including family health history in a structured, standardized, and interoperable format that can be integrated seamlessly with electronic clinical decision support tools.

Working with the Indian Health Service

AHRQ sent the *U.S. Preventive Services Task Force Guide* to all IHS primary care clinics in March of 2008.

Conference Support

AHRQ provided partial support for the *Annual AI/AN Research Conference* in 2008 and 2009.

RECENT ARTICLES PUBLISHED FROM AHRQ - SUPPORTED GRANTS

Cancer

Geographic Access to Cancer Care in the U.S.

Cancer. 2008 Feb 15;112(4):909-18.

Onega T, Duell EJ, Shi X, Wang D, Demidenko E, Goodman D.

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Background: Although access to cancer care is known to influence patient outcomes, to the authors' knowledge, little is known regarding geographic access to cancer care and how it may vary by population characteristics. This study estimated travel time to specialized cancer care settings for the continental U.S. population and calculated per capita oncologist supply.

Methods: The closest travel times were estimated using a network analysis of the road distance weighted by travel speeds from the population or geographic centroid of every ZIP area in the continental U.S. to that of the nearest cancer care setting under consideration: National Cancer Institute (NCI)-designated Cancer Centers, academic medical centers, and oncologists. Alaska and Hawaii were excluded because travel in these states is often not road-based. Population and geographic characteristics including race/ethnicity, income, education, and region were derived from U.S. Census 2000 data and from rural-urban commuting area classifications. Oncologist supply per 100,000 residents in Hospital Referral Regions (pHRRs) was estimated by region.

Results: Travel times of ≤ 1 hour were estimated for 45.2% of the population to the nearest NCI Cancer Center, 69.4% to the nearest academic-based care, and 91.8% to any specialized cancer care. Native Americans, non-urban dwellers, and residents in the South had the longest travel times to the nearest NCI Cancer Center compared with the overall U.S. population (median [interquartile range (IQR)] in minutes: 155 [62-308], 173 [111-257], and 164 [70-272], vs 78 [27-172], respectively). Travel burdens persisted for Native Americans and non-urban populations across all 3 cancer care settings. For all population strata, travel times markedly increased as the degree of cancer care specialization increased. The median oncologist supply for pHRRs was 2.83 per 100,000 individuals.

Conclusions: There are population groups with limited access to the most specialized cancer care settings.

Grant Support:

1 P20 RR018787/RR/NCRR NIH HHS/United States

T32HS000070/HS/AHRQ HHS/United States

Diabetes

Relation between the Level of American Indian and Alaska Native Diabetes Education Program Services and Quality-of-Care Indicators

American Journal of Public Health. 2008 Nov;98(11):2079-84. Epub 2008 May 29.

Roubideaux Y, Noonan C, Goldberg JH, Valdez SL, Brown TL, Manson SM, Acton K.
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Arizona, Tucson, AZ 85716, USA.

Objectives: The relation between the level of diabetes education program services in IHS and indicators of the quality of diabetes care were examined to determine if more-comprehensive diabetes services were associated with better quality of diabetes care.

Methods: In this cross-sectional study, the IHS Integrated Diabetes Education Recognition Program was used to rank program services into 1 of 3 levels of comprehensiveness, ranging from lowest (developmental) to highest (integrated). The quality-of-care indicators were compared among programs of differing levels with the 2001 IHS Diabetes Care and Outcomes Audit. Quality indicators included patients having recommended yearly examinations, education, and laboratory tests and achieving recommended levels of intermediate outcomes of care.

Results: Most of the 86 participating programs were classified at or below the developmental level; only 9 programs (11%) were ranked at higher levels. After adjusting for patient characteristics, program factors, and correlation of patients within programs, the researchers associated programs that were more comprehensive with higher completion rates of yearly lipid and hemoglobin A1C tests ($P < .05$).

Conclusions: System-wide improvements in diabetes education are associated with better diabetes care. The results can help inform the development of diabetes education programs.

Grant Support:

P01 HS10854/HS/AHRQ HHS/United States
P30 AG1 5297/AG/NIA NIH HHS/United States
P60 MD000507/MD/NCMHD NIH HHS/United States

Disparities

Race and Ethnicity Coding Agreement between Hospitals and between Hospital and Death Data

Medical Science Monitor. 2008 Mar;14(3):SR9-13.
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Background: Little is known regarding the reliability of hospital coding for race and ethnicity, particularly for Hispanics, Asians, and American Indians. These questions were assessed using hospital and mortality data from a large, diverse state.

Materials/Methods: The researchers used California hospital discharge data from 1998-2000 and linked death data. Crude agreement and kappas were assessed for race and ethnicity coding between admissions to different hospitals and between hospital admissions and death data.

Results: Overall kappas for race and ethnicity were higher between hospital and death data than between different hospitals. Kappas between hospital admission and death certificate data differed by

race and ethnicity. Reasonable kappas were observed for Blacks (0.92), Asians and Pacific Islanders (0.88), Hispanics (0.77), and Whites (0.76), but not for American Indians (0.27) or others (<0.01). Crude agreement for race and ethnicity varied for Asians and Hispanics based on country of origin. It was highest for persons born in China (93%) and Southeast Asian (93%) and Mexico (82%) and lowest for persons born in India (38%) and for "Other Spanish/Hispanics" born in (42%) and outside the US (46%).

Conclusion: Race and ethnicity coding agreement between hospitals and between hospitals and death certificate is generally good for most major and ethnic groups and subgroups with the notable exception of American Indians, persons of other races, and selected Asians and Hispanics born in certain countries.

Grant Support:

R01 HS10910-02/HS/AHRQ HHS/United States

Elder Health

Education is Associated with Physical Activity among American Indian Elders

American Indian and Alaska Native Mental Health Research. 2008;15(1):1-17.
Sawchuk CN, Bogart A, Charles S, Goldberg J, Forquera R, Roy-Byrne P, Buchwald D.
University of Washington, Harborview Medical Center, Box 359911, 325 9th Avenue,
Seattle, WA 98104, USA. (sawchuk@u.washington.edu)

Although educational attainment and physical activity levels tend to be positively associated in majority populations, this relationship has not been investigated in AI/AN elders. This study examined the association between education and physical activity among AI/AN elders (N = 107) using self-report and behavioral outcomes. Regression models showed that higher education was significantly associated with total caloric expenditure for moderate intensity physical activities and distance traveled during a 6-minute walk test of fitness. Additional research is needed to understand modifiable personal, social, and environmental physical activity barriers in these populations.

Grant Support:

5 P01 HS 10854-02/HS/AHRQ HHS/United States

A Randomized Trial to Increase Physical Activity among Native Elders

Preventive Medicine. 2008 Jul;47(1):89-94. Epub 2008 Mar 26.
Sawchuk CN, Charles S, Wen Y, Goldberg J, Forquera R, Roy-Byrne P, Buchwald D.
Department of Psychiatry and Behavioral Sciences, University of Washington,
Seattle, WA 98104, USA. (sawchuk@u.washington.edu)

Objective: Physical inactivity is common among older populations and American Indians. The objective was to compare two methods for increasing physical activity and walking among American Indian elders.

Methods: Researchers conducted a two arm randomized trial to increase physical activity in 125 American Indians aged 50-74 years at the Seattle Indian Health Board in 2005. Participants were randomized into either an activity monitoring (N=63) or activity monitoring with a pedometer (N=62)

arm over a six-week period. Outcomes included self-reported physical activity and well-being, and the 6-min walk test.

Results: There were no group differences in self-reported physical activities and well-being. The 6-min walk test yielded no between-group differences. All participants increased the frequency of leisure walking ($p<0.01$), frequency of all exercise-related activities ($p<0.01$), frequency of moderate-intensity exercise activities ($p<0.01$), and improved weekly caloric expenditure for all exercise activities ($p<0.05$) by the end of the trial.

Conclusions: Pedometers did not confer enhanced performance on the physical activity outcomes beyond those achieved through self-monitoring. Physical activity can be promoted among at-risk groups in a brief, inexpensive manner in primary care. Exercise prescription and culturally relevant enhancement strategies may optimize physical activity outcomes for elder American Indians.

Grant Support:

5 P01 HS 10854-02/HS/AHRQ HHS/United States

Perceptions of Care

Multi-method Evaluation of Health Policy Change: An Application to Medicaid Managed Care in a Rural State

From Research Briefs, Feb. 2009: <http://www.ahrq.gov/research/feb09/0209RA36.htm>

HSR: Health Services Research 43 (4), pp. 1325-1347.

Waitzkin, H., Schillaci, M., and Willgring, C.E.

The researchers studied the impacts of Medicaid managed care (MMC) in New Mexico at the individual, organizational/community, and population levels. They used a combination of sequential surveys to understand the impacts of MMC on individuals, ethnographic methods to assess effects for safety net institutions and local communities, and secondary databases to determine how sentinel events changed as population-level indicators. Three statewide surveys, performed at 9-, 18-, and 27-month intervals, found barriers to care, access, and utilization. For example, the 27-month survey found that 25 percent of Medicaid respondents reported a cost barrier to care. However, in general, Medicaid patients had relatively favorable experiences following implementation of MMC. In contrast, the ethnographic interviews found that personnel in safety net organizations experienced the transition to MMC as stressful and chaotic. The organizations experienced heightened financial stress and mental health services declined sharply. Analyses of databases showed that immunization coverage levels decreased significantly after MMC implementation.

Grant Support:

AHRQ Grant HS09703

Research Infrastructure Development

Personal Journeys, Professional Paths: Persistence in Navigating the Crossroads of a Research Career

American Journal of Public Health. 2009 Apr; 99 Suppl 1:S20-5. Epub 2009 Feb 26.

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Persistence in a research career can be readily understood within the trainee models that have emerged from undergraduate and graduate instruction. These models offer a common language for discussing training processes; serve as guides for assessing trainee needs; promise to render training programs that are more comprehensive and attentive than are current programs to the factors that contribute to academic and scientific persistence; and enable us to measure the elements that logically belong in research career development programs with greater precision, internal consistency, and generalizability.

Grant Support:

P01 HS10854/HS/AHRQ HHS/United States

P30 AG15297/AG/NIA NIH HHS/United States

P60 MD000507/MD/NCMHD NIH HHS/United States

ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

The Assistant Secretary for Planning and Evaluation is the principal advisor to the HHS Secretary on policy development in health, disability, aging, human services, and science; and provides advice and analysis on economic policy. ASPE leads special initiatives on behalf of the Secretary, and provides direction for HHS-wide strategic, evaluation, legislative, and policy planning. ASPE also is responsible for data and information policy development and coordination within HHS. Integral to this role, ASPE conducts research and evaluation studies, develops policy analyses, and estimates the cost and benefits of policies and programs under consideration by HHS and/or Congress.

ASPE conducted the *Characteristics of American Indians and Alaska Natives Participating in Temporary Assistance for Needy Families Program* study to gain a greater understanding of the characteristics and participation of AI/ANs in state and Tribal Temporary Assistance for Needy Families (TANF) programs over time. Administrative caseload data submitted to HHS by state and Tribal programs were used to obtain a full picture of the caseload sizes and characteristics of these populations.

Findings indicate that similarly to non-AI/AN TANF caseloads, caseloads for AI/AN families in state and Tribal programs have declined since the early 1990's. Furthermore, there has been an increase in TANF participation among AI/AN populations that coincides with the introduction of Tribal TANF programs, but does not reach mid-1990's levels. In addition, the findings reveal that differences exist with regard to the proportion of child-only cases, average grant amounts, average number of recipients per family, and work participation when comparing non-AI/ANs in state programs and AI/ANs in state and Tribal programs. Finally, the data clearly show differences in geographic location and travel time among the three groups; AI/ANs in state and Tribal programs are more likely to live in areas with greater travel times to urban areas, suggesting greater difficulty in accessing employment and health and human services. A research brief describing the study and its findings can be found at:

<http://aspe.hhs.gov/hsp/09/AI-NA-TANF/rb.shtml>.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Overview of Public Health Research at CDC

CDC and its National Centers and Offices support and foster research that creates knowledge, tools and interventions that people and communities need to promote health, prevent disease, injury and disability, and prepare for threats at home and abroad. The following are CDC's role in regards to developing and enhancing public health research:

- Developing and maintaining a CDC-wide research agenda and enhancing and leveraging resources for research;
- Evaluating and monitoring CDC's overall research portfolio progress in meeting the CDC research agenda;
- Enhancing CDC extramural research by developing, supporting and training in standardized best practices across CDC for the grant life-cycle; and
- Developing and supporting new research initiatives and peer review and grants management activities for cross-cutting research and public health priorities.

Research Support and Peer Review

CDC uses grants and cooperative agreements mechanisms to support extramural research projects. All extramural research applications to CDC are peer reviewed. Under the peer review process, applications undergo two levels of review. The initial merit review is conducted by a panel of external experts and overseen by a Scientific Review Administrator. The purpose of the secondary review is to consider programmatic and policy priorities in addition to the merit evaluations and rankings from the primary review. The secondary review is performed either by senior Federal officials or an advisory committee whose members are external to CDC. For more detail see the following internet site at:

<http://www.cdc.gov/od/science/PHResearch/peerreviewpolicy.htm>.

Grants and cooperative agreements are administered by scientific staff known as Program Administrators. In addition to the administration of research projects, Program Administrators interact with scientific investigators, assist with program planning and development, evaluate grantees' scientific progress, and identify opportunities for future research.

Federal Collaboration on Health Disparities Research

CDC, in collaboration with the U.S. Department of Health and Human Services' Office of Public Health Science (OS), Office of Minority Health, and the U.S. Department of Education's (DoED) Interagency Council on Disabilities Research (ICDR) has brought together Federal partners (HHS and non-HHS) during 2006-2007 to explore the complex nature of health disparities and the role research could play in advancing the elimination of health disparities. In a series of meetings with Federal partners across government, CDC jointly with HHS OMH and DoED ICDR formed the Federal Collaboration on Health Disparities Research (FCHDR), to provide an opportunity for Federal agencies to pool scientific expertise and resources to apply research findings faster and more effectively and efficiently in an effort to eliminate health disparities. These Federal representatives have worked across disciplines and missions to identify research priorities and strategies for cross-agency research collaboration. Such a coordinated effort can lead to greater improvements in the health of populations disproportionately affected by disease, injury and disability, including, but not limited to, racial and ethnic minorities,

women, children, immigrants, rural populations, people with disabilities, and elderly people or older adults. FCHDR is an outgrowth of CDC's efforts to develop *Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006–2015*.

Public Health Research Needs

The CDC publication, *Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006–2015* (also referred to as the *Research Guide* and available at:

<http://www.cdc.gov/od/science/PHResearch/cdcra/> has served as a critical resource for research areas that should be addressed during the next decade by CDC and its partners in response to current and future public health needs and events. Health protection research is research that supports health promotion, prevention of injury, disability, and diseases, and preparedness activities. Many Federal agencies have a distinguished and long track record of support of health-related research in their specific focus areas, and many agencies are guided by their own research agendas. What distinguishes the *Research Guide* from other health-related research agendas is that it is the first-ever comprehensive, long-term, national resource spanning all areas of health protection. The *Research Guide* is also intended to build on and complement the work of other Federal agencies and their research agendas.

The *Research Guide* will inform research initiatives that address other critical public health needs and research priorities of other agencies. CDC has developed the *Research Guide* with extensive input from its staff and a wide range of partners and stakeholders, including external researchers, other Federal agencies, state and local health departments, professional associations, universities, non-governmental organizations, business and worker organizations, community groups, American Indian and Alaska Native governments, Tribal leaders and organizations, and the public-at-large.

Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006–2015 serves the following purposes:

1. Describe the range of research most needed to provide critical evidence for the improvement of existing and the establishment of new public health programs and interventions.
2. A distinguishing and essential feature of CDC research is that it fills critical gaps necessary to improve public health programs, services, and response.
3. Improve the effectiveness of a broad range of public health disciplines through supporting innovative, cross-cutting, interdisciplinary and foundational research.
4. This research may cut across several public health fields and thus have a profound impact on the ability to protect and improve public health.
5. Serve as a platform for discussions with Federal partners about opportunities to collaborate in addressing the most pressing current and future public health problems.
6. Many public health needs can best be met through a coordinated research strategy involving multiple Federal agencies, which together can leverage their unique strengths and resources to more effectively solve national and global health problems.
7. Provide a basis for discussions with state and local partners about identifying opportunities for collaboration to better address health needs across the United States.
8. CDC will identify research gaps, fulfill research needs, and communicate research findings by collaborating with state and local entities that carry out the work of public health.

9. Promote opportunities to partner with academic institutions, professional associations, international agencies, Tribal organizations, businesses, worker organizations, and non-profit and community-based organizations to address institutional and community research needs.
10. Working with a wide range of partners to address public health can ensure that research findings are beneficial, practical and tailored to all groups of people and their communities.
11. Plan for and promote public health research needs. To be successful, effective communication and promotion of research needs and priorities are needed to improve health and public health practice.

AI/AN-Related Research Efforts

Research that addresses health issues facing AI/AN populations has long been a priority at CDC. As evidenced by the breadth of topics in the publications highlighted herein, research on this front takes place across many areas of expertise and within multiple CDC Centers/Offices. Our partners in the work that produced these publications have included the Indian Health Service and other Federal agencies; Tribal epidemiology centers; Tribal and Alaska Native health organizations; state health departments; and academic institutions. The focus of AI/AN-related research at CDC has been broad and includes infectious diseases and immunizations; cancer; diabetes; injury prevention; violence/suicide; environmental health; maternal and child health; health disparities; and public health policy research.

Selected Bibliography¹, 2008-2009 CDC AI/AN-Related Publications

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Byrd KK, Holman RC, Bruce MG, et al. Methicillin-resistant *Staphylococcus aureus*- associated hospitalizations among the American Indian and Alaska Native Population. *Clin Infect Dis*. 2009;49:1009-15.

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Dicker LW, Mosure DJ, Kay RS, et al. An ongoing burden: chlamydial infections among young American Indian women. *Matern Child Health J*. 2008;12:S25-29.

Espey DK, Wiggins C, Jim M, Miller B, Johnson CJ, Becker T. Methods for improving cancer surveillance data in American Indian/Alaska Native populations. *Cancer*. 2008;113(5 suppl):1120-30.

¹ Citations listed may also represent activities outside of the scope of the research and funding mechanisms described in the body of this document.

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Henderson JA, Espey DK, Jim MA, German RR, Shaw K, Hoffman RM. Prostate cancer incidence among American Indian and Alaska Native Men, United States, 1999-2004. *Cancer.* 2008;113(5 suppl):1203-12.

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INDIAN HEALTH SERVICE AND NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES

The IHS and the National Institute of General Medical Sciences (NIGMS) of NIH have a joint partnership supporting the Native American Research Centers for Health (NARCH). The NARCH initiative, currently in its ninth year, supports partnerships between AI/AN Tribes or Tribally-based organizations and institutions that conduct intensive academic-level biomedical, behavioral and health services research. This funding mechanism develops opportunities for conducting research, research training, and faculty development to meet the needs of AI/AN communities. As a developmental process, Tribes and Tribal organizations are able to build a research infrastructure, including a core component for capacity building and the possibility of reducing the many health disparities so prevalent in AI/AN communities. Specifically, the purposes of the NARCH initiative are to:

- Develop a cadre of AI/AN scientists and health professionals engaged in biomedical, clinical, behavioral and health services research who will be competitive in securing NIH and AHRQ funding;
- Increase the capacity of both research-intensive institutions and AI/AN organizations to work in partnership to reduce distrust by AI/AN communities and people toward research; and
- Encourage competitive research linked to the health priorities of the AI/AN organizations and to reducing health disparities.

The grant for these activities goes from IHS to the Tribal partner, which then subcontracts with the research intensive institution(s). This keeps the community in charge of the research, but draws on the university's expertise to accomplish the scientific and training goals of the NARCH. There is no research line in the IHS budget. The IHS therefore depends on the research agencies (such as NIH and AHRQ) for all of its NARCH funding. NIGMS funds the bulk of the research training and the core activities of each NARCH. The NARCH program then looks to the other institutes and centers to fund research projects that fall into their scientific areas.

In Fiscal Year 2009, the NARCH program issued over \$8 million in grants, which brings the total going to NARCH grantees (Tribes and Tribal organizations) over the nine years of the program to over \$52 million. Recent research projects and findings are included for some of the NARCH grantees including: Southcentral Foundation; Albuquerque Area Indian Health Board; Chickasaw Nation; Northern Plains NARCH; and Inter Tribal Council of Arizona. For more information on the NARCH program, please see: <http://www.ihs.gov/MedicalPrograms/Research/narch.cfm>.

Southcentral Foundation

Southcentral Foundation (SCF) in Anchorage, Alaska is an Alaska Native healthcare organization established by Cook Inlet Region, Inc. in 1982 to improve the health and social conditions of AI/AN people, enhance culture, and empower individuals and families to take charge of their lives. SCF contracts under P.L. 93-638, the Indian Self-Determination Act, are to provide a broad range of health and related services. SCF provides health-related services to over 56,000 AI/AN people in Alaska.

Cultural and Ethical Implications of Specimen Banking among Alaska Native People

Principal Investigator: Denise Dillard, PhD

The Indian Self-Determination Act, which has enabled AI/AN people to assume responsibility for management of health care delivery, has also allowed for AI/AN management of other programs such as research and utilization of samples from AI/AN people stored in the Alaska Area Specimen Bank (AASB). In the past 60 years, the AASB has been used for dozens of epidemiologic studies, but to date the ethical and cultural implications of tissue banking have not been explored among the AI/AN population.

SCF's Research Department Director Denise Dillard, PhD (Inupiaq), as the Principal Investigator of the "Ethical and Cultural Implications of Specimen Banking Among Alaska Native People" (NOT GM-05-104), has undertaken a 3-year study funded by NARCH Grant Number U26IHS300131 of the IHS with support from the NIH's National Human Genome Research Institute (NHGRI). This project uses community consultation and qualitative methods to explore the following questions about the Alaska Area Specimen Bank (AASB): 1) How did the AASB start and what has it been used for?; 2) What is the current composition of the bank?; and 3) What are Alaska Native's thoughts about research using specimens and biobanking?

The history of the AASB was explored through archival document review and 18 interviews with researchers who had accessed the AASB. The composition of the AASB was determined by examining a de-identified data set supplied by the CDC Arctic Investigation Program. AI/AN people participated in 29 focus groups statewide to provide their views regarding research using specimens and biobanking. Preliminary project results reveal that the AASB contains specimens from over 87,000 individuals, most (81%) of whom are Alaska Natives. Initial analyses of focus groups have revealed two broad categories of participant responses. The first category (research process) includes how Alaska Natives want research to be done and what should happen to specimens. Context (the second category) includes elements such as historical experiences with research which influence how Alaska Natives think about research and biobanking. Results of this project may influence the policies of the AASB and serve as a resource for other biobanks with specimens from Alaska Native people.

Pilot Study of Prenatal Alcohol Exposure among Alaska Native and American Indian Infants

Principal Investigator: Denise Dillard, PhD

SCF's Research Department Director Denise Dillard, PhD (Inupiaq), as the Principal Investigator of the "Prenatal Alcohol Exposure among Alaska Native/American Indian Infants," has undertaken a 3-year study funded by NARCH Grant Number U26IHS30001/01 of the IHS with support from NIH's NIGMS. This study seeks to determine the relationship between self-reported prenatal alcohol exposure and

detection of fatty acid ethyl esters in meconium of Alaska Native infants. While there were challenges in receiving Institutional Review Board (IRB) and Tribal approval, as well as in recruiting, 125 women participated in the study with 95 meconium samples collected. Of the participating women, 67 (54%) reported never drinking alcohol during their pregnancy, 46 (37%) drank only in the first trimester, 2 (2%) drank only in the second trimester, 3 (2%) drank only in the 3rd trimester, 6 (5%) drank in two of three trimesters, and 1 (1%) drank in all three trimesters of pregnancy. Participants were also asked questions regarding use of hygiene products and medicines. There were 101 (81%) participants who took prenatal vitamins during pregnancy, with 71 (57%) reporting that they took prenatal vitamins daily or almost daily. Pain relievers were used by 80 (64%) participants, the majority of whom used pain relievers approximately once a month. There were 88 (70%) women who reported using hand sanitizer and 59 (47%) women who reported using mouthwash during pregnancy. One in every five women reported using cold medicine at least occasionally during pregnancy. Other medications were used, but by fewer women and with less frequency. The meconium analysis for FAEEs by mass spectrometry is expected to be complete by November 2009, at which time the association between exposures to alcohol and the detection of FAEEs will be analyzed. Such results may assist with early detection of fetal alcohol syndrome and increase the occurrence of early intervention for this condition.

Tobacco-Free Alaska Native Families

Principal Investigator: Denise Dillard, PhD

SCF's Research Department Director Denise Dillard, PhD (Inupiaq), as the Principal Investigator of "Tobacco-Free Alaska Native Families," has undertaken a 3-year study funded by NARCH Grant Number U26IHS30001/01 of the IHS with support from the NIH's National Institute of Drug Abuse (NIDA). This longitudinal study seeks to determine the relationship between self-reported tobacco exposure and saliva cotinine levels for mothers of Alaska Native infants and the infants themselves. The study involves up to eight visits, one in each trimester and one at each of five well-baby visits. Four hundred women consented to participation, and follow-ups are ongoing given the longitudinal nature of the study.

The CDC provided 209 valid maternal saliva cotinine analyses for 147 distinct participants. Findings indicate over 40 percent of the 147 women continue to use cigarettes or smokeless tobacco during pregnancy. Almost three-quarters of participants (n = 109) reported exposure to second-hand smoke during pregnancy; 57 (39%) of these women were not smoking in the trimester of reported second-hand exposure and their cotinine levels were significantly higher than non-exposed non-smokers. Only 7 (5%) smoking women reported using quit-assist products, such as a medication or nicotine replacement therapy. These results may indicate a need for increased assistance with tobacco cessation for pregnant women, as well as increased education about the effects of second-hand exposure for the mother and fetus. For women who reported smoking, Pearson's correlation coefficient was calculated between the self-reported average daily number of cigarettes smoked and the logarithm of cotinine separately for each trimester. (The logarithm was used to fit an approximately normal distribution.) For those who smoked in trimester 1 (n = 19), 2 (n = 36), and 3 (n = 31) respectively, Pearson's correlation coefficient and p-value for the test of no correlation ($\rho = 0$) was as follows: $\rho = 0.60$ (p = 0.007), $\rho = 0.33$ (p = 0.051), and $\rho = 0.24$ (p = 0.20). The correlation declined each trimester and further study is needed to understand this relationship. Possible hypotheses include changes in nicotine metabolism, smoking habits, and accuracy of self-report over pregnancy, as well as possible sampling issues. Next steps include fitting mixed-effect linear models to account for the repeated measures across trimesters and expand analysis to include additional cotinine measurements from the CDC.

Albuquerque Area Indian Health Board

Tribal Cancer Control Project

Principal Investigator: Dr. Kristina Flores

It is essential to learn more about the factors that contribute to low cancer screening and cancer survival rates for Native Americans and to develop culturally appropriate interventions to address these disparities. This project employs a community-based participatory research approach to identify the barriers and facilitators to cancer prevention for Navajo men and women. This project is in collaboration with the Alamo and To'Hajiilee Band of Navajo, the Albuquerque Area Indian Health Board, and the University of New Mexico Cancer Center. Tribal Advisory Panels in each community inform and direct this project. Focus groups were facilitated to understand how community members view cancer in addition to the obstacles and avenues available to them for cancer prevention. Several issues related to cancer prevention emerged from these discussions, such as taboos about cancer, modesty during medical exams, the cost and quality of healthcare, referrals, and the overall need for culturally appropriate cancer information and support groups. A cancer-related survey was developed using this information and is currently being delivered in each community. Throughout this project, cancer education and training sessions are held to build community capacity around cancer knowledge, research, and grant writing. A Cancer 101 module called "What is Cancer?" was translated and videotaped in both Navajo and English in response to the community's request. Upon completion and analysis of the survey, specific recommendations will be developed and disseminated to the community, clinics, and relevant state agencies.

Listening to Each Other Curriculum Development

Principal Investigator: Dr. Nina Wallerstein

Utilizing a community-based participatory research (CBPR) approach, the University of New Mexico (UNM) Masters in Public Health Program worked with Tribal research teams in Jemez Pueblo and Ramah Navajo to adapt and implement an existing evidence-based Native American Family Intervention Project (from the Ojibwe people) to reduce risky behaviors in third and fourth graders. Given the interest in whether and how evidence-based programs can be implemented in and translated to other cultures, findings will address the process of working with two very different Tribal advisory committees and Tribal communities to co-create a culturally specific version for their communities. Potential outcomes of the CBPR process may include intervention additions as well as capacity building, ownership of the program and future sustainability.

Project outcomes to date include:

- Both communities adapted curriculum to their Tribal communities.
- Jemez Pueblo launched a Family Circle Curriculum program under Tribal Department of Education for purposes of sustainability.
- Jemez Pueblo submitted NARCH V application to develop a "Family Listening" center that will collaborate with other SW Tribes.
- Increased number of Tribal community research partners in two Tribal communities.
- Continued development of university research team.

Community-based Participatory Research Pilot Project

Principal Investigator: Dr. Nina Wallerstein

This pilot study was funded by the National Center for Minority Health and Health Disparities and administered through the Southern Colorado/New Mexico NARCH. The CBPR research team collaborated with 25 currently funded CBPR research projects to emerge with a preliminary set of guidelines and variables related to participation and partnership that will become critical to include in further CBPR studies.

Specific pilot project outcomes included:

- Developed a preliminary set of guidelines and variables related to participation and partnership that will become critical to include in further CBPR studies.
- Provided initial information and recommendations for the proposed community guide about which CBPR elements are essential for community and academic partners in order to create a successful partnership.
- Collected qualitative data from the Navajo Nation IRB, as the premier community controlled research process in the United States, to probe more in-depth CBPR processes, models, and outcomes.
- Developed a comprehensive secondary literature review of instruments and scales that address variables in the CBPR model.
- Publication of Chapter 21: What Predicts Outcomes in Community-based Participatory Research? In Minkler & Wallerstein (eds.) CBPR for Health: Process to Outcomes, 2nd edition, Jossey-Bass, 2008.
- Successful NARCH V grant - collaborated with the National Congress of American Indians to address gaps in CBPR research knowledge to better understand the promoters and facilitators to effective CBPR.

UNM Student Development Project

Principal Investigator: Dr. Gayle Diné-Chacon

The student development project aims to build the capacity of both Tribal communities and the University of New Mexico Health Sciences Center (UNMHSC) to collaboratively attract, recruit, and retain Native American students into health research career programs. The project is based on a theoretical framework, which posits that any successful minority-serving program must take into account differences in context and cultures. Therefore, critical aspects of this project will include: mentoring that provides role models, targeted recruitment efforts, opportunities to contextualize learning, networking advice and opportunities, and parental, familial, and community involvement. This student development project will focus its efforts along the educational continuum, from secondary school through graduate studies, to maximize its reach and effectively stimulate interest and retention in health research careers.

Accomplishments resulting from this project to date include:

- Five students who participated in NARCH activities while in high school are attending college.

- Developed a fiscal management system between Tribal communities and UNMHSC to implement activities.
- Established a student support navigation system.
- Recruited AI mentors enrolled in UNMHSC medical school, pharmacy, public health, occupational therapy, and nursing.
- Implemented a mentor program at UNMHSC for AI graduate, undergraduate, and secondary school students, and between AI faculty, researchers, and students.
- Nine American Indian students enrolled in UNM medical school (Fall 2009). This is the highest number of students enrolled since the UNMHSC Medical School was established.

Chickasaw Nation

Overall Principal Investigator: Tina Cooper, M.D.

Prevention of Secondary Disabilities in Native American Children with Fetal Alcohol Spectrum Disorders

Principal Investigator: Lisa Swisher, PhD

Researchers at the University of Oklahoma Health Sciences Center (UOHSC) Child Study Center have partnered with the Creek and Cherokee Nation Behavioral Health Clinics to implement and evaluate Native American children with prenatal alcohol/drug exposure and their families. The specific aims of this project are to reduce or prevent secondary conditions (e.g. behavior difficulties, parenting stress), and to provide education/advocacy to NA families to aid in their use of resources for their children with prenatal exposure to alcohol. Originally the project sought to compare a Parent Support Management (PSM) intervention with an evidenced-based intervention, Parent Child Interaction Therapy (PCIT), which would be applied to this high-risk population. Both intervention programs would also include an education and advocacy component. Those targeted for the study are Native American children (3-7 years) and their families. Similar modifications were proposed for PSM. Native American professionals will conduct all therapeutic services. Families recruited for the study will receive a baseline interdisciplinary evaluation by a team of professionals. Following the educational component, families are to be randomized to the 12 session intervention components. The families in each will be evaluated at baseline, after education/advocacy, at midpoint of treatment, post intervention, and 6 and 12 months from completion of intervention. Behavior and parenting stress measures, placement changes, child maltreatment reports, and service utilization will be gathered.

Student Development Project

Principal Investigator: Dr. James J. Tomasek

The NARCH Summer Undergraduate Research Program is designed to offer outstanding Native American undergraduate students intensive, hands-on research opportunities in the laboratories of a select group of UOHSC biomedical faculty members and mentors. Studies show that undergraduate research programs are essential to the successful recruitment of highly motivated and talented graduate students. A significant dimension of these programs is to introduce students to the rigorous academic preparation required for biomedical research careers and to encourage them to select the UOHSC for their graduate education. These programs have proved to be an excellent avenue to recruit women and under-represented minorities, particularly American Indians, into the field of biomedical research.

The overall objectives of the Oklahoma NARCH (ONARCH) Student Development Program are to:

- Increase the number of American Indian undergraduate students who apply to, matriculate into, and graduate from programs at UOHSC that lead to degrees in health sciences and in biomedical research.
- Help place American Indian graduates from UOHSC into academic research positions.

Funds from the NARCH grant provided stipends for six American Indian students who participated in the 2009 Summer Undergraduate Research Program. At the conclusion of the nine-week program, participants submitted their scientific abstracts and presented their findings at a closing poster session, which included a keynote speaker and a reception.

Understanding Rheumatic Disease in Oklahoma Tribal Members

Principal Investigator: Judith James, MD

The long-term research goal of the program is to understand the etiology and pathogenic mechanisms of autoantibodies in systemic rheumatic disease. Rheumatic diseases, such as rheumatoid arthritis, systemic lupus erythematosus, scleroderma, and osteoarthritis, have all been shown to be increased in prevalence and severity in American Indian communities. The impact of the increase of these incredibly morbid diseases on the welfare of members of the Oklahoma Tribal Nations is compounded by the serious limitation placed on contract health care and the decreased availability of rheumatic disease care to many Oklahomans based upon manpower issues. The specific aims of the project are to:

- Define the serologic and clinical features which differentiate the rheumatic disease of Tribal members with European-American, African-American and Mexican-American counterparts to aid in refinement/improvement of diagnosis and clinical care.
- Understand the pathogenesis of unique autoimmune responses in American Indian patient rheumatic disease processes.
- Provide educational opportunities for students with American Indian heritage interested in careers in biomedical research or clinical care.

Eighty-eight patients have been enrolled in the observational aspect of the study. Demographic, clinical, therapeutic and disease activity data have been collected for each enrolled individual and demographic and rheumatic disease histories have been obtained for parents and grandparents of each patient. Of the 88 currently enrolled patients with complete clinical data extraction available, 14 (19%) have systemic lupus erythematosus [SLE], 8 (9%) have systemic sclerosis [SCL], 32 (36%) have rheumatoid arthritis, and 15 (17%) have other forms of arthritis including polyarticular arthritis, atypical RA, osteoarthritis, and polyarthralgias. Blood samples from each recruited patient were collected and transported to the Oklahoma Medical Research Foundation (OMRF) for autoantibody analysis. Rheumatic disease clinics have been established at the Chickasaw Nation's Carl Albert Indian Health Facility and the Cherokee Nation's Three Rivers Health Center.

ONARCH Faculty Development and Mentoring Program

Principal Investigator: Valerie N. Williams, PhD

This project is a collaboration among the Chickasaw Nation, Cherokee Nation, and UOHSC's Faculty Development Office. This study aims to:

- Develop research methods and an educational and mentoring structure to support enhanced research knowledge and skills development for ONARCH participants in the established UOHSC faculty development and mentoring program.
- Recruit and engage Native American health professionals, Tribal health system and IHS professionals in the UOHSC faculty development and mentoring program.
- Evaluate faculty development outcomes and share the interdisciplinary model and results with other academic health centers and Native American Tribes nationwide.

Research project mentors were identified and named as the project's "Faculty Advisors." Formal agreements were developed with these individuals to assist with curriculum development and review, didactic presentations to participants, and mentoring and feedback to participants on their individual research projects. Six participants were selected to participate in the 2008-2009 program year.

Aberdeen Area Tribal Chairmen's Health Board

Northern Plains NARCH is a program of the Aberdeen Area Tribal Chairmen's Health Board (AATCHB). AATCHB was established to provide the Indian people of the Aberdeen Area (Iowa, Nebraska, South Dakota and North Dakota) with a formal representative board as a means of communicating and participation with the Aberdeen Area Indian Health Service and other health agencies and organizations on health matters. The specific objectives of the Northern Plains NARCH are to:

- Develop and implement culturally sensitive community-based research to address health disparities among the Northern Plains AI population through academic and community partnerships.
- Enhance the partnerships between the Northern Plains Tribal communities, AATCHB, Aberdeen Area Indian Health Service, the 11 Tribal Colleges and Universities in the Aberdeen Area, and Aberdeen Area-research-intensive institutions.
- Mentor and collaborate with AI/AN researchers.

Under the umbrella of the Northern Plains NARCH there are three pilot projects, each addressing a health priority of the Northern Plains Tribes.

Screening for Asthma among Children in Northern Plains Tribal Communities

The purpose of this pilot study is to test the feasibility and utility of conducting an asthma screening program—using both questionnaires and spirometry—for AI/AN children in two Northern Plains Tribal communities. Focus groups were utilized to help determine how best to conduct asthma screenings in these two communities. Four hundred and fifty children between the ages of 6-18 years of age who were of AI/AN descent were screened for asthma using written questionnaires and spirometric measures. Those who were deemed to be at-risk for asthma were referred to their health care provider. Parents were informed of the results of the screenings. Phone calls were made to the parents or other

guardian(s) to determine outcomes of the results of referrals. Following the screenings, an educational program about asthma was presented to children at both sites.

Results of initial focus group discussions indicated community members were open to having the screening completed, however there were issues of concern related to: 1) mistrust of researchers; 2) concern about asthma; 3) trigger identification; 4) screening follow-up; 5) help for children; and 6) education of community members. Preliminary findings from the screenings identified that 51 percent of the children were referred as a result of written screening; 30 percent had normal written screening and spirometry; 10 percent had a diagnosis of asthma prior to screening and had abnormal spirometry and written screening; 2 percent were not diagnosed with asthma prior to screening and had an abnormal spirometry and written screening; 6 percent of the participants had incomplete records; and 1 percent of the children had inconclusive findings. These results will be important for identifying children at risk for asthma and assessing the effectiveness of such a screening program. Future studies need to examine interventions directed toward assisting these children to live as normal a life as possible.

Predicting Insulin Resistance in Native American Youth

Diabetes has become an epidemic in Native American communities. Early in its course, many have few symptoms so unrecognized diabetes is common in adults. There is little data on prevalence of either diabetes or pre-diabetes in Native American youth who are also at higher risk for diabetes than other youth groups. Researchers conducted a prospective cross-sectional screening of Native American youth 5-18 years of age to identify not only the current prevalence of diabetes and pre-diabetes, but the possible role of stress with insulin resistance and obesity in Native American youth to help guide new strategies for prevention. Data collected included height, weight, calculated BMI% for age and sex, abdominal circumference, blood pressure, fasting and 2h glucose after a glucose challenge, fasting lipids, urine protein and highly sensitive C reactive protein (hsCRP), and 25-hydroxy-vitamin D. Parents were asked about weight of the child at birth, history of gestational diabetes, family history of diabetes, and parent perception of risk and diabetes knowledge. Youth 12-18 years were also asked questions about exercise and diet behaviors, diabetes knowledge, number and frequency of cultural and/or spiritual activities, and a number of tools to assess different types of stress in their lives (CES-D for depression, life event survey, alcohol and substance abuse, post-traumatic stress disorder (PTSD), historical grief, racial discrimination, and stress at school or on the school bus). Recruitment was intended to screen all youth, regardless of perceived risk, which occurred through health, school, and community events.

Results indicate that among those screened to date (n=195; 100M/95F), prevalence of diabetes was 1 percent and pre-diabetes was found in 6 percent. Mean BMI% was 77.7 ± 1 . Insulin resistance as assessed by homeostatic model of insulin resistance (HOMA-IR), increased with BMI%, age, and family history of diabetes. Diabetes knowledge was good for both youth and adults (85% got all questions correct). BMI% was associated with HOMA-IR, systolic blood pressure, fasting and 2h glucose, fasting insulin, urine alb/creat, hsCRP, HDL, and fasting triglycerides (all $p < 0.01$). BMI was inversely correlated with eating breakfast ($p = 0.0006$). BMI but not HOMA-IR was lower with smoking ($p = 0.06$) and methamphetamine use ($p = 0.01$). BMI was lower with greater pow-wow participation ($p = 0.02$). BMI and HOMA-IR were higher with school bus stress ($p < 0.009$). There was also a trend toward greater HOMA-IR with higher CES-D score ($p = 0.07$). Neither BMI nor HOMA-IR was associated with negative or positive life events, racial discrimination, PTSD, historical grief, exercise minutes, or sedentary activities. Vitamin D concentration was low in the population (mean= 17.5 ± 0.4 mg/dl). Conclusively, elevated BMI% was common and clearly associated with diabetes and vascular risk based on insulin resistance score as well as its association with other biologic features of the metabolic syndrome. Multiple potential factors likely contribute, including obesity, skipping breakfast, stress

because the number of negative life events was consistently high even though it did not correlate with insulin resistance, low vitamin D, and depression. Strategies that incorporate cultural activities (such as pow-wows), increase vitamin D, or address behavioral health may be helpful in addressing risk in Native American youth.

Mood Disorder Assessment Validation with Northern Plains Indians

Many psychological tests for mood disorders are used with American Indian behavioral health clients, however; very few have been examined to see if they are valid, reliable, and culturally appropriate for this population. This study examines the psychometrics of common measures of depression, anxiety, and substance use with Northern Plains Indians (NPI).

Six hundred male and female adult NPI will be recruited from IHS and Tribal behavioral health clinics to complete a series of assessments. The participants will be recruited from three groups: 1) diagnosed depressed (by clinician), 2) diagnosed anxious (by clinician), and 3) no mental health diagnosis (control). Each group will consist of 100 male and 100 female participants. Participants will receive \$10 in gift/gas cards and the Tribe will receive \$5 per participant for compensation. Assessments include depression, anxiety, hopelessness, rumination, culture, quality of life, substance abuse, substance use, demographics, and the clinician's diagnosis code. Analysis will include comparison between groups, those use or non-use of substances within each group, psychometric measures of validity and reliability for each assessment, and factor analysis to determine if the same symptoms relate to the diagnosis for the general population. Thus far 270 participants from 5 of 7 approved sites have completed the assessments. Data has been collected from 86 male and 182 female participants between the ages of 16 and 72 years. At this point participants are classified into the following diagnostic categories: Depressed (31%); Anxious (36%); Co-Morbid (23%); Substance Abuse (26%); and No Diagnosis (54%). Substance use reports indicate that 64 percent smoke tobacco (20% for spiritual purposes); 46 percent use alcohol (38% binge drink); 16 percent use marijuana; 24 percent use methamphetamine; 18 percent use cocaine; 6 percent use heroin; and 8 percent use illegal intravenous (IV) drugs. Data collection and analysis is continuing for this project with the hope of creating normative data for the psychometric measures among Native Indians.

Inter Tribal Council of Arizona

This section highlights some of the key accomplishments under the University of Arizona/Inter Tribal Council of Arizona (ITCA) NARCH partnership. NARCH-1 funded two studies and faculty development. The community study sites were funded directly by ITCA, while the faculty development and research technical assistance was coordinated by the Native American Research and Training Center. NARCH-3 focused primarily on faculty and student development, although the University of Arizona (UA) staff/faculty continued to work with Tribes interested in developing health-related research applications. In addition to these activities, UA staff also planned and hosted selected research conferences. Publications from these research conferences are summarized below.

Building a Community's Capacity: The Hualapai Research Project

The purpose of this project was to strengthen the Hualapai community's capacity to develop, implement, and sustain a school-based intervention that will promote healthy eating and increased physical activity in elementary school age youth. The objectives were: 1) to create and support a community task force that will guide the development of the school-based wellness program; 2) to document and evaluate the efforts of the community task force to identify strategies and behaviors that lead to the development and

institutionalization of a school-based wellness program; 3) to test the usefulness and validity of selected methods and measures of community capacity building and participatory evaluation methods for use in health promotion program development, implementation, and maintenance in a Native American community; and 4) to assess the effectiveness of the school-based wellness program by comparing the targeted chronic disease risk factors in youth with and without exposure to the intervention.

The project resulted in: 1) development and evaluation of a Community Wellness Team (CWT), a 19 member volunteer coalition developed to advise the project and to influence local health policy and activities to promote youth wellness; 2) implementation and evaluation of physical activity sessions with youth at the Hualapai elementary school; 3) implementation and evaluation of a healthy lifestyles summer camp for youth at risk for diabetes; 4) coordination of a school-based wellness training for school staff; 5) integration of physical activity in annual community-based activities; and 6) dissemination of project outcomes.

Publications

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Use of Alternative Medicine by Pascua Yaqui Patients with Diabetes

The purpose of this project was to investigate the role of alternative medical approaches (including traditional Yaqui healing practices) on diabetes management, glucose control, and quality of life for Yaqui Tribal members living with Type II diabetes. The objectives were: 1) to characterize the frequency, nature (type), and reason for use or non-use of alternative medicine with allopathic medicine by Yaqui patients living with Type II diabetes by means of in-depth interviews; 2) to describe the practice of alternative medicine in the Yaqui community by interviewing practitioners of alternative medicine (including traditional Yaqui healers) providing services to Yaqui patients; and 3) to describe the similarities and differences between those clients who use alternative medicine and those who do not use alternative medicine.

Results of this project contributed to health care service and public health research by: 1) adding to the growing body of knowledge regarding alternative medicine and traditional healing as a practice and as a model of a culturally appropriate health care delivery system; 2) developing Tribally-based research methodology in the area of sample strategy; 3) developing Tribal research infrastructure through the creation of Tribal positions, providing training, and increasing research awareness activities; and 4) increasing AI/AN student participation in research and assisting in research skills development of

graduate and summer research assistants by providing formal training opportunities and experience in data collection and analysis. The Tribal Project Director entered an MPH program at the University of Michigan, and two of the graduate students who participated in this project have continued to work on Tribal-based research projects. One of these two students has currently applied for a Fulbright Scholarship to study abroad.

NARCH/AIRCH 3 Research Core Conference Publications

Culturally-Based Substance Abuse Treatment for American Indians/Alaska Natives and Latinos

The following nine articles were a result of a conference held April 17-19, 2006, in Tucson, Arizona, titled “Culturally-Based Substance Abuse Treatment for American Indians/Alaska Natives and Latinos.” The conference and proceedings received the generous support from the Center of Excellence in Partnerships for Community Outreach Research on Health Disparities (EXPORT) Project at the College of Public Health, University of Arizona, funded by the NIH/National Center for Minority Health and Health Disparities, Grant 60MD000155-03; and the American Indian Research Center for Health, Inter Tribal Council of Arizona, funded by IHS/NIGMS, Grant U26IHS3000007.

The Conference Proceedings was published as a special issue in the *Journal of Ethnicity in Substance Abuse*, Vol 8 (3): 207-358. The nine articles are as follows:

Introduction to the Proceedings for the Conference: Culturally Based Substance Abuse Treatment for American Indians/Alaska Natives and Latinos

Scott Carvajal, PhD, MPH; Robert S. Young, PhD.

Epidemiology of Substance Abuse among Latinos

Sherry Lipsky, PhD, MPH; Raul Caetano, MD, MPH, PhD.

Some Thoughts about the Epidemiology of Alcohol and Drug Use among American Indians/ Alaska Native Populations

Robert S. Young, PhD; Jennie R. Joe, PhD, MPH.

Cultural Practices and Spiritual Development for Females in a Native American Alcohol and Drug Treatment Program

Jenny Chong, PhD; Yvonne Fortier; Traci L. Morris-Carlsten, PhD.

The Community Pulling Together: A Tribal Community-University Partnership Project to Reduce Substance Abuse and Promote Good Health in a Reservation Tribal Community

Lisa R. Thomas, PhD; Dennis M. Donovan, PD; Robin L.W. Sigo; Lisette Austin; G. Alan Marlatt, PhD; in collaboration with the Suquamish Tribe.

Latino/a Culture and Substance Abuse

Melba J. T. Vasquez, PhD, ABPP.

Shifting Perspectives: Culturally Responsive Interventions with Latino Substance Abusers

Miguel E. Gallardo, PsyD; Shannon J. Curry, MA.

Mexican Americans and Historical Trauma Theory: A Theoretical Perspective

Antonio L. Estrada, MSPH, PhD.

Women and Substance Abuse: Gender, Age, and Cultural Considerations
Sally J. Stevens, PhD; Rosi A.C. Andrade, PhD; Bridget S. Ruiz, MA.

Activity: Childhood Obesity/Diabetes Prevention in Indian Country: Making Physical Activity Count!!

The following seven articles were a result of a conference held December 2-4, 2008, in San Diego, California, titled "Activity: Childhood Obesity/Diabetes Prevention in Indian Country: Making Physical Activity Count!!" The conference and proceedings received generous support from the American Indian Research Center for Health, Inter Tribal Council of Arizona, funded by the IHS/NIGMS, Grant U26IHS3000007; and the Center of Excellence in Partnerships for Community Outreach Research on Health Disparities (EXPORT) Project at the College of Public Health, University of Arizona, funded by the NIH/National Center for Minority Health and Health Disparities, Grant 60MD000155-03.

The articles have been submitted for review to the *Journal of Public Health Management and Policy Practice*. Expected date of publication is fall 2010.

Commentary: Conference on Physical Activity Measurement for American Indian Children at Risk for Obesity and Type 2 Diabetes Mellitus
Jeanette Hassin, PhD; Jennie R. Joe, PhD; Robert S. Young, PhD.

Measuring Physical Activity: Practical Approaches for Program Evaluation in Native American Communities
James F. Sallis, PhD, San Diego State University.

Physical Activity Measurements: Lessons Learned from the Pathways Study
Scott B. Going, PhD, University of Arizona.

Physical Activity in Young American Indian Children: Formative Research and Lessons Learned from the Wisconsin Nutrition and Growth Study (WINGS)
Alexandra Adams MD, PhD; Ron Prince, MS; Katie Hammes, MD; Kate Cronin, MPH.

A Latent Profile Analysis of Neighborhood Recreation Environments in Relation to Adolescent Physical Activity, Sedentary Time, and Overweight
Gregory J. Norman PhD; Marc A. Adams, PhD; Jacqueline Kerr, PhD; Sherry Ryan, PhD; Scott C. Roesch, PhD; Lawrence Frank, PhD; James F. Sallis, PhD.

Childhood Obesity in California Indian Children
Dennis Styne, MD, University of California, Davis.

The Problem of Childhood Obesity/Diabetes in Indian Country
Kelly Moore, MD, FAA.

Other Publications

Joe JR (2008). Health Issues in the U.S. Pp 97-105 in *Handbook of American Indians: Indians in Contemporary Society, Vol 2*. G. Bailey, ed. Washington, DC: Smithsonian Press.

NATIONAL INSTITUTE ON DRUG ABUSE

Methamphetamine and Other Drugs (MOD) in American Indian and Alaska Native Communities

The Process of MOD Research Partnerships between Community and Institutionally Based Researchers

The Methamphetamine and Other Drugs (MOD) in American Indian and Alaska Native communities 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 AI/AN communities in particular. Because few data exist on methamphetamine and other drug use in AI/AN 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 AI/AN 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 AI/AN communities. As noted below, this goal was expanded at the request of AI/AN partners to include documentation of the strengths and resources already existing in these communities.

Several points are noteworthy in the MOD projects. First, although NIDA expressed specific interest in focusing on methamphetamines in AI/AN communities, 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, during the development of research partnerships based on the principles and approach of community-based participatory research it became clear that the uniqueness of each AI/AN community/organization required NIDA to develop similar but distinct research protocols across the Nodes, even though some issues would be the same or similar across AI/AN 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. The 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.

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 Federal-wide 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 NIDA's 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 AI/AN communities; lessons learned and recommendations for others interested in ethical research with AI/AN communities are also presented. This introduction provides a brief of the project and how the overall MOD project was developed and implemented and is followed by brief process reports from each of the participating Nodes. Please note that AI/AN community research partners have participated in writing and/or reviewing this report.

There are five Nodes of the NIDA Clinical Trials Network participating in the MOD project: Pacific Northwest, Oregon/Hawaii, Southwest, Ohio Valley, and California/Arizona. Each of these Nodes is partnering with AI/AN communities in their Regions, including Tribes (reservation and urban), treatment agencies, health consortiums, and/or urban health centers. 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.

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

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 project 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 AI/AN communities. Data collection, analyses, interpretation, and reporting back to the AI/AN partners will be completed by February 2010.

The project was developed to build effective, ethical research partnerships with AI/AN communities as the essential first step to better understand and document the issues related to prevention and treatment needs of AI/AN 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 AI/AN 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.

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 five CTN MOD Process reports below.

California-Arizona Node

The California-Arizona (CA-AZ) CTN Node is working with an American Indian Tribe in Arizona and an urban AI/AN 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 AI/AN treatment program was willing to conduct research, and thus the project focused on building and strengthening working relationships. In particular, relationships have been established with key contact persons in each AI/AN 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 AI/AN 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 CA-AZ Node AI/AN 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.

Ohio Valley Node

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 members of the Aberdeen Area Tribal Chairmen's Health Board (AATCHB) 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 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 (AAPDA) 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.

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 AAPDA 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. 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 July 31, 2009. 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.

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.

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

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 NPAIHB 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 (IRB) of the Portland Area Indian Health Service.

By consensus resolution, the 43 Tribal delegates of the NPAIHB identified methamphetamine use prevention and treatment as a "Key Indian Health Issue."

(http://www.npaihb.org/health_issues/issue_methamphetamine). The OR-HI Node is working with two large reservation communities: one community of 4,000 is located in 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

AI/ANs. Combined, the two rural community sites and the urban site provide a sample of drug use among AI/ANs 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:

- Conduct interviews using a standardized questionnaire routinely used in treatment clinics: the Addiction Severity Index, or “ASI”.
- 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 the spring of 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.

Pacific Northwest Node

The Pacific Northwest (PNW) CTN Node is working with several AI/AN communities in Washington State and Alaska. The 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. The PNW Node is committed to collaborating with community partners at every step of the research process and utilizing a CBPR/TPR approach in its work. The 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 the PNW Node has partnered, each were invited to participate and then requested approval and permission to proceed with developing the research partnership and research protocols. 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 the 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 University of Washington 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 Service IRB. In some cases, it has been necessary for communities to obtain a Federal-wide 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 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 as 12 focus groups; similarly, PNW Node 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, the PNW Node has 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, the 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 the permission to do so. These data will be analyzed to assess possible trends in primary substances upon treatment admissions and other treatment trends.

Southwest Node

There is a perception that methamphetamine use is prevalent in American Indian communities, yet limited data are available. In the reports the Node came across that pertained to the 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 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, the Southwest Node 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. The 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 findings to future efforts in prevention, treatment research.

The Southwest Node 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 that sparked curiosity 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.

As the Southwest Node 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. The Southwest Node therefore had its first encounter with "creative tension" (a term used by one of the Tribal collaborators) between the research agenda the Southwest Node 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 the first "aha" moments as the Southwest Node began to work within the community-based participatory research approach. The Southwest Node discovered that the agencies own curiosities and questions weren't necessarily the same questions held by the community partners and needed to back-track to begin with asking the question of "what questions do you need to be answered in your community?" Questions the Tribal community partners had included:

- 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 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?

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 the Southwest Node to better understand.

Together with the communities, it was 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 ASI self-reported substance use for people presenting for treatment.

In some ways, it's what the Southwest Node knew 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. Attempts to come in with the identification of the problem, and the community leaders gently reoriented the approach from the prescriptive "we have what you need..." to the evocative "what ideas do you have? How can we help you answer those?"

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 the Southwest Node as investigators and the larger group of agency staff. The Southwest Node underestimated the impact of the larger treatment provider community and assumed the Western top-down chain of command. However, for many agencies the clinical staff as a whole needed to hear the proposal, discuss the pros and cons, and make a collective decision as a group.

Then a larger community of support was needed, so the Southwest Node attended chapter house meetings and Tribal councils during monthly meetings to discuss the research in more detail. Prior to applying for approval from the Navajo Nation to conduct the MOD project, the Southwest Node was asked to seek support from at least two Navajo chapter houses. The Southwest Node sought support from the three chapter houses in the areas where they planned to partner with community treatment agencies. Having the support of the local chapters, they were able to seek further support from the local agencies. Once receiving the agency and Tribal support and detailed aims of the study, they 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. The Southwest Node will then receive feedback including revisions/changes and will then 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 the Southwest Node completed the IRB application for the Navajo Nation, one of the agreements the Southwest Node 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 the study. Therefore, the Data Sharing Agreement had to be amended to give sole data 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.

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